The University Of Sheffield.

“Battling on Numerous Fronts”

Mother’s narratives of caring for their child who experiences chronic pain.

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Abstract

The thesis explores how parents narrate their experiences of caring for a child who lives with chronic pain, and how these narratives intersect with education, health and family systems. Using a critical realist ontology and interpretivist epistemology, chronic pain is understood as both materially real and socially mediated, and parental accounts as situated meaning-making rather than objective reports. Narrative Oriented Inquiry (NOI) provided the methodological framework. Three mothers, recruited via schools and a parent–carer forum in two English regions, participated in in-depth narrative interviews about their child's pain, schooling, healthcare contacts and family life.

The findings show that parents engage in substantial "narrative labour": cognitive, emotional and relational work to make their child's often invisible pain legible to professionals, schools and extended family. Diagnostic visibility and "professional parental capital" shape whose stories are heard as credible, raising equity concerns for families without such resources. Parents drew on a set of carer-specific illness narrative typologies which extend existing illness narrative frameworks by focussing on caregiver illness narratives and system-facing storytelling.

The thesis makes three main contributions. First, it demonstrates the value of Narrative Oriented Inquiry for understanding how mothers of children with chronic pain construct and negotiate their caregiving stories across education, health and family systems. Second, it develops the concept of narrative labour to describe the cognitive, emotional and relational work involved in making a child's often invisible pain legible to others, and shows how this labour is shaped by diagnostic visibility and professional parental capital. Third, it extends existing illness narrative frameworks by identifying carer-specific illness narrative typologies and highlighting how mesosystem trust across school–health–family systems can either erode or sustain parental confidence. These contributions position educational psychology

as having a distinctive role in recognising parental expertise, reducing repeated retelling and working systemically to address epistemic injustice.

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Table of Abbreviations

Abbreviation	Meaning
ALSPAC	Avon Longitudinal Study of Parents and Children
BPS	British Psychological Society
CRPS	Complex Regional Pain Syndrome
DEdCPsy	Doctor of Educational and Child Psychology
DHSC	Department of Health and Social Care
EP	Educational Psychologist
EPs	Educational Psychologists
hEDS	Hypermobile Ehlers–Danlos Syndrome
HCSA	Health Conditions in Schools Alliance
IASP	International Association for the Study of Pain
IHP	Individual Healthcare Plan
JFMS	Juvenile Fibromyalgia Syndrome
JIA	Juvenile Idiopathic Arthritis
LA	Local Authority
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NOI	Narrative Oriented Inquiry
PCS-P	Pain Catastrophizing Scale – Parent Version
PHE	Public Health England
PTG	Posttraumatic Growth
PTGI	Posttraumatic Growth Inventory
QNI	Queen's Nursing Institute
RAiISE	Raising Awareness of Invisible Illnesses in Schools and Education
SAPHNA	School and Public Health Nurses Association
SEND	Special Educational Needs and Disabilities
SENDCo	Special Educational Needs and Disabilities Coordinator

Chapter 1: Introduction

Chronic pain is experienced by one in five children and young people worldwide (Chambers et al., 2024; King et al., 2011). However, this figure is unlikely to be widely recognised outside specialist contexts, particularly among those with limited direct contact with chronic pain. Many of these children show no visible signs of illness. Parents often face uncertainty and doubt when first advocating for the children. When trying to work with systems they can face challenges; within education settings, they may share medical reports and advice from doctors, they attempt to explain their symptoms and needs but can often feel unheard or misunderstood. In clinical settings their concerns may be softened into reassurance or redirected toward anxiety. At home they carry on with ordinary routines while also managing appointments, disrupted sleep, and pain that can intensify or fade without warning. In this thesis, I focus on how parents describe living in that space.

These narratives are not treated as background detail; they are the main material.

Telling stories is universal and they function as more than a simple recollection of events. The process helps us make sense of our thoughts and organise events, they support us in managing uncertainty. From the perspective of parents of those experiencing chronic pain, stories are often used to garner support and/or act as a gatekeeper to resources. The way in which these stories are delivered and received affect the support which is offered and how their child is seen. As a consequence, these stories involve significant effort and often occur against a backdrop of limited understanding. Later chapters explore how this effort can be understood as a form of narrative labour, particularly when parents are required to translate their child's pain repeatedly for different audiences.

I was guided by a single research question: How do mothers narrate their experiences of caring for a child who experiences chronic pain? I avoided breaking this into smaller questions. Doing so might have produced neater categories, but it also could have narrowed what parents chose to share. A narrative approach allows participants to decide what matters and how events link together over time. Parents are approached as meaning makers, not as sources of isolated facts about their children.

Three mothers took part in narrative interviews. Each care for a child living with chronic pain. Recruitment came through Special Educational Needs Coordinators and a parent carer forum in two English regions. The children's conditions differ. One has juvenile idiopathic arthritis with uveitis. Another experiences hypermobility later understood as Ehlers Danlos Syndrome alongside chronic fatigue. The third lives with pain associated with colitis and features suggestive of neurodiversity and anxiety. This variation is not used to compare diagnoses. It reflects how diverse paediatric pain presentations can be and allows exploration of how different labels shape what parents can say and how seriously those accounts are taken.

Two of the three mothers have worked in education or social/health care roles. Their experiences highlight what I refer to as 'professional parental capital'- the familiarity they have in relation to the systems, their awareness of policies and understanding of terminology which gives them additional credibility and perhaps makes it harder for them to be ignored. However, having this knowledge can lead to frustration; they are often more aware of the services they should be receiving, the gaps are harder to ignore, and they can feel as though they should be able to cope because of their profession and/or experience.

This leads to an equity question that remains open. If navigating support partly depends on insider knowledge or confidence with bureaucratic language, families without that background may face greater difficulty. The analyses suggest this capital operates as both resource and burden and invites educational psychology to consider how access to knowledge might be shared more fairly.

The research takes a critical realist ontological position alongside an interpretivist epistemology. Chronic pain is treated as materially real. Our understanding of it is always shaped through language, relationships, and context. Parents' accounts are therefore neither transparent facts nor simple constructions. They are situated attempts to interpret and respond to complex educational and health systems.

Knowledge here is generated through interaction rather than discovered at a distance. Narrative Oriented Inquiry (NOI) was chosen because it supports that view. Instead of fragmenting interviews into small, coded units, NOI attends to how stories are told, what they emphasise, and how they unfold within the interview itself. Participants are not handing over fixed accounts. They are shaping them in conversation, responding to questions, pauses, and what feels possible to say.

This area is of particular interest to me for a number of reasons. Firstly, my partner has lived with Rheumatoid Arthritis and Fibromyalgia since adolescence and I have witnessed the impact of chronic pain, I witness and experience the constant but fluctuating nature of her conditions daily. Everyday life can be challenging to navigate; it is full of unpredictable turns and false summits; joyful activities are difficult to plan for or access and the pain is ever-present.

Prior to meeting my partner, I was unaware of how much effort it can be to maintain routines that are ordinary to others, how she is required to 'retell' her story frequently

and how she lives in a world in which doubt and invisibility is a constant. I also notice how she tells different narratives about her life dependent on the audience and/or context she finds herself in. These experiences shaped my interest in the topic and my sense that it deserved attention.

Another experience that I feel has influenced my interest in this area was when I worked as a keyworker in a residential school. I supported a young person with juvenile fibromyalgia and her family. Their experiences involved repeated dismissal and difficulty gaining recognition. That work left lasting questions about how systems respond when there is no cure and no clear recovery path.

Most recently though, during my training as a Trainee Educational Psychologist I found myself returning to issues of social justice and systemic practice. I have become increasingly interested in narrative practices and in understanding the relationships between systems around children and families.

These experiences and connections bring strengths and risks. They may support empathy and attentiveness to nuance. They also create the possibility of assuming too much or seeing my own experiences reflected in others. To manage this, I kept a reflexive journal throughout the study and used supervision to examine assumptions and emotional responses. In interviews I tried to position myself as a learner, allowing participants to shape or challenge my interpretations.

The theoretical framework brings together several strands of academic theory. Narrative theory, including Bruner (1986, 1990), Frank (1995), and Riessman (2008), informs the view that people understand their lives through story and that how something is told can reveal as much as what is said. Parents, however, speak about a child’s illness rather than their own, often directing their stories toward

institutions such as schools and hospitals (Kleinman, 1988; Knepper & Arrington, 2016). Their accounts can therefore be more strategic and system facing than those found in traditional illness narratives.

Fricker's concept of epistemic injustice provides another lens. Testimonial injustice occurs when someone is treated as less credible because of prejudice, resulting in a wrong done to them as a knower (Fricker, 2007). When parents' reports of their child's pain are reduced to anxiety or overreaction, this is not simply misunderstanding. It can erode trust and discourage future help seeking. Related discussions in disability studies, including work on mad mothering and institutional gaslighting, highlight how strong advocacy by mothers can be negatively interpreted. Similar dynamics appear in chronic pain contexts.

These narratives also sit within wider systemic structures. Bronfenbrenner's ecological systems theory positions the child within interconnected layers of family, school, healthcare, and policy (Bronfenbrenner, 1979). Rolland's family systems illness model considers how illness trajectories intersect with family development and why certain stages can feel particularly demanding (Rolland, 2005). The focus here is on identifying systems, examining how trust operates between them, how information moves, and whether families encounter consistency or contradiction over time.

This thesis offers an original contribution in three related ways. It brings narrative inquiry into the field of educational psychology to illuminate how mothers of children with chronic pain make sense of their caregiving within and across systems. It introduces and elaborates the concept of narrative labour and carer-specific illness narrative typologies as a way of understanding the hidden work that parents do to

secure recognition and support. It also foregrounds mesosystem trust as a key mechanism linking family, school and health, with implications for how educational psychologists might work more responsively with families living with chronic pain.

In later chapters I develop these ideas in detail. The literature review considers research on paediatric chronic pain, family life, and schooling, paying attention to where parental perspectives appear and where they are absent. The methodology chapter sets out the philosophical and analytic decisions, including the use of Narrative Oriented Inquiry and the ethical issues involved. The analysis chapter presents each parent's narrative in depth, followed by discussion that explores shared patterns and develops ideas such as pain aware schooling and mesosystem trust. The final chapter brings the strands together, notes the study's limits, and reflects on what this means for educational psychology practice and for future research.

Paying close attention to how mothers narrate life with a child in chronic pain provides an important lens on how families navigate educational and health systems, and on where those systems enable or constrain recognition, support and equity.

Chapter 2: Critical Literature Review

2.1 Introduction

The prevalence rate cited at the outset of the introduction represents a significant demographic reality: a ratio of one in five children equates to approximately six children within an average UK classroom. This statistic carries profound implications for familial dynamics, educational attainment, and long-term health trajectories (Chambers et al., 2024). However, quantitative prevalence rates and diagnostic classifications capture only a fragment of this phenomenon. Such metrics frequently obscure the lived experiences of families, specifically how parents conceptualise their child's suffering and navigate fragmented institutional systems. In the face of systemic ambiguity, parents often engage in sustained advocacy while managing considerable uncertainty, a process that highlights their pursuit of institutional recognition and validation.

Accordingly, this chapter examines how parents construct narratives regarding the care of a child with chronic pain, positioning these accounts as the central focus of inquiry.

Narrative scholars have argued that stories are not simply descriptions of events but mechanisms through which people construct meaning, negotiate identity and make sense of disruption (Frank, 1995; Kleinman, 1988). Within the context of paediatric chronic pain, parental narratives may therefore provide important insights into how families understand and respond to their experiences. Rather than assuming the functions these narratives serve, this review examines the existing evidence concerning parental meaning-making and considers how narrative approaches may

contribute to understanding family experiences. Perhaps the narratives support the parents to maintain a family identity amidst the threat of illness taking over.

As noted in Chapter 1, I approach chronic pain from a critical realist perspective, holding together its biological reality, and my epistemological position is interpretivist.

My positioning as a Trainee Educational Psychologist in the UK shapes this review's particular lens. I am acutely interested in whether educational systems genuinely support these families or inadvertently compound their struggles. I am concerned with how psychological knowledge can inform practice that honours both family expertise and professional understanding, avoiding either dismissing parental experience as "mere subjectivity" or positioning parents as sole bearers of knowledge about their child's needs.

Underpinning this approach is the biopsychosocial framework, which conceptualises pain not as a simple sensory readout of tissue damage, but as an emergent property resulting from the reciprocal interaction between neurobiological signalling, psychological processing, and social contexts (Palermo & Eccleston, 2009). Central to this systemic framework is resilience, which is formally defined here not as a static personality trait, but as a dynamic process of positive adaptation and functional maintenance despite significant medical adversity (Tugade & Fredrickson, 2004).

2.2 The Growing Prevalence of Chronic Pain in Childhood

Chambers et al. (2024) conducted a systematic review and meta-analysis of 119 studies involving more than one million children and adolescents internationally. The review included studies of varying methodological quality and substantial heterogeneity in sampling approaches, outcome measures and definitions of chronic pain. Although the pooled estimate suggested that approximately 20.8% of children

experience chronic pain, the authors cautioned that prevalence estimates varied considerably across populations and settings. Headaches and musculoskeletal pain are the most frequent, affecting about 25.7%. In the UK, chronic pain hits about 43% of the total population, and teenagers show especially high rates.

A notable limitation identified by Chambers et al. (2024) was the underrepresentation of marginalised populations, including ethnic minority groups, families from lower socioeconomic backgrounds and non-English-speaking communities. Consequently, prevalence estimates may not fully capture the burden of chronic pain among populations already facing barriers to healthcare access and support.

Despite its growing prevalence, chronic pain in children remains largely overlooked in public health and education policies. I suggest that this gap is partly due to the hidden nature of paediatric pain, but may also reflects how healthcare systems categorise suffering. Acute pain receives immediate attention because it is visible, urgent, and straightforward to diagnose. In contrast, chronic pain persists over time and blends into daily life. This continuous nature often makes the condition less visible, leaving it more vulnerable to being underestimated or dismissed.

2.3 Defining Chronic Pain

The International Association for the Study of Pain (IASP) defines chronic pain as “pain that lasts or recurs for longer than three months.” (Raja, 2020; National Institute for Health and Care Excellence, 2021), though it could be argued that this clinical threshold masks the complexity of the phenomenon.

Contemporary understandings of paediatric chronic pain increasingly draw upon a biopsychosocial framework rather than a purely biomedical model. Friedrichsdorf et al. (2016), in a clinical review of paediatric pain assessment and management, argue

that chronic pain emerges through the interaction of biological processes, psychological responses and social influences across development. Whilst the review provides a comprehensive synthesis of clinical and theoretical literature, it is not an empirical study and therefore cannot establish causal relationships between these factors. Nevertheless, it reflects a growing consensus that chronic pain is best understood as a multifaceted phenomenon that extends beyond tissue pathology alone.

The importance of social context is further reflected in Palermo and Chambers' (2005) narrative review of family influences on paediatric chronic pain. Drawing together evidence from studies examining family functioning, parental responses and treatment outcomes, the authors argue that families represent a critical context for understanding, assessing and managing chronic pain in childhood. However, much of the literature available at the time was cross-sectional and focused on predominantly North American samples, limiting conclusions regarding causality and cultural generalisability. Despite these limitations, the review highlighted the importance of considering chronic pain within the broader relational systems in which children live.

This broader conceptualisation is reflected in the International Association for the Study of Pain's revised definition of pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020, p. 1977). This definition acknowledges that pain may exist in the absence of observable tissue damage and emphasises the subjective nature of pain experience. Within paediatric populations, chronic pain encompasses a heterogeneous group of conditions, including inflammatory and disease-related disorders such as Juvenile Idiopathic Arthritis and sickle cell

disease, connective tissue disorders such as hypermobile Ehlers-Danlos Syndrome (hEDS), and centralised pain conditions including Juvenile Fibromyalgia Syndrome and Complex Regional Pain Syndrome.

A growing body of research suggests that diagnostic uncertainty and the often-invisible nature of chronic pain can create additional challenges for children and families. In one of the earliest qualitative studies exploring adolescent experiences of chronic pain, Jordan et al. (2007) conducted interviews with adolescents and their parents and found that the absence of visible pathology frequently led to uncertainty, repeated help-seeking and efforts to secure validation from others. Parents often described pursuing additional investigations not solely to identify a cause, but also to justify the legitimacy of their child's pain to professionals, schools and wider social networks. Although the study provided rich insight into family experiences, its relatively small sample and qualitative design limit the extent to which findings can be generalised.

Subsequent quantitative research has demonstrated that diagnostic uncertainty remains common even following specialist assessment. Tanna et al. (2020), studying children and adolescents attending a multidisciplinary paediatric pain clinic and their parents, reported that between 66% and 77% continued to experience some degree of diagnostic uncertainty following evaluation. Whilst the clinic-based sample may not represent all families living with chronic pain, the findings suggest that uncertainty often persists even after contact with specialist services.

The significance of diagnostic labels is further illustrated by Wakefield et al. (2023), whose qualitative research explored experiences of stigma among adolescents living with chronic pain. Participants with Juvenile Idiopathic Arthritis, a condition supported

by identifiable inflammatory markers, generally reported experiencing less scepticism regarding their pain than young people with fibromyalgia or hEDS. The authors argue that the visibility of biomedical evidence may influence how pain is interpreted by others. However, as the study relied on self-reported experiences, conclusions regarding broader societal attitudes should be drawn cautiously. Nevertheless, the findings are consistent with wider literature suggesting that conditions lacking clear biomedical markers may place additional demands on families seeking recognition and support.

Similarly, Bianchim et al. (2024), through qualitative interviews with parents of children living with chronic pain, identified the considerable emotional labour involved in explaining and legitimising symptoms that remained largely invisible to others. Parents described repeatedly having to make their child's suffering understandable to healthcare professionals, schools and extended family members. Although qualitative findings cannot determine how widespread these experiences are, they provide valuable insight into the social processes through which pain is recognised, questioned or validated. Collectively, this literature suggests that parental experiences extend beyond managing symptoms alone and often involve navigating uncertainty, seeking legitimacy and negotiating understanding across multiple systems.

2.4 Impact on education: attendance, attainment and school engagement.

Across multiple studies, researchers describe the impact that chronic pain can have on educational participation and school engagement. In their review of paediatric chronic pain, Eccleston et al. (2021) synthesised evidence from clinical and psychosocial research and reported that families frequently experience uncertainty

when attempting to balance their child's health needs with educational expectations. Parents often described feeling concerned about school attendance, academic progress and the potential long-term consequences of missed learning opportunities. Whilst the review provides a comprehensive overview of current knowledge, many of the underlying studies were conducted in specialist healthcare settings, which may overrepresent families experiencing more severe or complex difficulties.

Concerns regarding school attendance are not new. Palermo (2000), drawing on research examining functional disability among children and adolescents with chronic pain, identified school absence and reduced participation in educational activities as common consequences of persistent pain. Importantly, the impact extended beyond missed lessons, with difficulties in maintaining peer relationships, participating in extracurricular activities and sustaining engagement with learning also reported. However, much of the early literature relied on cross-sectional designs, making it difficult to determine the direction of these relationships. For example, poor attendance may contribute to educational and social difficulties, but challenges within school environments may also exacerbate pain-related distress. Nevertheless, the evidence consistently suggests that managing education becomes a significant concern for many families and often represents a key area of tension between health needs and educational expectations.

Palermo & Chambers, 2005, p. 1 state that ‘Chronic pain is a widespread developmental health issue that affects a large proportion of children and adolescents’ and ‘can lead to significant affect on daily functioning’ (p.1). More recent research report that students experiencing chronic pain have 4.2 times higher odds of chronic absenteeism (Groenewald et al., 2020). Forgeron et al. (2010) conducted a systematic review of 42 studies, examining social functioning and peer

relationships among children and adolescents experiencing chronic pain. The review synthesised evidence from multiple quantitative and qualitative studies and found consistent associations between chronic pain, school absence, reduced participation in social activities and difficulties maintaining peer relationships. However, the authors noted considerable variability in study quality and highlighted the need for more longitudinal research capable of examining developmental trajectories over time.

Using data from the Avon Longitudinal Study of Parents and Children (ALSPAC), Mullen et al. (2025) examined the relationship between adolescent chronic pain and later educational outcomes within a large UK birth cohort. The longitudinal design represents a significant methodological strength because it allows examination of outcomes over time and adjustment for potential confounding variables. However, as with all observational studies, causal conclusions remain limited. The authors found that chronic pain predicted reduced progression into higher education but did not significantly predict standard measures of academic attainment. Sleep difficulties partially mediated this relationship, suggesting that educational consequences may arise indirectly through associated difficulties rather than pain alone.

Mullen et al. (2025) suggest that many students stay on track with their work despite mental health struggles or bullying. Strong relationships with parents and schools seem to act as a buffer. A parent might see their child suffering and exhausted, yet the child is still passing their exams. This coexistence of struggle and success troubles linear stories of failure or resilience, parents may experience distress about their child’s psychological vulnerability and social isolation, whilst also observing perseverance and academic success.

Using a qualitative design with semi-structured interviews, a UK study by Sherwood et al. (2025) involving 21 adolescents and 21 parents investigated "presenteeism," where students attend school despite experiencing debilitating chronic musculoskeletal pain.

The findings suggest that although attending school was often seen as positive and a display of ‘resilience’, there is a cognitive and emotional cost; whilst they may be attending school, they may be struggling to concentrate. It can push them to exhaustion and over time, pushing through the pain often leads to absence later. This creates a repeating cycle of coping and then collapsing. Parents describe this as an impossible dilemma: encouraging school attendance can feel like forcing their child to suffer, whereas allowing them to stay home raises fears about falling behind academically and becoming socially isolated.

While the study's approach successfully captures the hidden, internal struggles of these families, its reliance on a small, specific clinical sample limits its generalisability to broader, non-musculoskeletal chronic conditions or diverse socioeconomic contexts. Ultimately, these explicit insights prove that standard school attendance data is an inadequate metric that completely masks student vulnerability and true educational wellbeing.

Other qualitative research on pain-related stigma in juvenile idiopathic arthritis (JIA) documents how adults and peers respond to children’s accounts of pain. Using semi-structured interviews and reflexive thematic analysis, Wakefield et al. (2023) found that adolescents with JIA frequently experienced their pain being framed by teachers, school nurses and family members as exaggeration, attention-seeking or

“just anxiety”, and described feeling disbelieved, isolated and pressured to minimise symptoms in school and social contexts.

In a related study, Irish et al. (2025) conducted separate semi-structured interviews with young people with JIA and their caregivers, identifying how pain-related stigma in social and educational settings prompted what they term a “narrative struggle”, in which caregivers repeatedly defended the reality and seriousness of the child’s condition and worked to preserve their credibility over time. These two studies offer rich, situated accounts of how stigma can shape the emotional wellbeing, social participation and advocacy work of both adolescents and caregivers. Their findings converge with wider evidence that stigma is adversely associated with pain intensity, disability and depression across chronic pain conditions, as demonstrated in a recent systematic review and meta-analysis by Hickling et al. (2024), which reported small to moderate positive correlations between higher stigma and poorer pain-related outcomes. At the same time, both JIA studies draw on relatively small, self-selecting samples recruited from specialist rheumatology services in high-income contexts, with limited sociodemographic diversity reported, which constrains the transferability of their findings to the wider JIA population and to other diagnostic groups. Their focus on particular cultural and healthcare settings also means that important variations in how adolescents experience, interpret and resist pain-related stigma across different communities and education systems may not be fully captured.

2.5 Navigating Healthcare System

A recurring thread in research with families of children with chronic pain is the complexity of navigating healthcare systems and the prolonged pathways many families experience before receiving effective support. Studies consistently describe

lengthy diagnostic journeys characterised by uncertainty, multiple referrals and repeated assessments. For example, Jordan et al. (2007) conducted qualitative interviews with adolescents experiencing chronic pain and their parents, identifying uncertainty regarding diagnosis as a significant source of distress. Parents frequently described seeking additional consultations and investigations in an effort to better understand and legitimise their child's symptoms. Whilst the qualitative design enabled rich exploration of lived experiences, the relatively small sample limits the extent to which findings can be generalised beyond similar clinical populations.

More recently, Teggart et al. (2023) explored the experiences of families accessing specialist pain services and similarly found that parents often described healthcare pathways as fragmented and difficult to navigate. Participants reported uncertainty regarding referral processes, treatment options and available sources of support. Families identified professional guidance and care coordination as valuable when available. However, the study also highlighted how responsibility for coordinating appointments, communicating between services and advocating for support frequently fell to parents themselves. As with much qualitative research in this area, participants were recruited through specialist services, meaning the experiences of families who disengage from services or struggle to access specialist provision may be underrepresented.

Structural factors within healthcare systems may further shape these experiences. Although access to specialist paediatric pain services has improved in recent years, provision remains variable across different geographical regions within the UK (Eccleston et al., 2021). Consequently, families' experiences may be influenced not only by the nature of their child's condition but also by local service availability and referral pathways. However, relatively little research has directly examined how

regional variation affects family outcomes, highlighting an area requiring further investigation.

Parents frequently describe the practical and emotional burden associated with navigating multiple services. Hinton and Kirk (2016), in their exploration of parental experiences of chronic childhood illness, found that parents often felt responsible for repeatedly recounting medical histories, coordinating communication between professionals and maintaining continuity across services. Similar findings were reported by Teggart et al. (2023), where participants described uncertainty regarding future care pathways and frustration when information was not consistently shared between professionals. Although these studies focus on subjective experiences, together they suggest that healthcare navigation can constitute a substantial form of emotional and organisational labour for families.

Research examining chronic pain and medically unexplained symptoms has also highlighted how diagnostic ambiguity may influence interactions between families and professionals. Wakefield et al. (2023), through qualitative interviews with adolescents experiencing chronic pain, found that participants frequently reported experiences of disbelief, minimisation and scepticism regarding their symptoms. Likewise, Jordan et al. (2007) identified repeated efforts by parents to secure validation and recognition of their child's pain through further assessments and specialist consultations. Whilst these studies cannot establish the prevalence of such experiences, they provide important insight into the social consequences of conditions that lack readily observable biomedical markers. Collectively, the findings suggest that diagnostic uncertainty may affect not only treatment planning but also how pain is understood and recognised by others.

Several studies further indicate that parents adapt their communication when interacting with healthcare professionals (Jordan et al., 2007; Hinton & Kirk, 2016). However, the empirical literature has devoted relatively little attention to understanding these communicative processes theoretically. Narrative scholarship may therefore offer a useful interpretive framework. Frank's (1995) concept of narrative surrender describes circumstances in which individuals modify or suppress aspects of their experiences in response to dominant institutional narratives. Similarly, Goffman's (1963) concept of impression management highlights how people may alter presentations of self in order to establish credibility within particular social contexts. Although neither concept was developed specifically in relation to paediatric chronic pain, both may offer useful lenses through which to understand how parents navigate healthcare encounters characterised by uncertainty and the need to establish legitimacy.

Alongside statutory healthcare provision, families frequently access support through charities and third-sector organisations. Organisations such as Pain Concern provide information resources, podcasts and guidance relating to chronic pain management and transitions to adult services (Pain Concern, 2018; 2019). Such resources may offer practical advice, emotional support and opportunities for connection with others experiencing similar challenges. However, engagement with these forms of support is likely influenced by wider social factors. Roman-Juan et al. (2025) note that socioeconomic circumstances can affect access to health information and support resources, suggesting that families may differ considerably in their ability to benefit from self-directed sources of information.

Across studies, there is consistent evidence that healthcare navigation involves both practical and emotional challenges. Whilst many families eventually access valuable

sources of support, the pathway is frequently characterised by uncertainty, repeated explanation and ongoing efforts to secure understanding across multiple professional contexts. These findings provide an important foundation for exploring how parents construct narratives around healthcare experiences and make sense of their child's chronic pain over time.

These studies suggest that families' experiences are shaped by both structural features of the healthcare system and the emotional and interpretive work parents do to navigate it. While high-quality intervention is possible, the pathway to accessing it can be difficult and uncertain. For Educational Psychologists, these findings call for reflection on how educational systems may help reduce fragmentation, provide continuity of care, and support parents during periods when medical answers are slow to emerge and meaning-making is ongoing.

2.6 Awareness and support in school

As discussed above, parents frequently report the need to advocate for their children within healthcare settings, particularly when symptoms are poorly understood or invisible. Similar patterns appear in educational contexts, where recognition of chronic pain and other invisible health conditions can vary considerably between schools and professionals. Quantitative and qualitative studies indicate that children and young people with chronic pain are at increased risk of reduced school participation, peer difficulties and misunderstanding by staff and classmates (Forgeron et al., 2010; Logan et al., 2009; Groenewald et al., 2020; Ødegård et al., 2020). These studies collectively suggest that chronic pain is associated with more frequent school absence, lower school engagement and more social isolation, although findings on academic performance and competence are more mixed, with

some evidence that adolescents can maintain or even exceed peers' attainment despite significant pain (Ødegård et al., 2020).

Forgeron et al. conducted a systematic review of primarily cross-sectional, questionnaire-based studies examining social functioning and peer relationships in children and adolescents with chronic pain, synthesising quantitative and qualitative evidence from predominantly North American and European samples (Forgeron et al., 2010). The review concluded that, across these studies, young people with chronic pain tended to have fewer friends, report more loneliness and social withdrawal, and experience higher rates of peer victimisation than pain-free peers, although the heterogeneity of measures and the predominance of self- and parent-report limited the ability to draw firm conclusions about mechanisms or direction of effects (Forgeron et al., 2010). The authors highlighted the need for longitudinal designs and more diverse samples to understand how social difficulties develop over time and in different contexts, rather than assuming a uniform impact of pain on peer relationships.

Logan et al. used a cross-sectional design with adolescents referred to a tertiary paediatric pain clinic, combining adolescent self-report, parent report and school records to examine the association between chronic pain, depressive symptoms and school functioning (Logan et al., 2009). They found that many adolescents reported declines in grades and perceived academic competence following the onset of chronic pain, and that depressive symptoms partially mediated the relationship between pain and school impairment (Logan et al., 2009). The clinic-based nature of the sample and the cross-sectional design mean that the findings reflect young people with more severe or complex presentations and do not allow causal

inferences, but they do underline how emotional wellbeing and pain interact in shaping school experiences.

Using a large, nationally representative parent-reported survey in the United States, Groenewald et al. compared school functioning between children with and without chronic pain, adjusting for sociodemographic and health covariates (Groenewald et al., 2020). Children with chronic pain had significantly higher odds of chronic absenteeism and poorer overall school engagement, even after adjustment, suggesting that pain status is independently associated with school difficulties at a population level (Groenewald et al., 2020). However, the reliance on parent report, the cross-sectional design and the absence of detailed measures of school climate or support means that the mechanisms through which chronic pain leads to impairment remain only partially understood.

Ødegård et al (2020). conducted a mixed-methods systematic review, synthesising 14 quantitative and qualitative studies on adolescents' chronic pain, school functioning and school personnel responses. The review reported that chronic pain generally had a negative influence on attendance, participation in school activities and social functioning, but also noted conflicting findings regarding academic performance and competence, with some studies indicating that adolescents maintained or exceeded peers' academic outcomes (Ødegård et al., 2020). Methodologically, the authors highlighted that most included studies were small, cross-sectional and used varied outcome measures, and that there was a lack of robust research on how teachers and school staff respond to pain in practice, pointing to a need for clearer guidance and higher-quality empirical work in school settings.

One organisation that has sought to address these challenges is RAiISE (Raising Awareness of Invisible Illnesses in Schools and Education), a UK-based initiative founded by Sophie Ainsworth following her experiences of navigating education whilst living with lupus. Ainsworth's conference abstract describes RAiISE as a young-person-led project that used workshops and focus groups with young people, parents, education staff and health professionals to co-create an information pack for schools (Ainsworth, 2018). This early-stage, user-led research design enabled stakeholders to identify common themes of miscommunication, variable staff knowledge and difficulties responding to fluctuating conditions, and to shape the content and format of resources intended to support teachers (Ainsworth, 2018). However, as a single-site, descriptive project reported in abstract form, it provides process-level insight into co-production and perceived relevance rather than robust outcome data on changes in attendance, attainment or wellbeing, and it remains unclear how widely the materials have been implemented or evaluated beyond initial feedback.

A notable feature of RAiISE's approach is its emphasis on participatory and co-produced resources. The information pack and subsequent school-facing materials were developed collaboratively with young people and families, aligning with broader trends in education and healthcare towards recognising lived-experience expertise and sharing decision-making (Ainsworth, 2018). Conceptually, tools such as health passports, classroom prompts and guidance for staff can be situated alongside mechanisms described in the wider chronic illness and disability literature, which use written plans and visual cues to make invisible needs more legible to institutions. Empirically, however, the current published work on RAiISE focuses on describing the co-creation process and summarising

stakeholder feedback; formal evaluations using controlled or longitudinal designs are not yet available. This means that, at this stage, RAiISE's resources are best understood as promising, co-produced responses to identified gaps in practice rather than as interventions with an established evidence base.

Challenges relating to communication between families and schools have been documented more broadly. Logan et al. (2008), discussed above, found that parents of children with chronic health conditions often experienced uncertainty about school procedures, responsibilities and the extent of support available, and that mismatched expectations between home and school could exacerbate distress. Other studies have highlighted how teachers may feel under-prepared to support pupils with chronic pain, reporting limited training, uncertainty about the biopsychosocial nature of pain and concerns about balancing flexibility with perceived fairness (Eccleston et al., 2021; Wakefield et al., 2023).

Across this literature, difficulties appear to arise not only from individual prejudice but also from organisational processes, variable communication systems and gaps in shared understanding about roles and responsibilities.

In England, statutory guidance identifies Individual Healthcare Plans (IHPs) as an important mechanism for supporting pupils with medical conditions (Department for Education, 2014). The guidance emphasises collaborative planning, clear allocation of responsibilities and regular review, with IHPs intended to record how a child's condition might affect day-to-day schooling and what adjustments are required. From an educational psychology perspective, IHPs can be viewed as a potentially useful narrative and systemic tool: they provide a formalised space where families and professionals articulate their understandings of a child's needs and agree concrete

actions. Empirical evidence, however, suggests that implementation is uneven. A survey of 117 schools found only 23 schools (20%) had a medical conditions policy that followed statutory guidelines; many schools had no policy at all or a policy of poor quality (Health Conditions in Schools Alliance [HCSA], 2017). These findings suggest that the existence of a national framework does not guarantee consistent practice, and that IHPs may function more as aspirational documents in some settings than as actively used tools for coordination.

School nursing services are frequently identified in guidance as key partners within multidisciplinary support arrangements, including in the development and review of IHPs (Department for Education, 2014; Public Health England & Department of Health and Social Care, 2026). However, workforce data indicate that school nursing capacity in England has declined over the last decade, with substantial reductions in posts and increasing safeguarding and mental health demands shaping what can realistically be offered (Royal College of Nursing, 2026). Workforce surveys conducted by SAPHNA found that the majority of school nurses reported insufficient staffing levels to meet increasing demand, particularly in relation to safeguarding and mental health responsibilities (SAPHNA et al., 2024). Against this backdrop, it is unsurprising that support arrangements look very different across schools and localities, even though the underlying statutory framework is the same. For educational psychologists, this variability matters because it shapes the context into which family narratives are introduced and the extent to which schools can act on jointly constructed plans.

Further research is needed to examine how collaborative approaches and tools like Health Passports or IHPs can be implemented, adapted and sustained across a wider range of educational contexts, including those serving communities with fewer

existing resources. For educational psychology, this highlights a dual task: working with individual schools to make better use of existing frameworks, while also advocating at system level for the conditions under which collaborative, pain-aware practice can flourish.

2.7 Family Functioning and parental wellbeing

Socio-structural evaluations indicate that families disproportionately shoulder the emotional and organizational labour of navigating highly fragmented institutional systems. A similar pattern emerges in family research, where chronic pain appears to shape everyday dynamics in complex and sometimes unpredictable ways. The literature has frequently focused on burden, yet more recent work suggests the picture is broader and at times more paradoxical, involving strain, adjustment, and, for some, unexpected growth.

In a systematic literature review synthesising 43 quantitative studies evaluating the family environments of youth with persistent pain, Lewandowski et al. (2010) suggested that families of children with chronic pain tend to show lower cohesion and greater stress compared with families of healthy children. Similarly, Palermo and Eccleston (2009) emphasised the relational nature of pain within family systems. While Lewandowski et al. (2010) synthesised quantitative data and Palermo and Eccleston (2009) offered a theoretical framework, both papers converge on the finding that parental responses may influence child pain intensity and disability, and that child distress may heighten parental anxiety in return. This reciprocal shaping suggests that emotional patterns within families are not simply reactions to medical symptoms but are part of a wider feedback loop that may sustain or alleviate difficulties over time.

More recent qualitative research brings some nuance to these findings. Ngo et al. (2022) interviewed 10 parents (8 mothers and 2 fathers) whose children were receiving care in a Sydney hospital describe parents experiencing their child's pain as constant and overwhelming, particularly when faced with uncertainty about diagnosis and school futures. This experiential strain is closely echoed in an earlier qualitative study by Jordan et al. (2007), which utilised Interpretative Phenomenological Analysis (IPA) to interview 14 parents (11 mothers and 3 fathers). They suggested that "not knowing" the cause of chronic pain, or the solution, was reported by many parents as intolerable, driving an exhausting search for a biomedical cure. Parents in their sample were motivated to not only "make sense of" their child's pain condition for themselves, but also to be able to justify their child's pain and their own parenting choices to an often sceptical external social network.

Furthermore, participants in a qualitative study by Skarstein et al. (2020), which investigated parental perspectives through semi-structured interviews with 17 mothers and 3 fathers, spoke about a profound sense of lost identity. These primary maternal caregivers described how the gruelling logistics of caregiving slowly overtook their employment, friendships, and hobbies, often forcing them to take medical leave or forfeit paid work entirely. The language used in these parental narratives conveys a felt sense of being constrained and unable to step back without guilt. This may reflect broader social expectations around caregiving and responsibility; because Skarstein et al.'s sample was predominantly comprised of mothers, these structural and emotional burdens appear heavily gender-oriented.

Conversely, researchers caution against framing parental responses as problematic in isolation. Caes et al. (2012) examined parental catastrophising using the Pain Catastrophizing Scale - Parent Version (PCS-P) and found it associated with

increased child disability. In their study, this disability was conceptualised as a functional trade-off where parents rigidly prioritise immediate "pain control" (stopping the discomfort and allowing avoidance) over the child's "activity engagement" (maintaining school attendance and daily routines). However, Caes et al. (2012) argued that such responses often reflect a protective instinct, such as love and fear, rather than pathology. Parents may focus on worst-case scenarios not because they are irrational, but because they are deeply invested in their child's wellbeing and are navigating systemic uncertainty without clear clinical guidance.

Alongside reports of distress, a growing body of literature identifies positive adaptation and resilience within the family system. For instance, Cox et al. (2021) conducted an Interpretative Phenomenological Analysis (IPA) utilising in-depth interviews with eight mother-father dyads (16 parents total) whose children were diagnosed with Complex Regional Pain Syndrome (CRPS). They explored parental resilience as a relational mechanism, uncovering a prominent theme of "masking reality in the face of pain," where parents purposefully manage their public emotional displays to buffer their children from parental distress. Similarly, Pope et al. (2025) and earlier qualitative work by Maciver et al. (2010), who interviewed 12 parents of children with chronic pain, highlighted that while all parents initially encounter profound distress, the majority successfully transition to an adaptive stance characterised by structural "stepping back" and gaining clinical mastery over fear-based emotional reactions.

This capacity to derive constructive meaning from significant stressors is captured in the concept of posttraumatic growth (PTG). Hungerbuehler et al. (2011) investigated this phenomenon by executing a longitudinal quantitative study tracking 126 parents (69 mothers and 57 fathers) of children diagnosed with chronic or critical illnesses

(such as type 1 diabetes or leukaemia) at 10- and 20-months post-diagnosis. Utilising the Posttraumatic Growth Inventory (PTGI), they demonstrated that higher initial levels of posttraumatic stress symptoms paradoxically predicted greater subsequent PTG, suggesting that the "seismic" cognitive disruption of a child's illness serves as a catalyst for reshaping a family's assumptive worldview. Within this framework, variables such as time elapsed since diagnosis, robust access to social support networks, and active cognitive reframing serve as crucial structural pillars. This adaptive capacity aligns with foundational observations by Tugade and Fredrickson (2004), whose experimental laboratory evaluations of psychological resilience demonstrated that resilient individuals consistently leverage positive emotions, such as humour, transient moments of joy, and persistent hope, to regulate physiological arousal. This emotional flexibility ultimately equips families with the psychological agility necessary to navigate long-term medical uncertainty.

While this body of literature provides valuable insights into the systemic and relational impacts of paediatric chronic illness, several overarching methodological limitations restrict its conceptual generalizability. First, a pervasive maternal bias exists across both quantitative syntheses and qualitative designs; despite framing findings around "parental" dynamics, samples remain heavily skewed toward mothers (e.g., Jordan et al., 2007; Skarstein et al., 2020; Ngo et al., 2022). By largely omitting paternal voices or collapsing them into a homogenized parental category, the literature risks misrepresenting gender-specific caregiving expectations as universal family experiences. Second, much of the foundational data relies on cross-sectional or retrospective designs, which struggle to capture the fluid, temporal nature of narrative meaning-making. While frameworks like those proposed by Palermo and Eccleston (2009) theorise dynamic, bidirectional feedback loops, static

methodologies cannot adequately map how these cycles unfold over time. Finally, several of the qualitative insights are derived from families actively embedded in highly specialised, tertiary multidisciplinary pain clinics (e.g., Ngo et al., 2022). These cohorts may represent families with distinct socioeconomic capital or those experiencing a severity of systemic friction that does not fully capture the experiences of parents navigating primary or secondary care settings without access to specialised institutional support.

Building on the need for approaches that recognise lived experience, narrative inquiry offers a further lens through which to consider how parents make meaning around chronic pain. If charities like RAiISE highlight and prioritise co-produced tools and participatory approaches, narrative frameworks may help illuminate how families themselves interpret and navigate these experiences over time.

2.8 Narrative frameworks: Frank's typologies and caregiver narratives.

In Arthur Frank's (1995) seminal work on illness narratives, he suggests typologies can offer a tool for mapping stories so that those patients within the stories can better understand themselves. As well as help 'listeners' on the outside, to perceive forms and regularities that may encourage new understandings. Frank identified three core narrative structures through which individuals make sense of illness: restitution, chaos and quest. Restitution narratives assume a return to prior health, following a familiar arc of illness and recovery, Frank states it is the belief that, "yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again." (p. 77). Chaos narratives are characterised by disorientation and fragmentation; they describe confusion and emotional strain, often portraying a perception of ongoing struggle without clarity about what might change. Quest narratives revolve around an

acceptance of illness and the pursuit of meaning. The quest narrative may be interpreted as a re-framing around ‘fate’ or a search to find positives amidst suffering. This can lead to helping others, volunteering and/or sharing their experiences.

Restitution narratives may appear familiar to many parents, reflecting the nature of western healthcare and a search for solutions or a cure. This search for recovery is predicated with hope and optimism but over time can dwindle. For some families this remains a sustaining storyline, for others the narrative becomes strained as pain persists without clear resolution. Moments of clinical uncertainty or statements about long-term symptoms can trigger feelings of inadequacy. It can evoke feelings of sadness and threaten anticipated futures. This was the case in Ngo et al., (2022) study, where many parents described a turning point when hopes for straightforward recovery are challenged, leading to a sense of disorientation and loss.

Experiences often also resemble the chaos narrative. These are often associated with uncertainty and a perceived loss of control, along with a feeling of fear and disorientation. Parents sometimes express feeling overwhelmed or trapped by circumstances that seem beyond their influence. These types of chaos narratives are common across many qualitative studies in paediatric chronic pain. Bianchim et al. (2024) suggests that this is most common when there is uncertainty around diagnosis or parents are struggling to navigate systems.

These stories of struggle are hard for others to listen to, so parents often hide them. This is often more prevalent in public places, for example, Cox et al. (2021) suggest that some parents privately articulate intense worry and confusion while presenting as composed and/or resilient in more public contexts.

Quest narratives introduce the possibility of meaning-making and adaptation within ongoing difficulty. Some parents describe developing new forms of purpose through advocacy, relationships with other families or shifts in personal values. Salvo et al. (2022) found that connecting with peers who share similar experiences can support movement toward shared meaning A quest narrative can also reduce isolation and foster a sense of collective understanding.

It is unlikely that parental stories remain fixed within a single narrative type. Instead, they appear to shift over time and in response to circumstances. A parent might return to restitution when a new treatment option emerges, experience chaos during periods of escalation or uncertainty, and move toward quest-like interpretations when stability allows for reflection and connection. Frank's typology therefore offers a helpful conceptual resource, although it benefits from careful, reflexive use that attends to the relational and indirect nature of parental suffering and the fluidity of meaning-making across time. When applied to parents supporting a child with chronic pain, these typologies may function as guiding concepts that support understanding rather than fixed categories (Frank, 1995). Meaning-making is shaped by witnessing a child’s distress and managing both the emotional and relational of persistent uncertainty (Kleinman, 1988) as well as practical elements. Parents develop caregiver illness narratives in which they effectively take on a child’s illness story as part of their own lives, while not experiencing symptoms in their own bodies (Knepper & Arrington, 2016). These accounts are distinct from patients’ first-person narratives and are strongly shaped by system-facing work: translating a child’s pain for professionals and negotiating communication in school and health systems (Knepper & Arrington, 2016). This structural tension exposes a distinct conceptual limitation within contemporary sociology: Frank’s typologies assume an embodied,

first-person illness experience. When applied to proxy or caregiver accounts, these frameworks must navigate the ontological shift of a parent who is actively translating and institutionalizing a child's pain trajectory without experiencing somatic symptoms themselves (Knepper & Arrington, 2016). Consequently, the literature requires a critical evaluation of whether existing typologies sufficiently capture vicarious narrative production, or if distinct, caregiver-specific narrative modes must be conceptualised.

2.9 Ecological and family systems perspectives.

Bronfenbrenner's ecological systems theory is widely drawn upon in both paediatric chronic illness literature and educational psychology, offering a way of thinking about children within interlinked environments such as family, school, healthcare and wider policy contexts (Bronfenbrenner, 1979). It conceptualises human development as occurring within “a set of nested structures, each inside the next, like a set of Russian dolls,” ranging from the microsystem to the macrosystem. (p. 3).

Carter and McGoldrick (2005), extend ecological thinking by focussing on family development over time, from a family therapy perspective. Their family life cycle model attends to how illness may intersect with or disrupt expected transitions. For instance, the demands experienced by a family with a young child learning independence may differ markedly from those faced by parents supporting an adolescent negotiating identity and autonomy. Developmental stage therefore shapes what coping involves and what challenges feel most salient.

However, ecological approaches have limitations that merit acknowledgement. Critics argue that the model can appear simplistic by focusing on structural layers while paying less attention to individual agency (Kausnik et al., 2023). Other factors

may not be fully accounted for, such as neurobiological factors or the specific proximal processes required to create particular outcomes (Tudge et al., 2009). In the context of chronic pain, positioning families as passive is inaccurate, as parents actively research and negotiate guidance to manage their child's health (Jordan et al., 2007). A narrative lens may therefore complement ecological framing by attending to how parents interpret and respond to the environments around them rather than assuming environments simply shape experience in a one-directional way.

From an educational psychology perspective, the ecological perspective still offers useful lens to view through. It highlights why work across systems matters, and why families frequently speak about ripple effects across home, school and healthcare. Parental narratives of school attendance policies influencing stress at home, or clinical uncertainty shaping willingness to engage in education. These may point to the interconnected nature of these contexts. Educational psychologists, situated at the intersections between settings, may be well placed to support communication, build shared understanding, trust between systems and help systems coordinate around a child’s needs. The challenge, perhaps, lies in combining this systemic awareness with genuine attention to lived meaning, as well as appreciation individual agency and the subtle relational work families engage in every day.

2.10 Resilience and Posttraumatic Growth

Resilience is frequently described as the process of adapting positively despite adversity. Within paediatric chronic illness research, resilience has often been used to explain why some families appear able to maintain functioning despite significant emotional, practical and financial challenges. However, the concept has also

attracted criticism, with scholars questioning whether resilience frameworks adequately acknowledge the structural conditions within which adaptation occurs.

Tugade and Fredrickson (2004) conceptualise resilience as involving psychological flexibility and the capacity to experience positive emotions alongside distress. Their work suggests that resilient individuals are able to alternate between confronting challenges and engaging in activities that sustain hope and wellbeing. Although influential, such approaches primarily focus on individual psychological processes.

More recent research has highlighted the importance of social and contextual factors. Access to supportive relationships, financial resources, flexible employment arrangements and responsive services may all influence a family's capacity to adapt. Consequently, resilience may be better understood as a relational and ecological process rather than an individual characteristic.

Qualitative research has identified tensions within parental understandings of resilience. Pope et al. (2025) reported that many parents described feeling pressure to appear resilient for the benefit of their children, even during periods of significant personal distress. Similarly, Skarstein et al. (2020) found that several mothers reported neglecting their own wellbeing in order to meet caregiving responsibilities. These findings suggest that externally visible resilience may not always reflect internal emotional experiences.

Critical perspectives argue that resilience discourse can inadvertently obscure systemic barriers. Where families experience long waiting times, fragmented services or inadequate educational support, adaptation may reflect necessity rather than genuine wellbeing. Perkins (2022) further argues that severe and prolonged

distress may limit opportunities for growth and adaptation, highlighting the importance of considering contextual constraints.

For Educational Psychologists, these debates suggest the importance of balancing recognition of family strengths with attention to systemic barriers. Supporting resilience may therefore involve not only strengthening coping resources but also addressing environmental factors that contribute to ongoing adversity.

2.11 Implications for Educational Psychology practice and identifying gaps

EP's must recognise that supporting families experiencing paediatric chronic pain may not rest solely at the individual level. Instead, EP's must attend to the wider systems and structures surrounding children and their caregivers. As discussed, chronic pain appears to sit within complex and sometimes fragmented healthcare and education systems, and cultural narratives that can minimise invisible illness. Within such contexts, traditional EP casework may not always be sufficient without parallel consideration of systemic influences.

Building from this, effective support may benefit from sustained, multisystemic collaboration. Schools can at times find it challenging to recognise and respond to chronic pain, particularly where symptoms are not observable. This may result in inconsistent access to appropriate adjustments, with families having to navigate complex communication across education and health services. EP's could play a valuable role in facilitating mesosystem communication, supporting the development of Individual Healthcare Plans (potentially informed by participatory tools such as the RAiISE Health Passport), and offering consultation and staff development grounded in psychological theory. However, such activity may require sufficient capacity and specific expertise; however recent research suggests that many EP's report feeling

underprepared to support this group without further training (Jeffery, 2023). This indicates a possible professional development need.

Furthermore, collaborative practice may require a shift in how professionals position expertise. Parents lived experiences arguably represent a unique form of knowledge that complements professional understanding. Viewing parents as co-designers of support, rather than solely recipients of services, appears consistent with relational and participatory approaches within educational psychology. Such a stance may help to foster trust, encourage shared problem-solving, provide reassurance and ensure work remains grounded in family context.

The hidden advocacy and interpretive labour performed by parents of children with chronic pain reflects a broader systemic phenomenon documented across the sociology of chronic illness and disability. This 'unseen labour', the continuous, uncompensated work of translating subjective symptoms, managing administrative institutional demands, and defending identity legitimacy, is not unique to paediatric pain; it mirrors the caregiving dynamics observed in neurodivergent populations, rare diseases, mental health conditions and other long-term conditions. For the discipline of educational psychology, identifying this commonality is vital. It shifts the practitioner's focus from treating the family's stress as an isolated, idiosyncratic response to their child's medical diagnosis, and instead frames it as a predictable consequence of systemic friction. By recognising that caregiver burnout and narrative chaos are often structurally generated by the labour of system-navigation, EP’s can better design systemic interventions that alleviate administrative and communicative burdens, rather than simply offering individual coping strategies.

2.12 Conclusion

This review has examined literature relating to paediatric chronic pain across healthcare, education, family and narrative domains. The evidence suggests that chronic pain is associated with a range of challenges extending beyond symptom management, including educational disruption, healthcare navigation difficulties, family stress and experiences of social misunderstanding.

The review also highlights several limitations within the existing evidence base. While substantial research has examined parental stress, family functioning and healthcare experiences, relatively little attention has been given to how parents construct and communicate narratives about these experiences. Existing studies frequently report issues relating to legitimacy, uncertainty, advocacy and meaning-making, yet these themes are rarely explored through a dedicated narrative inquiry framework.

Narrative theories, including Frank's illness narrative typology, offer potentially valuable conceptual tools for understanding how parents interpret experiences of chronic pain over time. However, further research is needed to examine how such frameworks operate within caregiver narratives, particularly where parents are navigating multiple systems on behalf of their children.

From an Educational Psychology perspective, the literature points towards the importance of collaborative, systemic and participatory approaches. Educational Psychologists may be well placed to facilitate communication between families, schools and healthcare services, support understanding of invisible health conditions and promote practices that incorporate family perspectives.

The literature discussed identifies a clear need for research that explores how parents narrate their experiences of supporting a child with chronic pain. Within this

thesis I seek to address that gap through the use of narrative inquiry, contributing to understanding of parental meaning-making within the interconnected contexts of family, education and healthcare.

Chapter 3: Methodology

3.1 Overview

In this chapter I outline my research question and how that informed and guided me to the methodological approach I used. I will then turn to the key philosophical concepts of ontology, epistemology, methodology, and methods are explored, and how these informed the overall research design. I then introduce the narrative methodology (Narrative Oriented Inquiry), along with the rationale for its selection, followed by a discussion of the ethical considerations relevant to working with parents who shared sensitive and deeply personal experiences.

The overarching aim of my research has been exploratory and interpretive. I wanted to consider how parents of children with chronic pain narrated their experiences and made sense of their experiences. These aims, specifically the desire to conduct qualitative research and to interpret the unique stories of the participants, were in close alignment with my ontological and epistemological position as a researcher.

The study I present in this thesis emerged from an earlier research plan that proved difficult to implement in practice. My initial topic, which focused more narrowly on a different population and recruitment route, did not generate sufficient participation despite extended efforts. This experience is not uncommon in qualitative research and prompted me, in consultation with my supervisor, to refine the focus and recruitment strategy in a way that remained aligned with my broader interests in chronic conditions, family experience and educational systems. Reflecting on this shift is important, because it highlights how methodological decisions are shaped not only by theoretical considerations but also by practical constraints and ethical responsibilities to participants.

3.2 Research Question

I was guided by a single, central research question:

How do mothers narrate their experiences of caring for a child who experiences chronic pain?

My rationale for the use of a single research question is as follows-

Narrative research is inherently focused on depth, context, and meaning-making rather than breadth or generalisability (Clandinin & Connelly, 2000). Riessman (2008) also highlights that narrative studies often concentrate on an individual or small number of cases, making a singular, open-ended research question both methodologically appropriate and sufficient to explore lived experience in rich detail.

At the start of my research journey I considered whether having multiple questions would provide more structure and direction, but I decided that this may act as a constraint. Therefore, a single guiding question was sufficient for my aims, it provides the necessary focus and flexibility to allow participants' stories to unfold naturally,

3.3 Ontological and epistemological positioning

3.3.1 Ontological position

Ontology concerns beliefs regarding the nature of reality (Lincoln and Guba, 1986). There is a continuum of philosophical beliefs ranging from Realism to Relativism (Willig, 2008). According to Realism, there is one objective truth that can be observed and measured. Conversely, relativist argues that "truth" is entirely dependent on the perspective, culture, or context of the person experiencing it. (Willig, 2008).

My stance as a researcher is as a Critical Realist. This ontological position believes that there is value in recognising the subjective experiences of social actors, whilst taking account of independent structures that may constrain or facilitate those social actors within that context (Sayer, 2010). The reality separate of people's conception does exist, but it is not accessible to direct observation (Bhaskar, 1998). Therefore, this stance allowed me to explore the insights and experiences of parents around the concept of chronic pain and caregiving, whilst also acknowledging that there are multidimensional structures and systems, such as healthcare protocols and social expectations, that may impact on the person, that are separate to their experience and not directly accessible to be explored (Bhaskar, 1998; McEvoy and Richards, 2002). Through my exploration of parents' insights around their child's illness, I sought to promote an understanding of a phenomenon that is complex, as opposed to measuring it or 'translating' it (Sobh and Perry, 2006).

From a critical realist perspective, I acknowledge that the phenomenon of chronic pain and the caregiving role exist outside of individual interpretation. However, I also recognise that parents' accounts of their experiences are shaped by the contexts they live in, such as, healthcare systems, family dynamics, and social narratives around illness and parenting.

3.3.2 Interpretivist epistemology

Crotty (1998) describes epistemology as, how we might know reality, how we might pursue knowledge, and what parts or types of knowledge are reasonable.

My epistemological approach was to observe and interpret meaning from the participants narratives. I aimed to understand the meanings parents assign to their caregiving experiences, recognising that these meanings are co-constructed through

dialogue between the participant and myself, the researcher (Fletcher, 2017). Therefore, the epistemological stance I adopted in this research was interpretivist. Interpretivism holds that knowledge is constructed through human interpretation and social interaction.

By adopting a critical realist ontology and an interpretivist epistemology, I positioned myself to explore the complex, multifaceted experiences of parents caring for a child with chronic pain. This philosophical stance supported a narrative inquiry approach, allowing for an in-depth understanding of participants' narratives while acknowledging the broader social structures that influence these experiences.

3.4 Narrative Methodology

In qualitative research, narrative methodology refers to a distinct approach to inquiry that is grounded in the assumption that people make sense of their experiences through storytelling. It focuses on the *form, content, and function* of narratives as a means of accessing and understanding human experience. As Clandinin and Connelly (2000) argue, narrative inquiry is the study of experience “as story,” where people “lead storied lives and tell stories of those lives.” (p. 19).

The narrative form is not simply a way of presenting data but is central to how individuals understand, and reflect on their lived experiences over time, as well as communicating it. Bruner (1986) differentiated between two fundamental ways of knowing: the logico-scientific mode, which seeks objective explanation through logical reasoning, and the narrative mode, which he characterises as being concerned with “the human plight in the human context” (p. 13). Rather than relying on formal propositions, the narrative mode constructs meaning through temporally structured stories. The latter aligns with the aims of this research, which seeks to

explore how parents make sense of their caregiving roles within the complex emotional and practical realities of supporting a child in chronic pain.

Narrative is not a passive recounting of events but an active, interpretive process. As Clandinin and Rosiek (2007) argue, storytelling enables individuals to create coherence and meaning across past, present, and anticipated futures. In this way, narratives function both as a method of understanding and as a vehicle for identity construction. Bruner (1986, 1990) contends that narrative is best understood as a dynamic act, *to narrate*, and serves to illuminate subjective experiences and shared interpretations of reality.

Narrative theory suggests that people naturally use storied forms to organise and give meaning to their experiences (Sarbin, 1990). These narratives allow individuals to impose structure and causality onto otherwise disjointed life events, offering clarity and emotional sense-making even in situations of uncertainty or distress (Polkinghorne, 1995; Murray, 2003). In the context of chronic childhood pain, parents are often navigating shifting identities and uncertain outcomes; narrative inquiry allows them to express how they can adapt, cope, reflect on their evolving roles and make sense of their experiences.

Narratives are shaped by social and relational contexts. The meaning created through storytelling is co-produced by the teller and their audience (Riessman, 2008). This view challenges the notion of the narrator as a detached reporter and instead positions them as an active meaning-maker within a specific cultural and interpersonal setting (Murray, 2003). As such, the narratives gathered in this research are not viewed as static or final representations of experience but as fluid

and dialogic constructions influenced by the interaction between myself and the participants.

Ricoeur (1991) offers a useful conceptual lens for understanding how people shape their identities through storytelling. He describes a dual process of *configuration*, in which events are arranged into meaningful plots, and *refiguration*, where the act of narration reshapes the narrator's sense of self. Similarly, Hiles and Čermák (2009, 2017) highlight the concept of *identity positioning*, where individuals select particular perspectives or emphases in their stories to assert specific aspects of self, influenced by such things as, context and emotion.

3.5 Alternative Methodologies considered

The selection of methodology is primarily shaped by the nature of the research question. In my thesis, I sought to explore the lived experiences of parents caring for a child with chronic pain. Given the subjective and deeply personal nature of these experiences, a qualitative approach felt most appropriate. Unlike quantitative methods, which aim to measure or generalise findings, qualitative research is concerned with understanding human experiences in their complexity and context (Riessman, 2008). It offers a flexible framework for capturing meaning, emotion, personal interpretation and appreciates nuance, all of which are central to the aim of my research.

In determining the most suitable qualitative methodology, I considered several approaches. Grounded theory, for instance, is a systematic methodology designed to develop new theoretical insights grounded in participants' actions and narratives (Charmaz, 2014). Case study methodology allows for an in-depth, contextual analysis of a phenomenon using multiple data sources (Yin, 2018), while

Interpretative Phenomenological Analysis (IPA) focuses on how individuals make sense of their lived experiences (Smith, Flowers, & Larkin, 2009). Each of these methodologies offers valuable tools for exploring complex human experiences and was considered for this research.

However, all three approaches presented certain limitations in relation to my research aims. Grounded theory and IPA typically involve breaking down experiences into themes or concepts, which can fragment the narrative flow. Similarly, case studies focus heavily on context and may draw attention away from the subjective meaning-making processes of individuals. As I was particularly interested in how parents narrate their caregiving journeys; emotional, relational, and meaning-making aspects of their experiences, I sought a methodology that could preserve the integrity of the participants' stories as whole, contextualised narratives.

Narrative inquiry emerged as the most suitable methodological choice. Narratives are not merely accounts of events but are deeply embedded in how people make sense of themselves and their worlds (Riessman, 2008). Stories allow individuals to organise and communicate their experiences, while also revealing the personal and social factors that influence and shape those experiences alongside cultural influences. In this sense, narrative research enables a rich, layered exploration of human meaning-making that aligns well with my critical realist stance, acknowledging both the real-life challenges of parenting a child in chronic pain and the interpretive frameworks through which these experiences are understood.

Narrative psychology offers a useful lens here, treating stories as a central medium through which people understand their lives, emotions, and identities (Bruner, 1990). Hiles et al. (2017) argue that narratives offer insight into the events that people

experience, their sense of agency, their values, as well as the process of self-construction. The way a parent chooses to tell their story can highlight what they find significant, what they prioritise and/or resist, and how they position themselves within broader social or medical discourses.

Additionally, narrative methodology honours the whole story rather than fragmenting it into categories or themes. It allows for a more holistic appreciation of each participant's experience and aligns with my aim to explore how parents construct meaning from their roles and responsibilities.

3.6 Data Collection

3.6.1 Narrative interviews

I chose narrative interviews as the primary method of data collection for this due to their capacity to elicit rich, contextualised accounts of lived experience. Given that the research aims to explore the emotional and relational experiences of parents caring for a child with chronic pain, a method that allows for the depth and complexity of personal stories to emerge was essential.

Narrative interviewing aligns closely with the Narrative Oriented Inquiry (NOI) framework (Hiles & Čermák, 2009), which views stories as vessels of information and active constructions of identity and meaning. In this tradition, participants are encouraged to reflect on and shape their experiences into a coherent narrative, allowing researchers to access not just what happened, but how individuals make sense of what happened and how they position themselves within those events (Riessman, 2008).

I explored the possibility of using a number of Narrative tools to support the interviews, such as the Tree of Life approach (Ncube, 2006), narrative mapping

tools, or timelines (Adriansen, 2012). These tools can be especially effective in facilitating storytelling, particularly for participants who may find it difficult to verbalise their experiences in linear or traditional formats. The Tree of Life, rooted in narrative therapy, offers a metaphorical structure in a visual and interactive way. Similarly, timelines can help participants to situate and sequence key events, aiding memory recall and encouraging reflection on change over time (Sheridan et al., 2011).

However, after reflection, I determined that unstructured narrative interviews would offer the most appropriate balance of flexibility and depth. Unlike structured tools, narrative interviews allow participants to control the flow of their stories, emphasising what they feel is important without being constrained by imposed frameworks or visual metaphors (Wengraf, 2001). This approach was also seen as particularly suitable for parents who may wish to recount their experiences in emotionally nuanced and context-sensitive ways.

Narrative interviews also honour the subjective and situated nature of knowledge, which is central to the epistemological stance of my thesis. As Polkinghorne (1995) argues, narrative methods do not seek to fragment experiences into isolated themes, but to preserve the integrity of the story and its meaning in the life of the narrator. This is particularly relevant in a context where parents may have experienced marginalisation or misunderstanding within medical, educational, or social care systems. Providing a space for their voices to be heard in full was therefore an ethical and methodological priority.

All interviews were conducted via Google Meet, this was a pragmatic and ethical decision shaped by participants' time constraints and geographical considerations.

This format enabled access to families across two regions without imposing travel burdens, while allowing participants control over their environment.

Benefits included natural domestic interruptions (pets) that revealed caregiving realities, reduced time for travel, and participants being comfortable in their own homes. Limitations of virtual interviews were considered, for example, virtual interviews may reduce embodied cues, these were mitigated through attention to vocal tone and paralinguistic markers.

3.6.2 Recruitment and participants

I recruited three participants, each of whom were mothers of a child experiencing chronic pain. Recruitment was carried out using purposive sampling, a common approach in qualitative and narrative research, which seeks to identify participants able to offer rich, relevant, and diverse insights into the phenomenon under study (Palinkas et al., 2015). Purposive sampling prioritises the selection of “information-rich cases” that enable in-depth exploration and conceptual understanding, rather than statistical representativeness (Patton, 2002, p. 230).

Within this approach, the aim is not to produce statistically generalisable findings, but to generate insights that may hold theoretical or analytic relevance beyond the immediate sample. As Patton (2002) argues, qualitative findings can be transferable where readers are able to recognise resonance and applicability within comparable contexts. The sample size aligns with accepted conventions in narrative inquiry, where depth and richness of individual stories are prioritised over breadth and generalisability (Riessman, 2008; Hiles & Čermák, 2009). Narrative research often involves a small number of participants to enable in-depth exploration of lived

experiences and identity construction through detailed, contextualised accounts (Clandinin & Connelly, 2000).

Two participants were recruited through Special Educational Needs and Disabilities Coordinators (SENDCos) at schools in a local authority (LA) in the Midlands area, one from a primary and one from a secondary setting. The third participant was recruited via a parent carer forum in a different LA within a Northern region. These forums act as peer-led spaces for parents and carers of children with additional needs and provided a valuable route into communities where lived experience of chronic health conditions is more visible.

Initial recruitment efforts included sharing an advert with all SENDCos in the LA where I am currently undertaking professional placement, as well as posting within Facebook support groups for parents of children with chronic pain. In addition, I reached out to parent carer groups across various LAs in England. These strategies were chosen to increase the diversity of perspectives and improve accessibility for potential participants, while maintaining a focus on the population most relevant to the study's aims.

While the number of participants may appear modest from a quantitative perspective, the focus on narrative depth supports this choice. From a critical realist ontological perspective, this small, purposively selected sample is appropriate because the aim is to illuminate the complexity of lived experience and the interactions across multiple systems, structural (school and healthcare), psychological (parent and child coping), and discursive (beliefs about chronic pain). Each participant's narrative contributes meaningfully to understanding how chronic

pain is experienced and how it is interpreted, along with the way it is acted upon within overlapping systems.

All three participants were mothers. Two of the three had professional experience in education or health-related roles, including familiarity with legislation, policy language and multi-agency processes. This professional knowledge appeared to shape both how they navigated systems and how they narrated their experiences, for example in their use of legal terminology or reference to statutory guidance. The sample therefore reflects mothers who are comparatively confident in dealing with services. This has implications for transferability and equity: families with less system knowledge, different educational backgrounds or fewer opportunities to engage with professional networks may encounter additional barriers and may tell different kinds of stories about care, school and support.

3.7 Data Analysis

I adopted the *Narrative Oriented Inquiry* (NOI) framework developed by Hiles and Čermák (2009), they describe Narrative Oriented Inquiry as “a pluralistic framework” that draws on multiple analytic lenses to remain sensitive to both “what” is told and “how” it is told. NOI provides a flexible and pluralistic approach, offering a set of interpretive strategies that can be used independently or in combination. NOI regards storytelling as a co-constructive act between researcher and participant, with narrative interviews seen as spaces for shared reflection and sense-making (Hiles & Čermák, 2009).

Reflexivity is a key component of this process. The researcher's positionality and interpretive lens inevitably influence the construction and understanding of narratives (Finlay, 2002). Therefore, I have taken care to approach my participants’ stories with

openness, acknowledging how my own perspectives and assumptions may shape the meanings interpreted.

Despite its increasing prominence, narrative analysis remains a relatively fluid and evolving area within qualitative psychology (Hiles et al., 2009). There is no single, standardised procedure for narrative analysis; instead, it offers a range of interpretive tools for understanding the structure, content, and function of stories. As Willig (2013) suggest, narrative analysis differs from other qualitative approaches by aiming to retain the integrity of the full account rather than segmenting data into discrete themes. The goal is to interpret stories in a way that is as non-intrusive and faithful to the participant's voice as possible, while acknowledging the researcher's role in shaping the narrative through interaction and interpretation.

A central analytic distinction within NOI is between *fabula*, the chronological sequence of events, and *sjuzet*, how the story is structured and told. While the *fabula* forms the backbone of the narrative, the *sjuzet* provides insight into the narrator's psychological and emotional processing of events, revealing deeper layers of meaning and identity work (Hiles & Čermák, 2017).

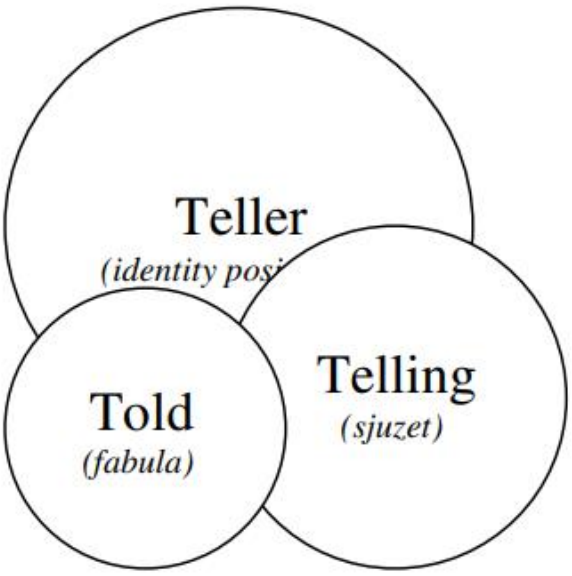

Figure 3.1: The relationship between the teller, the telling and the told (Hiles et al., 2009, p.9).

Within the NOI methodology, the interpretive schema proposed by Lieblich et al. (1998) are adopted, which offers four complementary approaches:

- Holistic-content: This involves exploring and linking overall themes of the story and identifying specific units of text which may illuminate the story as a whole.
- Categorial-content: This requires a division of the text into, smaller, separate units and analysing these discrete units using thematic analysis.
- Holistic-form: This is concerned with the fabula i.e., the overall plot or structure of the story.
- Categorical-form: This is concerned with the sjuzet, in other words, the distinct linguistic features and ways of relating a plot that supports the overall style of the story.

These approaches allowed me to engage with the narratives from multiple angles, respecting the integrity of the whole account while also examining patterns of meaning and expression.

Reflecting on the use of NOI in my thesis, I feel it provided an effective methodological framework for exploring how participants construct, interpret, and communicate their caregiving experiences in the context of chronic childhood pain. It enabled a nuanced and empathetic understanding of identity, struggle, and adaptation, while remaining sensitive to the relational and contextual factors that shape those stories.

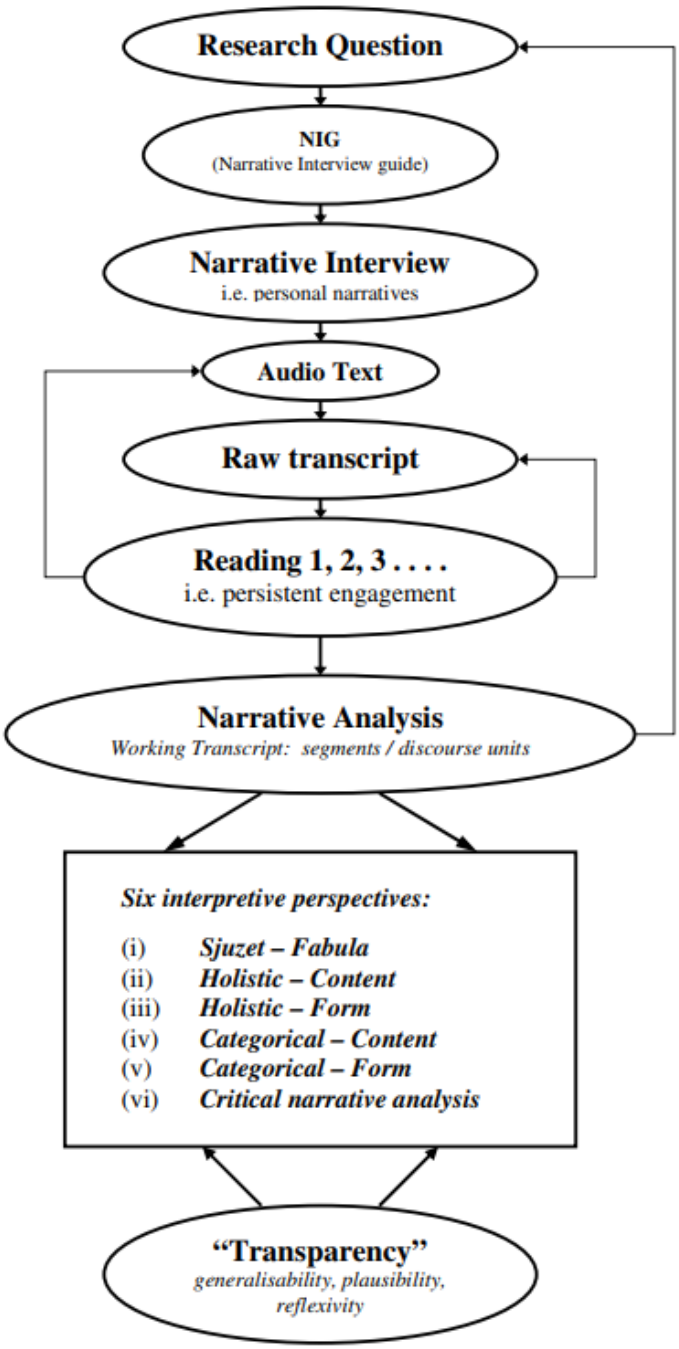

Figure 3.2: The Six-Stage Dynamic Model of NOI (Hiles & Čermák, 2009, p. 10)

3.7.1 Stage 1: Transcription, coding, segmenting into 'moves' and separating the Fabula and the Sjuzet

Consistent with the NOI approach, the first stage involved the transcription of interview data and deep, repeated engagement with the material through rereading

and relistening. Analysis proceeds by breaking the text down into numbered segments. Hiles and Cermak (2009) describe the process as the following: “Since narratives are basically a sequence of episodes, we define a segment as being roughly a self-contained episode, or ‘move’, in the telling of the story. This is not foolproof but is relatively straightforward and transparent. In our experience, this can be done, first with a quick read-through marking the segments, followed by a more careful read-through making adjustments (p.58). Notes on paralinguistic features were taken during the interviews and used to support the analytic process (see Appendices A, E and I) Transcriptions were generated using the Google Meet transcription and then I edited this by re-listening to the interview recording on numerous occasions.

The ‘moves’ were labelled (e.g., Move 3). Following the guidance of Hiles et al. (2009), I formatted transcripts as working documents, positioning the narrative on the left with a wide margin on the right for annotations.

A key aspect of this stage is the distinction between *sjuzet* and *fabula* (Hiles et al., 2009), drawing from Herman and Vervaeck’s (2001) conceptualisation of bounded and unbounded narrative elements. The *sjuzet* represents the “unbounded” dimension, the way the story is told, including asides, reflections, and emphases, which often reveals how identity is being constructed (Hiles et al., 2009). In accordance with common analytic conventions, I underlined segments identified as *sjuzet*.

In contrast, the *fabula* consists of the “bounded” elements, those aspects of the narrative that, if altered, would change the factual sequence of events (Hiles et al., 2009). Though some subjectivity is inherent in distinguishing *sjuzet* from *fabula*,

Hiles et al. (2009) note that a *fabula* read in isolation tends to resemble a flat retelling of the story.

3.7.2 Stage 2: Holistic–Content Analysis

Unlike thematic or discourse analysis, which typically dissects narratives into parts, NOI prioritises the integrity of the entire story (Hiles et al., 2009). The *holistic–content* approach (Lieblich et al., 1998) focuses on identifying and interpreting overarching themes and the central narrative thread in each participant's account.

To begin, I formed a global impression of each narrative and generated a summarising sentence that captured its essence. I annotated the transcripts with thematic notes, observing how core narratives emerged and reappeared across each participant's story (see Appendices A, E and I)

3.7.3 Stage 3: Holistic–Form Analysis

The *holistic–form* stage explores narrative typologies (e.g., tragedy, comedy, romance) and the structural characteristics of the *fabula* (Lieblich et al., 1998). In the holistic form stage of analysis, I focused on what kind of story each parent was telling overall, rather than analysing their accounts using traditional literary typologies such as romance, tragedy or comedy. Instead, I developed parent-specific narrative typologies grounded in these three narratives. I read each interview several times as a whole, paying attention to the overall plot shape, how the story moved between past, present and future, and how the parent described themselves and others. From this, I identified recurring ways of telling, such as battle or advocacy stories, burden or isolation stories, holding or containment stories, translation stories, and stories of cautious or contingent hope. I then examined how participants moved between these different ways of telling within and across their interviews.

3.7.4 Stage 4: Categorical–Content Analysis

As part of the categorical–content mode of analysis described by Lieblich et al. (1998), I explored the self-contained areas of meaning within each participant's narrative. The process started by reading through each move and making notes/codes in the left margin. Following this I grouped the codes into subcategories that reflected recurring patterns and unique features across the data, before further grouping of these into main themes (Hiles et al., 2009). Consistent with my interpretivist epistemology and realist ontology, I approached this process both inductively and deductively, drawing on theoretical insights while remaining open to new themes that emerged from participants lived accounts.

As recommended by Lieblich et al. (1998), I worked cyclically, re-reading transcripts, refining codes, and reinterpreting categories as new insights arose. I used a coding key to track emerging themes for each participant and updated it iteratively, eventually producing a consolidated version. A summary table was also developed to support the comparative analysis and organise my reflections during this phase (see Appendices, C, G and K).

3.7.5 Stage 5: Categorical Form Analysis

In Stage 5- Categorical Form analysis (Lieblich et al., 1998; Hiles & Čermák, 2017), I carefully analysed the *sjuzet*; the manner in which the story is told, to uncover emotional and psychological processes not evident in content alone. This stage involved a detailed examination of smaller interview sections selected for their intense emotional charge or the evident negotiation of a core personal dilemma. To explore the linguistic devices that strengthen the narrative's impact and indicate psychological stress, formal features were analysed within these selected

paragraphs (Lieblich et al., 1998). For example, mental verbs (e.g., *I think that, I reflected*); direct speech (used to vividly re-enact traumatic or crucial dialogue); intensifiers (e.g., *very, really*) or de-intensifiers (*a bit, kind of*); and repetitions of words or phrases. The objective was to glean information regarding how participants process and cope with their chronic caregiving experience, thus offering an alternative lens for interpreting the overarching thematic categories derived from the analysis.

3.7.6 Stage 6: Critical Analysis

The final stage of NOI involves critical reflection on how identity is constructed through narrative (Hiles & Čermák, 2009, 2017). Building on Emerson and Frosh (2004), Hiles and Cermak (2009) emphasises that identity is shaped by multiple interlinked identity positions within the *sjuzet*. This analytic stage is most effective when conducted after all previous stages are complete.

I returned to the transcripts with a focus on the *sjuzet*, guided by the following questions:

1. How does the participant position themselves within their narrative?
2. What type of narrative are they constructing?

This stage enabled me to further explore the interplay between narrative structure and self-construction, offering additional insight into participants' evolving identities within their storytelling.

3.8 Quality of the Research

NOI is a methodology aligned with the values of subjectivity, meaning-making, and contextual understanding. As such, it sits within an interpretivist epistemology and

cannot be judged by traditional positivist criteria like objectivity and reliability, or generalisability (Willig, 2013). Instead, the emphasis lies on the depth and richness of participants' stories, the internal coherence of interpretations, and the insights these narratives offer to professional practice.

Yardley (2000) proposes four broad principles for evaluating qualitative research: "sensitivity to context; commitment and rigour; transparency and coherence; impact and importance." (p. 219).

- **Sensitivity to context** – Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues. This can include the emotional, social, and cultural contexts in which participants narrate their experiences.
- **Commitment and rigour** – In-depth engagement with topic; methodological competence, skill; thorough data collection; depth/breadth of analysis. This is evident in careful narrative interpretation and transparent engagement with data.
- **Transparency and coherence** – Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method. This is demonstrated through reflexivity, ensuring methodological congruence, honest positionality, and logical flow.
- **Impact and importance** – Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers). Shown through exploring how these parental narratives can inform educational psychology and multi-agency support around chronic pain.

3.9 Reflexivity and Insider Positionality

A central element of qualitative research, particularly narrative research, is the researcher's reflexive engagement with their own positionality. Berger (2015) suggests that reflexivity involves "ongoing self-awareness and critical self-reflection on the researcher's potential biases and predispositions." (p. 220). This includes an ongoing awareness of how personal identity, background, and emotional

investments influence the research process (Berger, 2015). As already touched upon in the introduction chapter, I occupy a form of insider positionality within this thesis. Although I am not a parent of a child with chronic pain, my partner has experienced chronic pain since adolescence, and I often have to care for her. This position inevitably shapes my understanding, attunement, and emotional resonance with participants' stories. Bulk and Collin (2021) argue that insider research brings both potential strengths and challenges. On one hand, being an insider can foster trust between the researcher and participants and invite empathetic insight, and arguably, give access to deeper layers of meaning. It can also reduce the distance between researcher and participant and promote a relational connection that aligns with the goals of narrative inquiry. On the other hand, insider status may introduce risks of over-identification, emotional entanglement, and/or assumptive interpretation, where the researcher assumes they "already know" rather than staying open to each participant's unique perspective.

I engaged in critical reflexivity throughout the research, using field notes and journaling (see Appendix S) to ensure I was aware of any potential biases. I documented emotional responses, moments of resonance, and potential assumptions. I consistently asked myself: *Am I truly hearing this story on its own terms?* and *What am I bringing into this interaction?*

I am also a Father to a young daughter, which adds an addition layer of personal relevance. Although my daughter does not currently experience chronic pain, it is something both myself and my partner have wondered about, given genetic and environmental factors. This concern gave rise to an emotional connection with many of the parent participants, particularly around themes of uncertainty, helplessness, hope, and advocacy.

I feel as though these personal dimensions introduced a sense of emotional proximity, they also deepened my sensitivity to the emotional labour of parenting a child in pain, an insight that was especially valuable when interpreting moments of silence, frustration, or grief within narratives. I also acknowledge the privilege embedded in my role as a trainee educational psychologist.

I took steps to address this power dynamic by:

- Positioning myself as a listener and learner within the research relationship.
- Emphasising participants' ownership of their stories.
- Using open-ended prompts to invite narrative freedom.
- Respecting participants' decisions about what they were happy for me to share

During the recruitment process, I encountered an undercurrent of distrust and suspicion within some parent support groups I contacted, particularly in online spaces, regarding the intentions of researchers and concerns about where their shared information might ultimately be used. To address this, I intentionally adopted a reflexive and transparent approach, sharing my own positionality and experiences with participants. I drew on Bulk and Collin's (2021) insights into insider research and decided to disclose aspects of my personal connection to the research topic, including my role as a parent and my lived experience of navigating chronic pain within my family, through my partner's journey since adolescence.

I feel this act of sharing my 'story' served to bridge the gap between researcher and participant, fostering trust and relational openness. By making my motivations and

intentions explicit, participants were reassured about the ethical underpinnings of the research and its commitment to respecting their narratives. As a result, this approach appeared to increase participant interest and their willingness to engage in deeper, more meaningful storytelling. This aligns with the principles of relational ethics and reflexivity in qualitative research, which emphasise the co-construction of knowledge through authentic and transparent researcher-participant interactions.

3.10 Reflexive Analysis of Co-Construction in Practice

Having outlined my insider positionality, I now turn to how this shaped the research in practice, examining specific moments where co-construction was evident.

My opening question across all three interviews was: *"Can you tell me about your experience of caring for [child's name] and their pain, perhaps starting from when you first noticed something wasn't quite right?"*

The intention of this opening question was to position participants as expert narrators with authority over their story's starting point and emphasis. However, on reflection it also embedded assumptions: the phrase "when you first noticed something wasn't quite right" presupposed a narrative of gradual recognition and potentially, early dismissal. This may have primed 'battle' or 'diagnostic uncertainty' narratives. An alternative opening, *"What's it like day-to-day caring for [child]?"*, might have invited different narrative trajectories, potentially foregrounding adaptation or relationship rather than struggle.

During interviews, I noticed (from reflexive notes) that I tended to respond to descriptions of professional dismissal or system failure with affirmative phrases. While these responses built rapport and validated participants experiences, they may have reinforced a particular position in the participants, perhaps one of struggle,

burden, injustice, and potentially inhibited participants from expressing ambivalence, positive experiences with some professionals, or moments of acceptance without qualification.

Conversely, when Kelly briefly mentioned a supportive GP, I responded with a shorter acknowledgment ("That's good") before redirecting to pain management strategies. In retrospect, this asymmetry in my responses (longer, warmer affirmations for struggle; briefer acknowledgments for support) likely signalled to participants what I found valuable or interesting, potentially shaping subsequent narrative choices.

All three participants showed signs of upset during interviews. My response was consistent: pause, ask whether they wanted to stop or take a break, and wait silently until they indicated readiness to continue. No participant chose to stop, and all resumed after a short time.

While this ethical care was necessary, it may also have communicated that emotional testimony was perhaps expected. Did this inadvertently create pressure to perform vulnerability? Or did it create safety to express previously suppressed distress? I cannot know definitively, but I note that emotional intensity often increased following these pauses, suggesting either deepening trust or amplified performance of suffering, or both simultaneously.

As a male trainee EP, I occupied contradictory positions: insider regarding chronic pain experience (via my partner), but outsider regarding maternal caregiving and gendered dismissal. This likely shaped interviews in complex ways.

My insider disclosure, shared early in each interview, built trust. Kelly explicitly stated, "You get it, you know what it's like," when I mentioned my partner's chronic

pain. However, this shared identity may also have created pressure to frame stories in ways that aligned with my presumed experience, or to emphasise struggle and system failure (which had featured in my partner's journey) over other possible narrative threads.

My professional identity as trainee EP carried distinct implications. Kelly explicitly referenced my professional status when describing her own use of 'professional language' with schools: "You'll know what I mean when I say I had to pull out the legal language, the 'reasonable adjustments', the 'disability discrimination.'" This suggests she saw me as someone who would understand and validate strategic advocacy.

Yet this professional positioning may also have acted as a barrier to certain disclosures. Participants may have withheld expressions of feeling overwhelmed, incompetent, or resentful toward their child, anticipating judgment from someone in a professional caring role. Maddy's comment, "I always have to hold it together, even when I want to fall apart", may reflect not only her experience with professionals generally, but her performance for me specifically as someone affiliated with those systems.

My gender undoubtedly shaped what mothers chose to share. Following Butler's (1990) conceptualisation of performativity, I considered how the interview space might have invited specific performances of identity. Did the participants perform 'good mother' identities more strongly for a male interviewer perceived as potentially judging maternal adequacy? In this context, performance is not framed as a lack of authenticity, but as the discursive way in which individuals enact and reinforce identity through interaction (Butler, 1990). Did they emphasise strength and

advocacy, qualities often coded as masculine in Western culture, to gain credibility? Conversely, did my outsider status as a man enable some mothers to articulate frustrations or vulnerabilities they might withhold from female researchers, whom they might perceive as more critically evaluating their maternal performance?

These remain open questions but acknowledging them demonstrates epistemological humility: the narratives I gathered are not 'mothers' stories' in any universal sense, but 'the stories these mothers told me, as a male trainee EP with insider chronic pain experience, in this virtual context, at this moment in their caregiving journeys.'

In analysis, I was initially drawn to instances where participants described dismissal and having to 'fight' because these resonated with stories my partner has told about their own pain. My reflexive journal shows I initially coded many segments as 'battle' without considering alternative framings. For example, when Dani described a meeting with school where she "laid out all the evidence," I coded this as 'battle/confrontation.'

Supervision challenged me: "Could this also be read as 'education' or 'generous explanation' rather than battle? What if she didn't experience it as fighting?" This prompted me to revisit the surrounding narrative. Dani's tone was calm, her framing matter-of-fact; the 'battle' interpretation was mine, not hers. I recoded this as 'translation/explanation' and developed 'calibration' as a distinct narrative mode, adjusting communication to audience, which might have been missed without that reflexive interrogation.

Similarly, my identification of 'professional parental capital' may reflect my own middle-class privilege and professional socialisation. I recognised what Kelly and

Maddy were doing (using policy language, invoking legal rights) because I understand those codes, they're part of my professional training. It is possible I under-recognised or miscoded strategies used by Dani, whose professional background is less explicit in the transcript, because they didn't fit frameworks familiar to me. Her navigation might look different, perhaps more relational, less formally rights-based, and my analysis may inadvertently privilege recognisable 'professional' performances over other equally effective but less visible strategies.

Despite these reflexive efforts, much remains opaque: for example, what did participant chose not to say, and how did our interaction in this specific moment differ from how they might narrate their experience to audiences, such as, a GP, a fellow parent, a family member or a friend. The narratives analysed are therefore not 'their stories' but 'the stories they told me, in this context, for these purposes.'

This is not a limitation to be apologised for; it is the epistemological reality of narrative research. All narratives are co-constructed; all storytelling is situated and relational (Riessman, 2008). By making my contribution to this co-construction visible, I aim for transparency about the conditional, partial nature of knowledge generated through my research. These are not 'true' stories (though they are truthful); they are contextual, relational performances of identity and experience that reveal something important about how these mothers navigate chronic childhood pain in contemporary UK systems.

3.11 Impact and Importance

It is hoped that through this thesis I contribute to a growing body of work that recognises the family context, and especially parental perspectives, as central to understanding the experience of paediatric chronic pain. By focussing on the voices

of participants through narrative, I address a gap in the literature and offers insights into the emotional, relational, and systemic dimensions of caregiving.

The findings have potential impact in several domains:

- **Theoretically**- I expand the use of narrative inquiry within educational psychology and demonstrating how illness narratives can support identity construction and meaning-making.
- **Practically**- I inform how educational psychologists, teachers, and multi-agency professionals can work more empathically and relationally with families.
- **Culturally**- I challenge deficit-based narratives of parenting and illuminating the strengths, struggles, and invisible work that parents of children with chronic pain perform daily.

In addition to the above, it is hoped that by attending to mothers' stories, educational psychologists can better understand how professional systems (e.g., schools, healthcare, CAMHS) are experienced by families, and how these systems can either validate or invalidate their realities.

3.12 Ethical Considerations

Throughout the thesis, I adhered to the ethical standards set by the University of Sheffield (see appendix M for Ethical review application), the professional guidance of the Health and Care Professions Council (HCPC, 2016) and the British Psychological Society (BPS, 2014, 2018a).

From the outset participants were provided with detailed information about the research process, their rights, the nature of data collection, and how their narratives

would be treated (see appendix P for participant information sheet and Appendix Q for Participant consent form). Informed consent was secured and reiterated before each interview. Emotional sensitivity was prioritised during interviews, including the option to pause, take breaks, or withdraw without explanation. Follow-up opportunities were offered for participants to reflect further or receive additional support.

3.13 Consideration of Language

I was conscious about the language I used, as this was a central ethical consideration. Rather than pathologising families or positioning pain as a fixed identity, I refer to "mothers of children who experience chronic pain," within the thesis, reflecting the dynamic, lived experience of pain within a relational and social context. This aligns with the study's narrative orientation, placing emphasis on how families make sense of pain, rather than assuming that diagnostic labels fully explain it.

Chapter 4: Analysis

4.1 Overview and structure

The analysis chapter is organised by participant, conducting a multi-layered interpretation using the distinct components of NOI to inform the answer to my research question;

"How do mothers narrate their experiences of caring for a child who experiences chronic pain?"

Stage 1- Segmenting and Identifying Fabula and Sjuzet

The first step of NOI, which involves segmenting the transcript into 'moves', and separating the *fabula* and *sjuzet* was completed following the transcription process. This can be seen in the individual working transcripts (See Appendices, A, E and I). During this step I also found it helpful to create a master table to support my analysis (See Appendices, B, F and G).

Findings will be presented in the following way for each participant:

Pen-picture

I will begin by providing a brief descriptive overview of each participant to establish relevant background information and context necessary for understanding their narrative.

Stage 2- Holistic-content Analysis

This section will present the overall meaning and message of the narrative presented in a summary of the key themes that recur across the entire participant's narrative.

Stage 3: Holistic-Form Analysis

The focus here shifts to the structural and stylistic characteristics of the narratives, examining the narrative typologies and the way the story is shaped and unfolds.

Stage 4- Holistic-Content Analysis

I will then present the findings concerning specific topics and concepts identified within the narrative. This involves defining the main categories and subcategories, using concise, exemplary sentences to illustrate their meaning. (While detailed tables showing the frequency and examples of all quotes were compiled in the Appendices, the analysis chapter will focus primarily on the prominent subcategories, using these principal illustrative quotes.)

Stage 5- Categorical-Form Analysis

This section will delve into the linguistic features present in selected extracts. I will highlight relevant linguistic elements and pay close attention to paralinguistic devices, such as shifts in tone of voice and the presence of pauses.

Stage 6- Critical analysis- Identity Construction and Positioning

Finally, I will offer a critical interpretation of the data, focusing on how the participant constructs and positions their identity throughout their narrative. I will draw upon key quotes and sections of the text that particularly reflect this process of identity negotiation and construction.

4.2 Dani- Data Analysis-

Pen-picture

Dani is a Mum of two boys Bennie (14) and Leo (12), both of which attend a local comprehensive secondary school. Leo has a diagnosis of Juvenile Idiopathic Arthritis (JIA) with associated Uveitis. Dani lives with her children and husband Paul. Dani approached me to participate in the research after seeing the research advert in an online support group.

4.2.1 Stage 1- Segmentation and separating the Fabula and Sjuzet

Please see Appendix A for the annotated working transcript

4.2.2 Stage 2- Holistic-content Analysis

In line with the Holistic Content stage, as suggested by Leiblich et al (1998), I read the transcript and listened to the interview on several occasions until a holistic pattern emerged. During this I found myself drawn to holistic 'major themes', which were noted in the transcripts (see Appendix A). These 'Major themes' informed the Overall Global Impression-

Overall Global Impression:

Dani's narrative presents a rich account of parenting a child with chronic illness, highlighting how the experience extends far beyond medical or clinical management. From the first signs of Leo's joint swelling at age three, through his diagnosis of juvenile idiopathic arthritis and subsequent complications such as uveitis and vision

loss, her story conveys the persistent challenges that shape and impact daily routines and social participation. It also shines a light on family dynamics. Life with Leo's condition is marked by unpredictability, with appointments, flare-ups, and medical interventions rarely following a predictable pattern, leaving the family continually adapting and negotiating uncertainty.

The practical and emotional burden Dani describes is substantial. She reflects on the constant effort required to meet Leo needs. She talks about needing to coordinate appointments and monitor Leo's symptoms, as well as advocated for appropriate support. These demands often intersect with feelings of guilt regarding her other son, Bennie. At times, she hints at the isolation this creates, particularly when systems of care are fragmented or inconsistent. Experiences with schools, for example, range from helpful adjustments to overlooked needs, forcing Dani to repeatedly intervene. This process may suggest both the resilience and resourcefulness she brings to parenting, but also the unfair reliance on parental advocacy where systems fail.

Despite the strain, there is a strong thread of adaptation and resilience running through Dani's story. She describes structuring daily routines to accommodate rest, whilst pacing family activities and finding small ways to embed predictability amidst uncertainty. Openness and honesty with her children appear central to her approach, fostering trust and enabling shared strategies to manage Leo's condition. She also reflects on moments of humour and pride, such as Leo's own growing confidence in managing his health. This may suggest that resilience is enacted by enduring difficulties and by creating opportunities for meaning and connection within them.

At the same time, Dani's narrative highlights how inconsistent support networks can exacerbate challenges. Miscommunication, procedural gaps, lack of continuity in

care and systemic pressures place additional demands on her, requiring repeated negotiation with healthcare professionals and educators. While she demonstrates considerable skill in navigating these complexities, her reflections implicitly raise questions about equity: families without comparable knowledge, confidence, or time may struggle even more, highlighting the uneven burden placed on caregivers.

The narrative further conveys how Dani's role and responsibilities as a parent evolve in response to both her child's needs and the limitations of external support. Dani frequently assumes duties that extend well beyond traditional expectations, for example, she acts as care coordinator and an advocate at different times. She describes this transformation with a mix of pride and surprise, capturing how parenting in this context becomes simultaneously strategic, emotionally charged, and deeply personal. The way she positions herself, balancing practical management with emotional labour, may suggest the subtle ways chronic illness reshapes identity and self-perception over time.

The importance of communication and relational honesty is also evident throughout. By engaging her children openly about the realities of Leo's condition, Dani fosters honesty, understanding, trust, and shared agency, allowing both practical and emotional challenges to be navigated collectively. Her narrative shows that parenting a child with chronic illness is multifaceted, it is about managing symptoms or accessing services, and also about sustaining connection, meaning, and cohesion amidst ongoing uncertainty. Her story offers a holistic perspective on what it means to live with chronic illness in a family context, highlighting both social and emotional dimensions.

4.2.3 Stage 3: Holistic-Form Analysis-

This stage asks what kind of story is being told, focussing on the overall plot shape and what typologies of telling organise the narrative when it is viewed as a whole, rather than what it is “about” thematically or ‘categorically’.

Overall plot shape

Dani’s interview has a cyclical, wave like form rather than a linear plot of onset–crisis–resolution. She repeatedly moves from describing periods of relative stability into remembered crises (diagnosis, flares, complications), and back again into present day reflections and imagined futures, producing a pattern of recurring disruption and re gathering rather than a single turning point,

For example, she describes the initial onset, *"Leo was 3 and a half... that week was the worst week of my life"* (Move 1) and later explains a relapse *"Leo is 12, nearly 13 now and he’s just had another flare up... we’ve had to kind of start the process again."* (Move 5) suggesting stability is temporary.

This looping structure mirrors the nature of Leo’s condition: *“calm before the storm”* (Move 48) is a motif that organises how time and experience are understood.

Within this, Dani frequently shifts between experiential segments (vivid, event focused scenes) and evaluative segments, for example, stepping back to comment on what these events mean for her, for Leo, and for the family- . The alternation between the two gives the story a pulsing rhythm: intense, specific episodes (e.g. “the worst week of my life” around diagnosis) are followed by broader reflections about changed identities, parenting and systemic fairness.

Parent specific narrative typologies

Reading across the whole transcript, several recurrent “types” or modes of storytelling can be distinguished. These are not rigid categories Dani names herself, but typologies I have constructed through analysis, which capture patterned ways in which she organises and evaluates her experience.

Battle narrative:

One dominant mode is a battle narrative, in which Dani frames her experience as continual fighting, with illness, with systems, and sometimes with others’ misunderstandings. In this typology she uses combative metaphors, talks of “battles” with school and hospital, and positions herself as repeatedly having to push back, insist, or refuse to accept inadequate responses. For example, in Move 4 Dani suggests that the NHS had made some mistakes around Leo getting his eyes tested sooner, but feels that she would be in a fight to gain answers, *“…I don’t think I have the energy to ever try and find out what happened (sigh), I do think that the NHS will probably all protect their selves, but Leo should have been screened for his eyes quicker than what he was.”*. Similarly in Move 7, Dani describes a battle with school around attendance, she feels she is *“...passed from pilar to post”* and unsupported by the school. The plot here is one of ongoing struggle without final victory: setbacks, small wins, then renewed challenges, mirroring the relapsing nature of Leo’s condition and the persistence of institutional barriers.

Burden–isolation narrative:

Running alongside the battle narrative is a burden and isolation typology. In this mode, Dani emphasises exhaustion, loneliness and lack of understanding from friends, sharing- *“..you're exhausted all the time because you’re constantly, it's tiring having kids anyway, but when you've then got kids with additional needs, and it's*

lonely like, people don't get it".(Move 7) *and "… but I do think people forget about you.."* (Move 25). She returns several times to being "exhausted all the time" and feeling that people with healthy children cannot truly grasp their reality- *"...you can talk to your best mate, but they don't get it cuz they've got healthy kids that are fine..."* (Move 8). The emotional movement here is less about change than about accumulation: small invalidations and ongoing care gradually add up to a heavy, private load.

Transformation Narrative

The transformation typology is structured as a developmental plot that maps a shift in Dani's perception of illness and mindset. Rather than a static explanation of her experience, she tells a story of 'becoming,' using a 'before and after' contrast to evaluate her growth. This mode of telling is characterised by a move from the 'naïve' parent of the past to the 'knowledgeable and outspoken' advocate of the present. She explicitly marks this transition by stating, *"Leo's illness has made.me change as a person, massively change"* (Move 7).

The form of this typology is defined by a growth in confidence to advocate; she recounts a time when she made a complaint about a professional (Move 33) and now sees herself who is, *"less willing to take rubbish"* (Move 35) from professional systems. She frames this change through the lens of psychological cost, stating that while she was once a *"whittler,"* she has *"never had anxiety like I've had since everything's gone on with Leo"* (Move 7) and in Move 9 describing her being *'...really anxious..'* and an *'overthinker'.* The story being told here is not one of *restoration to her old self, but of a permanent, irreversible evolution into a person who is* 'less

tolerant' of trivial complaints (Move 9) and defines herself through a hard-won, albeit anxious, expertise.

Relational Care Narrative:

Unlike the "battle" narrative which has peaks and troughs, the relational care typology uses a form of continuous management. There is no clear beginning or end to this story; instead, it is a steady, repetitive rhythm of emotional labour aimed at keeping the family unit intact. Dani's mode of telling here is polyphonic, she is constantly balancing the needs of her husband, the running of the household, her 'healthy' child, and Leo. She describes a perpetual effort to *"reassure Bennie"* and *"overcompensate"* (Move 6) for him, ensuring the narrative of their childhood isn't consumed by the 'void' of Leo's illness.

The narrative logic in this mode is one of 'emotional honesty.' She frames the family identity through a shared commitment to being "*honest"* and *"open"* (Move 10, 22 & 40), explicitly telling the interviewer*, "We've always, like, made him talk to us, like never bottle stuff up"* (Move 44). This typology functions as a 'steady state' plot where the goal is to maintain a 'team' dynamic (Move 55) and a culture of 'straightforwardness' (Move 43) that can withstand the recurring disruptions of the medical journey.

Emergent Hope Narrative:

The emergent hope typology utilises a mode of 'qualified optimism.' It rejects the 'restitution' plot (Frank 2013), where the child gets better and everything returns to normal, and instead focuses on finding meaning within the chronic condition. This is a story of adaptation rather than cure. Dani constructs this hope by highlighting that, "it's *hopefully not letting it stop him do anything that he wants to do* " (Move 49) and

framing Leo's stubbornness as a *"fire in him"* that is *"a good thing"* (Move 17). She also shared that they have a *"bucket list"* for Leo (Move 17)

The plot shape here moves toward the future, but it is a future that includes the illness. She tells a story of resilience, finding pride in the fact that Leo is a *"normal kid"* who *"plays football"* (Move 12) despite his vision loss. This mode of telling also looks outward; she evaluates her own trauma as a potential resource for others, expressing a desire to *"volunteer at Dr. N's clinics to speak to parents"* (Move 16). Within this typology Dani acknowledges the 'limits' of Leo's health while maintaining a focus on his aspirations to *"be a barber"* and "have kids" (Move 16).

Movement between typologies

These typologies are not neatly sequenced stages; Dani moves between them, sometimes within a single passage. For example, a story that begins as a battle with school may shift into burden/isolation *("people don't get it"),* then into transformation *("I don't just accept that now"),* and end in emergent hope through humour or pride in Leo. This fluidity is consistent with Hiles and Cermák's emphasis on narratives as polyphonic and multi voiced, where different storylines and identity positions intersect rather than a single dominant plot operating alone.

Seen through a holistic form lens, Dani's interview can therefore be understood as a weaving together of these parent specific typologies across a cyclical timeline, rather than as a single, linear illness story. This stage adds an account of the shape and movement of the narrative, the plots, tones and recurrent modes of telling.

4.2.4 Stage 4- Categorical-Content Analysis

105 raw codes were organised into 20 subthemes and condensed into four overarching themes (see Appendix C) for annotated transcript and table. The four overarching themes were as follows:

Navigating Uncertainty in Diagnosis and Systems

Dani's narrative frequently highlights extended periods of diagnostic uncertainty and the frustration of navigating fragmented healthcare and educational systems. Early signs, like Leo's limp, were initially dismissed or normalised: *"He was always a bit… lazy"* (Initial Concerns & Diagnostic Uncertainty). Over time, however, the lack of clear answers became overwhelming: "the worst week of my life" (Diagnostic Uncertainty). Variability in care further amplified stress, with missed opportunities for early intervention: *"He should have been screened for his eyes quicker… but we didn't know anything"* (Missed Screening; Information Gaps). Educational experiences also fluctuated, with primary school described as supportive *("Primary school were awesome…")* but secondary school bringing frustration: *"…Secondary school frustrated me"* (Positive vs. Negative Educational Experiences). These experiences illustrate the unpredictable and often opaque nature of systems parents must navigate, highlighting how uncertainty can shape emotional and practical responses.

Emotional and Psychological Impact on Parents

Parenting a child with chronic illness placed a substantial emotional and psychological burden on Dani. She described constant exhaustion and persistent anxiety: *"I'm exhausted all the time… it's lonely"* (Stress & Anxiety), along with waves of guilt and self-blame: *"You blame yourself… did I do something in pregnancy?"* (Self-blame). Isolation was compounded by others' limited understanding of her

experience: *“I can talk to friends, but they don’t get it… they have healthy kids”* (Lack of Understanding). Yet Dani’s narrative also shows emerging strategies for managing this stress. Over time she developed greater assertiveness with professionals: *“Now I speak more firmly to clinic staff”* (Personal Growth), and drew on humour to lighten difficult moments*: “Leo said I’m a rubbish carer… we laugh about it”* (Coping Strategies). This tension between vulnerability and adaptive strategies illustrates the balancing act of caregiving for a child with ongoing health needs.

Family Dynamics and Changing Parenting Roles

Chronic illness influenced parental roles, as well as, sibling and marital relationships. Dani worked to balance the needs of Leo with those of his brother Bennie: *“We constantly reassure Bennie… ‘he’s not our favourite”* (Balancing Sibling Needs). Sibling interactions were marked by a mix of conflict and loyalty: *“They fight but love each other… Leo would defend his brother”* (Sibling Relationship). Parenting approaches shifted in response to these dynamics: *“I probably baby Leo more… but I overcompensate with Bennie”* (Role Shifts). Marital communication was sometimes strained*: “Sometimes Paul and I don’t talk as much as we should”* (Marital Strain), although both parents clearly aimed to maintain family cohesion. These patterns highlight how chronic illness can ripple across the family, shaping routines, relationships, and perceptions of fairness and responsibility.

Resilience, Adaptation, and Looking Forward

Despite ongoing challenges, Dani and her family demonstrated resilience and adaptability in multiple ways. Leo’s bravery was a central theme: *“He injected himself first time… he’s so brave”* (Adaptability & Bravery). Daily routines were recalibrated

to manage uncertainty: *"We live one day at a time… calm before the storm"* (Acceptance), while fostering Leo's independence: *"He has to fight his own battles… I can't do everything"* (Fostering Autonomy). Supportive networks, such as The Children's Arthritis Association (CCAA) weekends, provided both practical assistance and emotional validation: "*Our CCAA weekend made us feel less alone"* (Support Networks). A shared family philosophy, *"Life's a bitch, but it is what you make of it",* captures the way Dani and her family consciously frame adversity as a space for agency and hope, and also underpins Dani's motivation to advocate for others in similar circumstances.

4.2.5 Stage 5- Categorical-Form Analysis

Throughout Dani's interview, one of the most striking features was how she used humour when talking about emotionally difficult experiences. The form of her narrative and the way in which she tells the narrative, or *sjuzet,* includes expressive techniques like humour, enactment, analogy, and shifts in emotional tone. These are not just stylistic features to support the storytelling; they help her manage strong emotions, connect with others, and make sense of her experiences. During this stage of analysis, I selected sections of her interview which best demonstrated this and noted the linguistic and paralinguistic features. (See Appendix D)

Move 16:

"We live for the moment, like we want to take Leo places to see stuff like abroad and… have a little bit of a bucket list for him, but obviously not a bucket list cuz hopefully he's not going to die (chuckles)."

Dani uses humour and analogy to ease the emotional weight of talking about Leo's future. The phrase "bucket list" usually refers to things someone wants to do before

they die, so using it in this context brings up serious fears. But Dani quickly softens it, “not a bucket list” and laughs. This shift helps her acknowledge those fears without being overwhelmed by them. The humour acts like a buffer, making it easier to talk about something painful.

She then imagines Leo’s future through playful enactment:

“He wants to be a barber. He wants to have kids. He’s going to get married. Well, one minute he’s having kids and getting married and then he’s living with us forever. So, kids and wife are not living with us (laughs).”

Dani brings Leo’s imagined future to life by quoting him directly and adding her own light-hearted commentary. The contrast between his plans and the idea of him living at home forever adds a comic contradiction, possibly designed to ‘lighten’ the difficult topic of Leo’s future. Whether conscious or not, this blend of seriousness and humour could be a strategy employed by Dani to stay emotionally balanced while talking about uncertainty. Her laughter also created a sense of closeness with myself, turning a difficult topic into a shared moment of warmth.

Move 40:

“Leo would never let anyone touch Bennie… Leo would make a beeline to make sure that he sorted it out for his brother.”

Here, Dani uses strong language, “never,” “make a beeline”, to show how protective Leo is. These words emphasise his loyalty and position him as a caring older brother. She then shares a humorous story:

“He used to try and push Bennie off of me quite a lot… Bennie winds him up now. He’ll come and cuddle me and say, ‘She was my mum first.’”

This quote shows sibling rivalry in a playful way. Dani re-enacts Bennie's teasing with affectionate irony, turning a potentially tense moment into something funny and relatable. Her tone invites the listener into a moment of everyday family life, full of emotion but also laughter.

Later, she reflects on Leo's emotional sensitivity:

"Leo literally sobbed the whole way through the film and… they take the mickey out of him now (chuckling) and say, 'You remember when we watched that film with the Frog.'"

Here, Dani mixes emotional intensity (*"literally sobbed"*) with humour and re-enactment. The family's teasing becomes a way of coping with Leo's vulnerability. The 'frog' story becomes a shared reference point, turning a moment of sadness into something they can laugh about together.

Dani's storytelling shows how she uses humour, enactment, and emotional shifts to talk about difficult experiences in a way that feels manageable and meaningful. These techniques help her stay resilient, connect with others, and turn painful events into stories that can be shared and understood.

Storytelling as Performance: Expressing, Justifying, and Resisting

Dani's storytelling is active and purposeful. She expresses her emotions openly:

"The worst week of my life."

She justifies her instincts by explaining how she knew something was wrong early on:

"Laziness."

She strongly resists dismissive comments like:

“He looks all right.”

Instead, she explains the hidden struggles Leo faces. She also pushes back against the idea that life owes them something:

“Life doesn't owe you anything.”

And she challenges the assumption that professionals understand her experience:

“They don't really care about the parent.”

Through her storytelling, Dani reclaims control in a situation where she often feels powerless. Her narrative becomes a way to assert her truth, challenge unfair systems, and show both vulnerability and strength. It also highlights how storytelling can be cathartic, potentially helping people process pain, build identity, and speak out against injustice.

4.2.6 Stage 6- Critical analysis- Identity Construction and Positioning

This final stage delves into how Dani positions herself within her narrative and the sort of narrative she constructs about herself and her family, focusing on the *sjuzet* to explore her interlinked identity positions. This builds on Emerson and Frosh’s (2004) work, highlighting that identity is constructed around interlinked identity positions (Hiles, 2007).

The *sjuzet* in Dani's narrative is the mechanism through which she constructs and presents her evolving identity. Her choices of emphasis, emotional tone, temporal shifts, and prioritised themes all contribute to how she positions herself. The narrative is a dynamic act of identity positioning in response to chronic adversity, communicating the self-image that Dani hopes to convey.

In this stage I returned to the transcript and noted in the margin the possible identity positions (IP's) within each 'move' (See Appendix A). I added the IPs to the master table (see Appendix B) which helped me analyse how Dani positioned herself through her narrative.

Dani actively constructs and negotiates multiple identity positions during the interview; this is to narrate her experience and to manage how she is perceived by me as the listener. Following Emerson and Frosh, identity here is interactional and performative, shaped *with* the interviewer rather than simply revealed. Dani positions herself as a number of identities, such as- a protective mother, an anxious planner, and a maturing advocate, inviting empathy and understanding while also asserting competence and emotional strength. Her narrative simultaneously anticipates judgement, counters potential criticism (e.g., fears of *"babying"* Leo), and seeks validation for her resilience. In doing so, she constructs a story that is both emotionally vulnerable and morally grounded, oscillating between fragility, responsibility, and empowerment. Dani's narrative strategy therefore functions to make sense of her experiences and also, to present a coherent and credible maternal identity in dialogue with the me.

Identity Positions (IP's)

Protective Carer

Dani positions herself as emotionally and physically devoted, "*babying*" Leo and shielding him from distress. This identity is constructed through emotional language, vivid caregiving descriptions, and withholding her own feelings to protect him. Her protectiveness functions as both strength and burden, giving structure to uncertainty while reinforcing responsibility.

“I probably baby him a lot more” (Move 6)

“I drop Leo off and then I'd go and cry” (Move 22)

Anxious Planner

Future-focused worry shapes Dani’s narrative, with constant anticipation of medical, emotional, and social risks. Shifts to future tense and detailed fears signal a vigilant, hyper-responsible identity. This position reflects both love and emotional cost, showing anxiety as a by-product of uncertainty and maternal responsibility.

“I always think of the future… my biggest anxieties is his future” (Move 10)

“His sight… that’s what scares me” (Move 16)

Maturing Advocate

Dani appears to progress from confusion to confidence, voicing growth into someone who challenges systems and asserts needs. This narrative of empowerment reconstructs her identity as capable and strategic, countering earlier uncertainty and emphasising agency.

“I’m more firm now… I can stick up for myself”

Isolated Mother

Loneliness surfaces repeatedly, framed by comparison to peers and difficulty being understood. This creates an identity marked by separation and emotional distance, reinforced by strained social connections and the unique challenges of chronic illness parenting.

“It becomes quite lonely… they don't get it” (Move 33&34)

Self-Sacrificing Carer

Dani positions herself as exhausted and describes self-neglect, presenting herself as someone who must cope alone. This role is infused with both pride and vulnerability; she recognises emotional strain but frames putting herself aside as necessary and inevitable.

“I think I put myself too much on the back burner” (Move 11)

Reflective Narrator

She frequently steps outside the story to evaluate past feelings and growth, signalling reflexivity and responsibility. This meta-position enables self-correction, emotional processing, and identity reconstruction.

“I don’t blame myself anymore” (Move 8)
“I’ve massively changed as a person” (Move 7)

Hopeful and Resilient Parent

Despite fear and fatigue, pride and hopefulness are found, and Dani shows determination to persevere. Her emphasis on strength positions her as shaping Leo’s resilience and maintaining meaning beyond illness.

“He is my little superhero” (Move 46)
“Don't let it win, Leo” (Move 49)

4.3 Kelly's Analysis

Pen Picture

Kelly is a mother of two boys, George (12) and Neil (8), both of whom experience joint hypermobility. Neil has been diagnosed with Ehlers-Danlos Syndrome, and he experiences symptoms including pain, fatigue, and challenges associated with hypermobility. Kelly herself lives with chronic pain conditions, which intersect with her caregiving responsibilities. She lives with her husband and has a supportive network of family and friends, which provides practical and emotional support in managing the complex needs of her family. Kelly volunteered to participate following being approached by the SENDCo from the school which Neil attends.

4.3.1 Stage 1- Segmentation and separating the Fabula and Sjuzet

Please see Appendix E for the annotated working transcript

4.3.2 Stage 2- Holistic-content Analysis

Overall Global Impression:

Kelly's account does not unfold as a straightforward medical journey. Instead, it reads like a process of constantly trying to interpret and respond to a mix of frustration, uncertainty, and a pressing need to remain resilient against structural and relational barriers. She isn't just "accessing services" in the traditional sense; she appears to be deeply embroiled in the exhausting emotional and cognitive labour of making sense of a system that, at times, seemed either unable or perhaps just unwilling to take her concerns seriously.

A striking thread running throughout her narrative is the sense of systemic and professional failure. Kelly's account of seeking a diagnosis for Neil is less about a clear medical path and more about a jarring collision with professional indifference. She describes a cycle of repeated attempts to find answers, only to be met by

experts who seemed far more interested in dismissing her than in actually being inquisitive. Being labelled as "neurotic" or having a doctor remark that they had "seen worse children" did more than just sting in the moment. These interactions appear to have fundamentally shifted how she views professional systems as a whole, transforming them into something seen as fragmented and largely inattentive. Because Neil’s symptoms were never quite connected from one appointment to the next, the family's distress was dragged out, leading to a slow but steady erosion of trust.

In the absence of any coordinated support, Kelly eventually felt forced into a leadership role that was never officially hers to take. She mentions having to "coordinate care constantly," effectively becoming the central bridge for all communication and advocacy. Her professional background seems to have played an important part in enabling this; she speaks about having the confidence to challenge decisions and push for recognition. While this reflects considerable personal strength, her narrative also implicitly raises equity concerns: families without similar skills, language, or confidence are likely to face greater barriers in securing timely and appropriate support.

Alongside these logistical and advocacy demands, Kelly’s narrative highlights the less visible social and emotional dimensions of living with an illness that others often cannot see. She frequently references the “invisible” nature of both Neil’s symptoms and her own health difficulties. This persistent invisibility seems to fuel a background anxiety about being judged, not just by peers but even by the professionals meant to help. It goes some way toward explaining why she might hesitate over something like a blue badge or a Disability Living Allowance application. Rather than a simple reluctance to seek help, this may reflect a deeper fear of being misinterpreted as

exaggerating or seeking preferential treatment. Such concerns add an additional layer of social suffering to already demanding circumstances.

The emotional toll of these experiences is evident. Repeated dismissal by professionals led Kelly to moments of self-doubt, captured in her question*, "am I crazy?"* The constant vigilance required to ensure nothing was missed, combined with the pressure to appear credible, contributed to sustained stress and anxiety. Her identity as someone who supports others professionally sits uneasily beside her lived experience as a parent encountering insufficient support, and this tension appears to amplify the psychological strain.

Kelly's story also shows how illness ripples through the most mundane parts of family and social life. Planning a simple afternoon out requires a constant series of adjustments, and sometimes, those plans just have to be scrapped if Neil is too tired or overwhelmed. Friends' expectations may not always align with what is manageable, leading to subtle forms of exclusion or discomfort. These are not dramatic events, yet over time they reshape routines and social participation. The narrative makes visible the cumulative, often hidden ways in which illness and uncertainty become a part of everyday life.

Kelly's account suggests a struggle for medical clarity and a broader negotiation of identity, credibility, and family life in the context of system-level shortcomings. It highlights the emotional and social labour often required of families who must advocate persistently in order to be heard, and the uneven burden this places on those with fewer resources or less confidence to challenge professional systems.

4.3.3 Stage 3: Holistic-Form Analysis-

Overall Plot Shape

At the level of narrative form, Kelly's account follows a circular, realisation type structure rather than a clean linear arc of onset, diagnosis, and resolution. The story begins not with a sudden medical emergency, but with a period of retrospective normalisation, where her younger son Neil's developmental delays are initially absorbed into existing family patterns. Kelly compares Neil's development against her older son, George, noting that since George walked late, she *"kind of just thought actually these are similar, er this is how it works"* (Move 1). This creates a narrative opening focused on routine rather than alarm, establishing a baseline that is only disrupted when Neil's struggles persist past the expected milestones.

The narrative rhythm then shifts into a prolonged 'chaotic' phase, characterised by a compounding list of symptoms, bowel issues, wetting, and fine motor delays, that the medical system initially fails to integrate (Move 4 & 26). Within this phase, the plot repeatedly cycles through a familiar structure: a new physical problem is introduced, followed by a period of increased action where Kelly becomes a stronger advocate, which is then brought to a momentary pause through temporary coping. These pauses are framed as temporary holding positions rather than resolutions, contributing to an overall sense of narrative continuation rather than closure.

A significant turning point occurs through systemic friction. The plot slows down during vivid, specific accounts of trauma, such as the "horrific" experience of infant blood tests, where the narrative dwells on the breach of trust between the child and professionals: *"he sort of, saw a hospital as a place where pain happens"* (Move 5). The second half of the narrative transforms into a plot which revolves around Kelly taking control, as Kelly abandons the failing public system to *"go private"* (Move 7). This move creates a sharp contrast in the story's tone, shifting from the frustration of being labelled *"neurotic"* (Move 6) to the validation of being *"listened to"* (Move 9).

The interview concludes not with an end to the illness, but with a stabilised plateau where Kelly is now *“leading”* and *“coordinating”* care as a professional advocate, moving from a position of uncertainty to one of weary, informed management.

Parent-Specific Narrative Typologies

Reading across the transcript as a whole, I constructed four recurring narrative typologies. These represent patterned ways in which Kelly structures and delivers her story:

Normalising narrative:

This typology is defined by the effort to frame medical anomalies as family quirks. Kelly structures her early story around comparison, using her older son's history to explain away Neil's delays. The narrative voice here is pragmatic and protective; she describes carrying Neil until he was five years old to maintain the flow of daily life, despite outside judgment: *“everyone would say to me, ‘really Kelly, should you still be carrying him now...’... and I'm like, ‘what can I do’”* (Move 3). This mode functions structurally to delay crisis, allowing the family to inhabit a space of “normal” childhood for as long as possible before the medical labels take hold.

Systemic Friction narrative:

This is the most dominant mode in the transcript, characterised by a plot of persistent resistance against authority. Kelly frames her experience as a *"constant chasing of an appointment,"* where the medical system is portrayed as obstructive and dismissive (Move 6). The narrative uses strong evaluative language to describe professionals who lacked *“empathy”* and *“child focus”* (Move 7). She recounts being told *“I’ve got worse children than him”* and feeling that if she didn't push, *“it just*

wouldn't happen" (Move 6). Structurally, this typology organises time as a series of bureaucratic battles where the goal is simply to be heard (Move 25).

Seeking Validation narrative:

In this typology, the narrative shifts toward a relief-based plot. It focuses on the psychological need to prove that her observations were accurate. The diagnosis of Ehlers-Danlos Syndrome (EDS) is narrated as a victory of maternal intuition over professional gaslighting (Move 8). She reflects on the internal toll of being ignored, stating, *"you start to think am I crazy? You know, you start to think yourself, I think I might be thinking something that's not here"* (Move 9). The form here is one of confirmation, where the private diagnosis serves as the moment she is "thankfully" validated as a reliable witness to her son's pain.

Professional Perspective narrative:

Kelly frequently uses a professionalised lens to evaluate her own story. Drawing on her own background in support roles, she critiques the medical system using clinical concepts like *"ethics," "values,"* and *"Carl Rogers"* (Move 10). This typology functions as a sense-making narrative, allowing her to distance herself from the *"neurotic"* parent label by positioning herself as an expert observer of systemic failure. She expresses concern for parents who lack her *"knowledge of a system or the self-esteem,"* framing her own advocacy as a form of specialised labour that should not have been necessary (Move 6). This voice returns at the end of the narrative when she critiques the school's lack of transparency: *"You noticed that [his wellbeing], but you've never said shared that with me"* (Move 37)

<u>Movement Between Typologies</u>

These narrative typologies do not appear in isolation. Kelly moves fluidly between them, often within a single stretch of talk. An account may begin as a *Normalising* narrative (Neil wanting to be *“just like his peers”*), shift into *Systemic Friction* as she describes conflict with the school’s refusal to provide an EHCP (Move 26), and then settle into a *Professional Perspective* as she analyses the school's failure to communicate Neil's emotional distress (Move 16).

This movement between narrative forms gives the interview a polyphonic structure, where different ways of telling coexist. Often *Seeking Validation*, a sequence is closed through a narrative, where Kelly reminds the interviewer (and herself) that *"thankfully"* the private consultant confirmed her fears were grounded in reality (Move 9). This fluidity is consistent with a narrative that resists the ‘passive’ patient role; by weaving together the roles of the protective mother, the validated observer, and the professional critic, Kelly creates a form that allows her to lead and coordinate her son's story in a system that she views as fundamentally broken.

4.3.4 Stage 4: Categorical-Content Analysis

A total of 198 raw codes were initially generated from the interview transcript. These were organised into 15 subthemes and subsequently condensed into 4 overarching themes. The themes reflect the interplay between individual, family, and systemic factors, and illustrate the complexity of navigating chronic childhood conditions. See Appendix G for annotated transcript and table which details codes, sub themes and themes.

Diagnosis & Health System Navigation

Kelly’s narrative traces a prolonged and uncertain journey toward understanding Neil’s health needs, beginning with early signs of difference in infancy. She

describes delayed gross and fine motor development, bum shuffling, joint instability, and ongoing pain, alongside contrasts with Neil's sibling and the absence of a clear family history. These observations sit within the *Symptoms and Differences* subtheme and establish Kelly's early sense that Neil's development did not fit expected patterns (Moves 1–5).

The diagnostic journey itself is characterised by delay, with some reassurance, and minimisation. Kelly recounts professionals playing down hypermobility and offering the family reassurance, despite her continued concerns. This period included invasive investigations and misdirection before a diagnosis was finally reached. Receiving a diagnosis brought relief and validation yet also introduced further uncertainty due to comorbid neurodevelopmental factors and unclear genetic explanations (*Onset and Diagnosis Journey*; Moves 6–11).

Navigating healthcare systems emerges as a sustained challenge. Kelly describes long waiting lists, inflexible appointment systems, and a lack of holistic, child-centred care within NHS services, contrasted with more responsive experiences in private healthcare. These accounts highlight systemic barriers that create inequity for families with fewer resources or less flexibility (*Navigating Healthcare Systems*; Moves 12–15). Over time, dismissive encounters contribute to Kelly adopting a stronger advocacy role, while Neil gradually begins to communicate his own needs, particularly in school contexts (*Experiences with Professionals and Developing Advocacy*; Moves 16–19).

Family Adaptation, Roles & Wellbeing

Family life is described as continually reshaped around Neil's needs, with adaptation becoming an ongoing process rather than a temporary response. Kelly describes

carrying Neil into later childhood, modifying journeys, planning around pain and fatigue, and engaging in trial and error to find accessible activities. These adaptations are often accompanied by humour and flexibility, functioning as coping strategies within the family (*Family Adaptation & Routines*; Moves 20–23).

Sibling relationships are portrayed as both supportive and complex. Kelly reflects on dilemmas around school choice and potential impact on Neil's older brother, while also highlighting closeness, shared activities, fairness and mutual empathy. Siblings are positioned as protective figures, particularly during transitions (*Sibling Impact*; Moves 24–26).

Kelly's professional background in children's services and advocacy shapes how she navigates parenting. She draws on professional frameworks to interpret her experiences, while also describing frustration with financial pressures and the high cost of specialist equipment. Professional knowledge is presented as both a resource and an additional burden (*Professional Identity and Parenting*; Moves 27–29).

Kelly describes the emotional impact, specifically anxiety, isolation, and the cumulative toll of ongoing advocacy. Experiences of medical trauma and self-doubt are recurring themes. As well as difficulties in prioritising her own wellbeing, despite a growing awareness of the need for self-care to sustain caregiving (*Emotional and Mental Health Impact*; Moves 30–32). Advocacy is framed as ongoing and largely parent-led, with Kelly repeatedly responsible for coordinating/leading support across health and education systems (*Advocacy*; Moves 33–35).

Social Inclusion, Stigma & Peer Relationships

Social inclusion features prominently, particularly in relation to peer relationships and identity. Kelly describes Neil's exclusion from sports and physically demanding activities, affecting both social participation and self-concept. Transitions are anticipated as especially vulnerable points for inclusion (*Peer Relationships & Exclusion*; Moves 36–37).

Stigma is closely linked to visibility and misunderstanding. Kelly reflects on discomfort around mobility aids, fear of judgement, and the challenges of living with an invisible condition. While aware of legal protections, she expresses concern about future discrimination, particularly in employment contexts (*Social Stigma & Public Perceptions*; Moves 38–39).

Educational settings are presented as uneven in their capacity to support inclusion. Kelly describes schools' limited understanding of hypermobility, inconsistent reasonable adjustments, and loss of support during transitions. Positive relationships with individual staff are valued, but systemic continuity is described as fragile (*Experiences of Educational Systems*; Moves 40–41).

Coping, Strengths & Community

Alongside challenge, Kelly's narrative contains clear accounts of coping and resilience. Neil's use of pain and fatigue scaling and self-awareness illustrate adaptive strategies for living with chronic pain. Kelly expresses hope grounded in Neil's academic strengths and everyday moments of competence rather than expectations of cure (*Hope, Coping & Resilience*; Moves 42–43).

Support networks are described as uneven. Kelly values honest friendships and peer connection but notes limited access to appropriate local support groups. Financial awareness and a commitment to reducing barriers for other families reflect strengths

shaped by lived experience (*Support Networks and Financial/Resource Barriers*; Moves 44–46).

4.3.5 Stage 5- Categorical-Form Analysis

Kelly's narrative, particularly in the sections describing the period before diagnosis and her later role as advocate, is richly emotive and conveys the complexity of her experience through both language and gesture. Two aspects stand out as particularly illustrative: the experience of being dismissed by professionals, and the ongoing responsibility of coordinating her son's care (see Appendix D for noted transcript).

Move 6-9

When recounting interactions with the paediatrician, Kelly's words do more than relay events, they convey the emotional weight of her experience. Her phrasing seems to externalise both the shame she felt and her insistence that her observations were legitimate. The use of direct speech, for instance, *"he just said… that 'you're neurotic',"* functions as more than a quotation; it draws the listener into the encounter, capturing the immediacy of the dismissal and the resulting sense of injustice. Similarly, descriptors such *as "The paediatrician… was not very empathetic, at all"* intensify her perception of the interaction. The repetition and emphasis appear to validate her feelings of being disregarded, underlining the depth of her frustration.

Statements containing cognitive verbs, like *"I think it, you start to think am I crazy?"* illustrate the mental effort required to maintain conviction under repeated invalidation. This interplay between external systemic pressures and internal processing may suggest that the emotional burden is about outcomes and about

sustaining a sense of personal authority when confronted by professionals who minimise parental insight. It hints at a tension that runs through the narrative: the challenge of asserting certainty in a context that constantly undermines it.

Following diagnosis, Kelly's language shifts to focus on her active and sustained advocacy. Repetition and temporal markers convey the intensity of her role: *"all this time, I've led his care really… I've been that person to coordinate care constantly."* The repeated *"constantly"* signals that advocacy is not occasional but an enduring part of daily life. Active voice reinforces her agency: *"I've led his care," "I'm leading and I'm saying he, we need to do this test."* These statements contrast sharply with the passivity of her earlier experiences, highlighting a shift from vulnerability toward proactive engagement with Neil's needs.

Structural shortcomings in systems further shape the emotional experience. For example, receiving school communications only in writing, *"no one's ever told me that, but it was just written down"*, elicits a strongly personal response: *"that's really hurtful."* Moments like this illustrate how procedural gaps compound psychological strain, reminding us that advocacy is often performed under conditions of uncertainty and partial information.

Through repetition, direct speech, intensifiers, and active constructions, Kelly's narrative conveys both the distress of professional invalidation and the sustained labour of advocacy. It suggests that personal certainty and agency are negotiated against structural limitations, highlighting the emotional and psychological core of her experience as a parent navigating complex systems.

4.3.6 Stage 6- Critical analysis and Identity Positioning

Kelly's narrative is a careful negotiation of legitimacy, strength, and emotional strain in the presence of a listener. She shifts between confidence and vulnerability, conviction and doubt, almost checking whether I recognise her experience as justified. At times she positions herself as someone who had to fight to be believed, and at others as someone exhausted by that same fight. Perhaps, this is not contradiction, but a purposeful identity performance shaped by earlier misrecognition from professionals.

Across the interview she works to hold several truths at once: that she trusts her instincts, that the system failed her, that she has become highly capable, and that this capability has come at a cost. The narrative moves through defensive certainty, relief, fatigue, and moral protection of her son's autonomy. She appears to anticipate judgement and uses the interaction to pre-empt it, possibly offering rational justification alongside emotional honesty. In doing so, she constructs herself as both expert and injured party, someone who had to transform under pressure and now carries the weight of that transformation.

Identity Positions (IP's)

Challenging Advocate

Kelly positions herself as someone who had to confront professionals when they failed her son. This stance appears both protective and defensive, shaped by a history of dismissal. She uses reconstructed dialogue to re-assert that she was reasonable and professionals were not.

"*He just said on numerous occasions… you're neurotic.*" (Move 6)

"*The frustration was huge, really.*" (Move 6)

Vindicated and Relieved Parent

Once a diagnosis arrived, she narrates a sense of emotional release and validation. Perhaps, this position works to resolve past shame and defend her maternal competence, inviting the interviewer to recognise that she *was right all along*.

“*I'm not crazy.*” (Move 9)

“*I always knew there was something.*” (Move 9)

Care Coordinator

Kelly emphasises her ongoing labour and practical authority, presenting herself as the one holding fragmented systems together. The repeated active phrasing reinforces competence rather than chaos.

“*I've led his care really.*” (Move 8)

“*I'm leading and I'm saying we need to do this test.*” (Move 7)

Empathetic Parent/Professional

She occasionally step’s back from her personal story to comment on systemic failings more broadly, aligning herself with professional understanding rather than just parental frustration.

“*Education of professionals just needs to be improved.*” (Move 35)

“*I really fear for other children who are going through a similar pain issue.*” (Move 6)

Advocate for Autonomy

Kelly guards her son’s personhood, resisting the medical gaze reducing him to symptoms. She speaks firmly, almost instructively, signalling moral urgency and agency.

“*Talk to him, he's the one we're here for.*” (Move 7)

“*He's the one who's struggling.*” (Move 7)

Emotional Martyr

She makes the emotional cost visible, but not in a self-pitying way, more as a protest against relational neglect by institutions. This position seeks empathy without appearing ‘hysterical.’

“*No one's ever told me that… and as a parent, that's really hurtful.*” (Move 37)

Exhausted, Isolated Carer

Despite her competence and strength, she allows vulnerability to surface. This softens her advocate stance and invites recognition of the toll this journey has taken.

“*You feel quite alone.*” (Move 36)

“*I really fear for other children…*” (Move 6)

4.4 Maddy- Data Analysis-

Pen picture-

Maddy is the mother of Faith, a teenage girl whose has a diagnosis of Colitis and experiences associated chronic pain. Maddy lives with Faith her two elder sons and her partner who is stepfather to the children. Maddy responded to an advert circulated in a SEND local parent carer forum.

4.4.1 Stage 1- Segmentation and separating the Fabula and Sjuzet

Please see Appendix I for the annotated working transcript

4.4.2 Stage 2 – Holistic-content analysis

During this stage, several holistic content threads became apparent across Maddy's narrative and were noted in the working transcript (see Appendix I). These threads informed the following Overall Global Impression, capturing how Maddy's story is organised at the level of lived experience rather than isolated events.

Maddy's narrative presents a sustained account of living with ongoing responsibility while parenting a child with a chronic health condition, within a context shaped by earlier relational disruption and neurodevelopmental complexity. The emphasis throughout the account is on how prolonged uncertainty, repeated engagement with professional systems, and Faith's ongoing distress have come to organise everyday family life. Parenting is described less as a series of responses to discrete events and more as a continuous state of management and adjustment.

A key organising feature of the narrative is Maddy's account of her increasing responsibility for coordinating and overseeing Faith's care. She describes a gradual shift from initially trusting professional reassurance to recognising that Faith's pain and needs were not being adequately acknowledged. This turning point marks the

point at which *living with ongoing responsibility* becomes central to her identity as a parent. From this moment onward, Maddy positions herself as more active and directive in decision-making. This role is presented as necessary rather than chosen, shaped by repeated experiences of delays and feeling dismissed, whilst experiencing fragmented support across medical and educational systems.

Faith's condition is described in physical terms but also, as something that affects the emotional security of the whole family. Maddy's account highlights how illness has reshaped expectations within the household. Daily life appears structured around anticipating difficulties, managing risk, and responding to fluctuating symptoms. This ongoing alertness contributes to *being the emotional anchor* within the family, as Maddy repeatedly positions herself as the person who absorbs distress in order to maintain a sense of safety and stability for Faith.

Maddy's professional background as a SENCO specialising in neurodiversity is woven throughout the narrative and forms a distinct content thread of professional knowledge, resource or burden? Her expertise clearly supports her understanding of Faith's needs. At the same time, this knowledge appears to intensify her frustration when educational systems do not respond in ways she considers appropriate. The narrative conveys how professional insight simultaneously enables advocacy while increasing emotional strain, particularly when systems fail to recognise what she perceives as obvious needs.

Interactions with healthcare, education, the wider family and friends form a substantial part of the narrative, reflecting the ongoing task of finding a way through systems. Maddy describes repeated encounters with complex processes and unclear pathways, often accompanied by a sense of isolation. Faith is positioned as

the first within the wider family to experience a condition of this nature, leaving Maddy without shared reference points or established strategies. As a result, much of the responsibility for problem-solving, coordination, and decision-making is experienced as resting with her.

Although the narrative contains significant distress, it also includes moments that function as indicators of continuity and hope. Maddy refers to brief but meaningful occasions when Faith engages in activities, shares enjoyment, or demonstrates resilience. Within a holistic content frame, these moments illustrate a building of resilience and coping, alongside support, and sustaining hope. This is not as an endpoint or resolution, but as something maintained through small, tangible experiences. Hope is held alongside strain, allowing the narrative to contain both difficulty and possibility without collapsing one into the other.

4.4.3 Stage 3 – Holistic Form Analysis

At the level of narrative form, Maddy's interview follows a repeating plot shape organised around difficulty and temporary holding. The narrative opens with what functions as a provoking moment, when Maddy describes how Faith's pain was initially "*kind of just downplayed*" by medical professionals (Move 1). This early dismissal establishes a struggle narrative, positioning the story from the outset as one in which being heard requires persistence rather than trust.

The interview then repeatedly cycles through a familiar structure. A new problem is introduced, most often related to pain, schooling, or treatment, followed by a period of intensified action in which Maddy uses advocacy or professional knowledge. These sections are then brought to a momentary pause through references to coping or partial stability, before the cycle begins again. Importantly, these pauses are

framed as temporary, rather than resolved, contributing to an overall sense of narrative continuation rather than closure.

Across the interview, Maddy regularly inserts explanation and reflection into accounts of concrete events. For example, when describing Faith's heightened distress, she pauses to interpret this through a neurodevelopmental lens, noting that Faith "*had some signs… that she was probably on the autism spectrum*" (Move 1) and that her "*coping strategies have lowered*." These explanatory moments perhaps function structurally as a sense-making narrative, allowing Maddy to organise emotionally charged experiences into something that feels more coherent and manageable before the story moves on.

Alongside this, the narrative repeatedly slows to dwell on endurance rather than action. Maddy describes herself as Faith's "*safe person*," while also acknowledging that this position makes her the "*punch bag*" for distress (Move 4). In these moments, the plot does not advance toward change; instead, it settles into a holding narrative, where Maddy plays the mediator (see Move 10). This is reinforced when Maddy describes "*walking on eggshells*," (Move 14) a phrase that signals sustained emotional vigilance rather than resolution.

Although the narrative is dominated by struggle and endurance, it also contains brief moments where the story is allowed to settle into what might be described as temporary hope. These moments are marked by language that explicitly limits their scope. For example, Maddy refers to "*glimmers of light out the other side*," (Move 25) or describes Faith engaging in activities such as climbing again, while carefully noting the need to manage limits and avoid setbacks. Stability here is narrated as

something that exists *for now*, rather than as an endpoint, reinforcing the ongoing nature of the plot.

Parent-Specific Narrative Typologies

Reading across the transcript as a whole, I constructed four recurring narrative typologies. These represent patterned ways in which Maddy structures and delivers her story:

Struggle Narrative:

This mode is evident in repeated references to resistance and pressure when dealing with systems. For instance, Maddy describes having to "*throw my weight around a little bit with her school*" (Move 16) and reflects that it feels like she is "*constantly fighting*" (Move 23) Structurally, this typology organises time as ongoing effort rather than progression toward resolution.

Holding Narrative:

This typology is visible when Maddy positions herself as the emotional anchor within the family. Statements such as "*I'm her safe person*" (Move 13) alongside "*I'm also the punch bag for it*" (Move 4) illustrate how the narrative dwells on containment and endurance. The plot slows in these moments, emphasising sustained emotional labour rather than change.

Sense-Making Narrative:

Maddy frequently interrupts event-based accounts with explanatory reflection, drawing on her professional background. Phrases such as "*there's a little bit of how I react to her because of my profession*" (Move 1) and references to anxiety, autism, and coping capacity show how explanation is woven into the story to impose order on uncertainty.

Temporary Hope Narrative:

This typology appears in moments where the narrative briefly settles. Maddy's references to Faith returning to climbing, or to "*glimmers of light out the other side*," (Move 25) are immediately tempered by caution and limitation. These moments signal continuation rather than arrival, allowing the story to hold hope without resolving tension.

Movement Between Typologies

These narrative typologies do not appear in isolation. Maddy moves fluidly between them, often within a single stretch of talk. An account may begin as a struggle narrative (e.g., describing conflict with school), shift into a sense-making narrative as she explains the difficulty through neurodiversity, and then settle into a holding narrative as she reflects on the emotional toll. Frequently, this sequence is closed, temporarily, through a provisional hope narrative, such as mentioning a coping routine or a small positive moment. This movement between narrative forms gives the interview a polyphonic structure, where different ways of telling coexist and overlap, shaping the distinctive form of Maddy's account.

4.4.4 Stage 4 Categorical Content-

A total of 115 raw codes were organised into 20 subthemes and condensed into five overarching themes (see Appendix K). The analysis of Maddy's narrative follows:

Systemic Invalidation and the Battle for Care

Maddy's narrative is heavily defined by the struggle to have her daughter's pain recognised by institutional systems. Early medical encounters were characterised by dismissal, where severe physical symptoms were normalised or misattributed: "they'd kind of just downplayed it and said it's that time we've been sensitive" (Move

1: Medical dismissal). This led to a "diagnostic limbo" involving repeated A&E visits and fainting before reaching a diagnosis of distal colitis (Move 1: Diagnostic limbo). Once diagnosed, Maddy describes the treatment path as a “minefield” of invasive enemas, infusions, and high steroid use that resulted in extreme fatigue and sleep deprivation (Move 1: The minefield of treatment). Educational experiences further mirrored this systemic failure; Maddy details an “attendance officer turned up on our doorstep” and teacher harassment that caused physical trauma, described as “T-Rex arms” due to anxiety-induced muscle seizing (Move 15: Educational conflict). Consequently, advocacy became a necessity, with Maddy “throwing [her] weight around” and leveraging her professional status to force the school to provide basic support (Move 16: Advocacy).

The Professional Mother: Knowledge as a Dual Identity

Maddy operates through a dual lens, where her identity as a SENCO (Special Educational Needs Coordinator) fundamentally shapes her caregiving. She reflexively applies a professional framework to her daughter's behaviour, identifying autism traits that were exacerbated by physical illness: *“there is a little bit of how I react to her because of um my profession”* (Move 1: The SENCO lens). However, this expertise often presents a *"burden,"* as Maddy is acutely aware of system failures, such as *"postcode lotteries"* and the impossibility of CAMHS waiting lists: *“she'll have aged out of the system before she gets there”* (Move 11: Knowledge as burden). This professional awareness creates a tension between being a problem-solver and a mother, where she focuses on *“head vs. body”* and strategies over comfort*: “sometimes your child just wants a hug”* (Move 24: Problem-solving vs. Comforting). To manage the resulting stress, Maddy adopts an *“introverted extrovert”*

persona, *"boxing off"* relationships and seeking solitude in the woods with her dog to decompress (Move 22: Managing the self).

The Shadow of Trauma and Mental Health

Faith's physical condition is situated within a broader context of relational trauma. Maddy traces Faith's current 'abandonment anxiety' back to an absent biological father, whom she refers to as a *"sperm donor"* (Move 1: Abandonment trauma). This historical trauma leaves Faith *"constantly waiting for her [stepdad] to go"* (Move 3). The physical illness has accelerated a psychological decline, marked by an inability to mask, severe OCD, and social isolation: *"she's not the silly girl she used to be"* (Move 11: Psychological decline). This distress is funnelled into a specific family dynamic where Maddy serves as both the *"safe person"* and the *"punch bag,"* receiving targeted outbursts and the 'punishment of silence' for up to 24 hours (Moves 3 & 23: The punch bag dynamic).

Family Dynamics and Support Systems

The family functions as a shifting support network anchored by Maddy's husband, Ollie. His background as a pragmatic paramedic provides a grounding, 'straight-talking' influence that counterbalances Maddy's emotional load (Move 14: Stepdad anchor). Sibling relations are characterised by a mix of conflict and connection; while the eldest brother clashes with Faith, the middle brother, described as *"Victor Meldrew"*, offers steady support (Move 12: Sibling relations). Maddy also highlights the strain on the wider family, including grandparents who struggled to understand neurodivergent behaviours, and the financial impact of travel and parking for specialist care in their hometown (Moves 12 & 24). Despite these pressures, Faith

finds connection through bouldering and online "E-pals" who share her experience (Move 26: Support networks).

Future Uncertainty vs. Resilience

The narrative concludes with a recalibration of future expectations. Maddy mourns the ‘derailing’ of Faith’s career plans to join the police and the necessity of dropping GCSEs to manage her health: *“she’s down to five [GCSEs]... we've had to be sensible”* (Move 12: Derailed futures). However, resilience is demonstrated through practical adaptation, such as planning for Faith to live in a future housing annex and encouraging her to take control by texting her own IBD nurse (Moves 18 & 26). By *“picking battles”* and celebrating *“glimmers of light,”* the family has moved toward an adaptive acceptance: *“that's all you can hope for... you just keep going”* (Move 25: Adaptation and hope).

4.4.5 Stage 5: Categorical-Form Analysis

Maddy uses enactment, mimicry, and shifts in tone to navigate the trauma of her daughter’s illness while maintaining her identity as a "cool and collected" professional. The below moves were selected to illustrate this-

Move 15 & 16:

In these moves, the narrative form is highly dramatic and adversarial. Maddy relies on enactment to bring the listener into the ‘fight’ with the school. When she describes the attendance officer arriving on her doorstep, she is not just recounting an event; she is recreating a violation of her private space. She uses mimicry to copy the attendance officer’s, unprofessional actions, *“just walked in and went ‘One minute’ and walked back out”*, which serves to expose the absurdity and coldness of the institution.

Maddy uses powerful intensifiers to label the school's behavior, such as *"harassed,"* and describes Faith as *"absolutely mortified."* These linguistic choices justify her own shift in tone as she moves from a vulnerable mother to a professional advocate. A key expressive technique in this section is her use of humour through the "T-Rex arms" analogy. This funny-sounding nickname for a terrifying physical seizure acts as a de-intensifier; it allows her to speak about her daughter's body shutting down without being overwhelmed by the raw trauma of the memory. However, she quickly follows this with a change in tone, switching to serious, clinical language (*"arm muscles had seized"*) to ensure the gravity of the medical crisis is not lost.

By speaking as another person, specifically quoting her husband's protective stance (*"I'm not being spoken to like that"*), Maddy allows the 'raw' anger of the family to be heard without breaking her own professional mask. The sjuzet here eventually shifts from a 'Combat' narrative to a 'Conversion' story, as she mimics the now-friendly phone calls from 'Jared,' perhaps signalling that she has successfully turned an enemy into a 'cheerleader.'

Move 22:

In Move 22, the form of the narrative shifts from external 'fighting' to internal 'boxing.;' The drama of enactment is replaced by reflexivity, where Maddy analyses her own psychological walls. She uses mimicry to copy her own 'public voice', *"Yeah, she's doing okay"*, to show how she uses language as a shield to shut down intrusive questions from others.

Her identity is presented through the use of humour and wordplay, describing herself as an *"introverted extrovert."* This labels her duality: the 'extrovert' who can 'throw her weight around' at school, and the 'introvert' who is 'not good at' the emotional

vulnerability of support groups. Maddy uses an intensifier when discussing her professional expertise (*“100% direct people to that”*) but notably relies on de-intensifiers like *“probably”* or *“to some extent”* when discussing her own emotional decline. This linguistic pattern reveals that she feels safer behind her professional title than she does in her private, helpless role as a mother.

The most significant formal device here is the structural metaphor of *"boxing off."* This explains the very shape of her narrative; she speaks in compartments to keep the difficult emotions from making her lose control. When she begins speaking as another person to ask, *“Well, what about me?”*, she is giving a rare, 3rd-person voice to her own suppressed needs. By the end of the move, she uses a de-intensifier to minimise her own pain, *“She’s the one actually going through it”*, effectively closing the ‘box’ on her own trauma to refocus on her daughter’s physical reality.

Maddy’s narrative moves between high-stakes enactment (to fight the system) and controlled compartmentalisation (to protect her mental health). Her use of mimicry and professional language allows her to transform from a ‘punch-bag’ mother into a competent expert, using the story itself as a way to ‘rein in’ the chaos of chronic illness.

4.4.6 Stage 6: Critical Analysis- Identity Construction and Positioning

Maddy’s narrative identity is a managed ‘performance of competence’. By utilising her *Knowledgeable Advocate* role as a shield, she is able to discuss the trauma of her daughter's physical decline without appearing overwhelmed. The *sjuzet*, characterised by the enactment of conflict and the mimicry of professional’s voices reveals a woman who manages the ‘buffer’ role of her home life by exerting professional control in the public sphere. Ultimately, she presents herself as a

capable navigator of a complex system, transforming from a parent ‘in limbo’ into a strategic partner in her daughter's long-term care.

Identity Positions (IP’s)

The Knowledgeable Advocate

Maddy positions herself as an expert who uses her professional background in Special Educational Needs (SEN) to navigate the school system. By using professional terminology and intensifiers (e.g., "100%"), she establishes herself as an authority who cannot be easily dismissed by institutions.

“I decided to throw my weight around a little bit and explained what my job was.” (Move 16)

“My professional head would 100% direct people to that.” (Move 22)

“I know the code of practice. I know what reasonable adjustments are.” (Move 17)

The Emotional Buffer

Maddy describes herself as the primary "safe person" who absorbs her daughter's frustrations. In this position, she uses mimicry of her daughter’s outbursts and vivid descriptions of emotional "spewing" to show how she contains the family's stress at her own personal cost.

“I’m the one that she trusts the most not to leave... I’m also the punch bag for it.” (Move 4)

“She will target me specifically... once I start that, it's hard to kind of rein it all in.” (Move 22)

“I get the outbursts, I get the stroppy behavior and the silences.” (Move 14)

The Institutional Negotiator

This position is defined by the "fight" for medical and educational recognition. Through the enactment of past conflicts, Maddy highlights the transition from being *"harassed"* by the school to forcing them to provide support through official professional backing.

“We have had a lot of fights with her school over their support.” (Move 6)

“I’ve still had to fight and throw my weight around a bit... to get what Faith needed.” (Move 17)

The Controlled Self (Compartmentalisation)

Maddy positions herself as someone who must *"box off"* her emotions to remain functional. This IP is constructed through the structural metaphor of boxes, showing a deliberate choice to maintain a ‘cool and collected’ front while admitting to the interviewer that she is ‘putting on a front’.

“I to some extent managed to box my different relationships off with different parts of my life.” (Move 22)

“I’m very good at putting on a front. I don't do well in social situations myself.” (Move 22)

“I would like to think I'm quite cool and collected.” (Move 22)

The Family Mediator

Maddy positions herself as the central point of balance between different family members' reactions to the illness. Using humour and de-intensifiers, she describes

her role in softening the ‘matter-of-fact’ approach of the paramedics in her family to ensure Faith feels understood.

“I probably play the peacemaker quite a lot.” *(Move 19)*

“I get my mum and dad complaining to me and then I get Faith complaining... I'm in the middle.” (Move 10)

“I lay it on a little bit thicker as well for her [sympathy].” (Move 21)

The Relationship-Oriented Partner

Maddy centres her reliance on her husband, positioning their relationship as her primary source of stability. This IP reflects both her vulnerability and her strength, as she frames her husband as the only person who can truly "*ground*" her.

“My poor husband is the main person that hears it all.” (Move 22)

“He's also though the only person that can calm me down when I am starting to sort of stress out.” (Move 22)

The Pragmatic Parent

Toward the end of the narrative, Maddy adopts a position of realistic hope. She moves from the crisis of diagnosis to a future-focused identity, celebrating small *"glimmers of light"* and teaching her daughter independence despite the illness.

“We’ve had to be sensible... seeing glimmers of light out the other side.” (Move 25)

“She’s actually texting her IBD nurse herself now... that's all you can hope for.” (Move 18)

4.5 Summary

Across the three analyses, Dani, Kelly and Maddy's narratives suggest both shared and divergent features of mothering a child who experiences chronic pain. Their stories point to common threads of narrative labour, systemic fragmentation, and ongoing attempts to balance protection, advocacy and family coherence, while also highlighting the distinctive effects of diagnostic visibility, professional capital and school context on how mothers are heard.

These within-case accounts provide the foundation for the next chapter. In Chapter 5, I move from individual narratives to a cross-case discussion that reconnects the findings to the literature, develops the proposed carer-specific narrative typologies and discusses the importance of building trust between systems. I also explore the implications for educational psychology theory, practice and future research.

Chapter 5: Discussion and Implications

5.1 Overview and return to the research question

In this chapter, I draw together the narrative analyses presented in Chapter 4 and consider how they address the guiding research question: *How do mothers narrate their experiences of caring for a child who experiences chronic pain?* Rather than adding new data, the task here is interpretive and synthetic. I examine patterns that cut across Dani's, Kelly's and Maddy's stories, relate these to the theoretical and empirical literature outlined in Chapter 2, and make explicit the thesis's conceptual and practice-focused contributions. In doing so, I also attend to the limits of what can be claimed on the basis of three narrative cases and consider the implications for educational psychology.

This discussion chapter moves from within case depth to cross case interpretation. It brings these findings into dialogue with existing research on paediatric chronic pain, returning to areas identified in the Literature Review, as well as exploring new insights, and considers what they imply for educational psychology (EP) practice. The chapter first discusses narrative labour and the experience of not being believed, before examining the role of diagnostic categories and 'professional parents' in shaping equity. It then considers school and attendance through the lens of pain aware practice, explores family level impacts and resilience, and examines how parents make sense of pain in relation to mental health and trauma. The chapter then extends existing theory by proposing carer specific illness narrative typologies and by combining Bronfenbrenner's ecological model with family systems illness theory and critical work on trust and "mad mothering". It concludes by outlining implications for EP practice and future research.

5.2 Narrative labour, narrative strain and being believed

As outlined in Chapter 2, psychologising children's pain or treating it as "just anxiety" has been identified as a key mechanism through which chronic pain is delegitimised in both healthcare and education. The participants narratives here show how such dynamics are lived in practice, and how mothers engage in narrative labour to resist or accommodate these interpretations depending on context. A central insight across the three cases concerns the amount of narrative work that mothers undertake. The literature review highlighted the exhausting labour required to render invisible symptoms legible and believable to systems and social networks. When a child's pain is not obviously linked to visible injury or disease markers, mothers must constantly translate embodied distress into stories that fit biomedical and educational norms, often in contexts where their testimony carries limited weight. This is consistent with research showing that observers, including clinicians, are more likely to doubt the authenticity of pain in the absence of clear physiological indicators, leading to under treatment and subtle forms of blame (De Ruddere and Craig, 2016).

The concept of epistemic injustice (Fricker, 2007) is useful here. Epistemic injustice occurs when someone is wronged in their capacity as a knower, for example, when their reports are not taken seriously because of stereotypes about their social identity or perceived emotionality. In health contexts, this can take the form of "testimonial injustice", where people's accounts of pain and disability are downgraded or dismissed (Carel and Kidd, 2014). Hydén (1997) and Frank (2013) both note that people living with illness often sense that they must mould their stories into acceptable forms, what Frank calls "narrative surrender", or risk not being believed. The review argued that parents of children with chronic pain are particularly vulnerable to such injustices because they do not inhabit the sick role themselves yet

speak on behalf of a child whose symptoms may be intermittent, invisible or ambiguous.

The participants narratives within this thesis exemplify these dynamics. All three mothers describe early encounters in which their concerns were minimised or dismissed. Dani recalls initial reassurance about Leo's limp, followed by a week she later labels *"the worst week of my life"* when his condition deteriorated rapidly. Kelly reports being referred to as "neurotic" and hearing comments such as *"I've seen worse children than him"*, which implied that her worry was disproportionate. Maddy describes pain being *"downplayed"* and struggles with how to be taken seriously without being seen as overreacting. These episodes do more than delay diagnosis; they shape how parents perceive themselves and the systems around them.

Across the interviews, parents respond by increasing their narrative labour. They collect and present detailed symptom diaries, rehearse explanations for appointments and school meetings, and consciously adjust their language to align with what they think will 'count' as evidence. Kelly, for example, talks about *"doing the maths"* around Neil's energy and school attendance, translating embodied experience into a kind of cost–benefit analysis to justify part-time timetables. Dani develops a battle narrative in which she 'fights' systems and questions professionals more assertively over time. Maddy draws on her professional knowledge of neurodiversity to offer psychological explanations that might be more acceptable to practitioners, while still insisting on the reality of her daughter's pain.

This narrative labour is emotionally and cognitively demanding. Participants not only describe factual events but continually worry about how they will be interpreted, where they may be judged and whether they will be believed. For Kelly, repeated

dismissal leads to moments of self-doubt encapsulated in the question, *"am I crazy?"*. Dani describes a mixture of pride in her advocacy and frustration that she must *"fight on numerous fronts"* to secure what she sees as basic care. Maddy's narrative oscillates between struggle and holding modes, as she tries to maintain a coherent story for herself and others amid systemic uncertainty.

For EP practice, these findings highlight that listening to parental narratives is not a simple matter of gathering information. Parents arrive in consultations having already told and retold their stories to multiple audiences, often under conditions of scepticism and stigma. They may therefore be wary, defensive or highly detailed in ways that reflect previous epistemic injustices, rather than current EP attitudes. EP's can respond in several ways:

- Recognising narrative labour explicitly ("You've had to explain this so many times") and treating parental accounts as valid data rather than merely subjective impressions.
- Naming epistemic injustice when appropriate, for example in multi-agency meetings where parental testimony has been consistently overlooked and reframing this as a systemic issue rather than a personal complaint.
- Using narrative tools, such as co constructing timelines, mapping "journeys" through services, or exploring alternative storylines, to help parents make sense of chaotic experiences without forcing their stories into overly tidy plots.
- Such practices align with relational EP approaches and with calls in the pain literature to treat parental knowledge as expertise rather than bias (Bianchim et al., 2024; Ngo et al., 2022).

5.3 Diagnostic categories, "professional parents" and equity

The literature review argued that diagnostic categories strongly influence how children's pain is understood and how parents' narratives are received. Conditions are often grouped into disease related pain (e.g. juvenile idiopathic arthritis, sickle cell disease), connective tissue disorders (e.g. hypermobile Ehlers–Danlos Syndrome) and centralised pain syndromes (e.g. juvenile fibromyalgia, Complex Regional Pain Syndrome) (Eccleston et al., 2004; Gatchel et al., 2007). These categories carry different levels of biomedical "visibility" and social legitimacy. For example, adolescents with JIA may face less overt suspicion because inflammatory markers and imaging can provide objective evidence, whereas those with fibromyalgia or hEDS often encounter doubts about the reality or severity of their pain (De Ruddere and Craig, 2016).

Teggart et al. (2023) noted that even when navigation programmes exist, families retain substantial responsibility for coordinating appointments, chasing results and sharing information across services. The review suggested that these structural features create a context in which parents must become informal case managers and interpreters of complex diagnostic landscapes.

My thesis situates three families within this picture. Dani's son Leo has a diagnosis of JIA with associated uveitis; there are clear disease markers, and treatment involves immunosuppression and regular ophthalmology monitoring. Kelly's son Neil has joint hypermobility, later conceptualised as Ehlers–Danlos Syndrome, and experiences significant pain and fatigue alongside Kelly's own chronic conditions. Maddy's daughter has pain associated with her diagnosis of Colitis and features suggestive of neurodiversity and anxiety. While all three families encounter doubt and fragmentation, there are subtle differences in how diagnostic categories shape their narrative options.

Dani's narrative focusses on missed opportunities within a recognisable disease framework. She expresses anger that Leo *"should have been screened for his eyes quicker"* and feels that professionals *"will probably all protect themselves",* but her son's diagnosis itself provides a relatively stable explanatory anchor. Her battle narrative focuses on securing timely and appropriate care within this framework. In contrast, Kelly and Maddy must work harder to translate less visible, more contested conditions into compelling stories. For Kelly, the combination of hypermobility, fatigue and her own health issues complicates interactions with professionals; she worries that her knowledge and insistence may be read as over investment. Maddy confronts age related barriers to investigating possible endometriosis and must hold together explanations involving pain, anxiety and neurodiversity.

Overlapping these diagnostic dynamics is the figure of the 'professional parent'. Both Kelly and Maddy draw on professional roles in education and health. Kelly's background in SEND gives her familiarity with terminology, processes and rights, which she uses to advocate for Neil in school and health settings. Maddy draws on a neurodevelopmental lens when interpreting Faith's distress and coping strategies. Dani, while not initially in a professional role, narrates a developmental trajectory towards becoming an informed advocate, saying that Leo's illness has *"massively changed her as a person"* and made her *"less willing to take rubbish"* from services.

These professional resources are ambiguous. On the one hand, they can facilitate access to support, as parents are better able to navigate systems, frame requests in acceptable language and persist when faced with resistance (Pelentsov et al., 2016). On the other hand, they may intensify frustration when systems fail to respond as expected and can contribute to an internalised sense that parents "should" be able to manage, which can exacerbate self-criticism. These narratives raise questions about

equity. If successful navigation depends heavily on professional knowledge, confidence and time, families without such capital may struggle even more to secure recognition and appropriate educational and health interventions (Nutbeam, 2008; Harris and Goodall, 2008).

From an EP perspective, this has several implications:

- EP's should be cautious about interpreting assertive or "pushy" parental behaviour as purely individual; instead, it can be understood as a structurally induced response to fragmented systems and historically unmet needs.
- EP's are well placed to advocate for more standardised, transparent pathways for supporting pupils with chronic pain, so that access to flexible timetables, home learning, exam accommodations and emotional support is not contingent on parental professional knowledge.
- EP's can help redistribute expertise by offering accessible psychoeducational sessions for parents on pain, school rights and support options, ideally in partnership with health colleagues and third sector organisations such as RAiISE and Pain Concern.
- These actions align with participatory and relational models of EP practice and begin to address the inequities highlighted in the review between families who can access specialist programmes and digital resources and those who cannot.

5.4 School, attendance and pain-aware practice

The literature review highlighted school as a main environment in which chronic pain is negotiated and where educational and psychosocial trajectories are shaped.

Quantitative studies indicate that children and young people with chronic pain experience more school problems, higher rates of absenteeism and greater risk of needing to repeat a year than their peers, particularly among adolescents (Groenewald et al., 2019). Longitudinal data from ALSPAC suggest that chronic pain predicts reduced progression into higher education even when secondary-school grades are similar, with sleep difficulties mediating some of this association (Mullen et al., 2025). These findings align with parents' reports of a paradoxical pattern of "resilient academic persistence" alongside high psychological and physical cost.

Sherwood et al. (2025) describe the "impossible dilemma" of presenteeism: young people attend school while in significant pain, striving to maintain peer relationships and a sense of normality, but often at the price of increased fatigue and subsequent "crashes". Fechner et al., (2023) show that in school contexts, invisible pain is sometimes reinterpreted as anxiety, low effort or attention-seeking, undermining requests for adjustments. The parents in this thesis describe precisely these dynamics. Dani recounts disputes with secondary school over attendance and support; Kelly talks about structuring Neil's week into "in days" and "out days" around his energy; Maddy describes mentally "doing the maths" every morning, balancing Faith's pain, fatigue and school demands. School becomes both resource (when flexible and believing) and risk (when rigid, punitive or disbelieving).

These experiences suggest that standard attendance and behaviour policies, often assumed to be neutral, can have disproportionate negative effects on children with chronic pain and their families. Home visits from attendance officers, standardised letters and threats of fines may be experienced as harassment when families are already juggling complex medical pathways and fluctuating symptoms. In Dani's and

Kelly's accounts, these responses reinforce a sense of being under suspicion, compounding the narrative strain and epistemic injustice discussed earlier.

At the same time, all three mothers highlight moments of good practice. A primary school that offers reduced timetables, rest spaces and regular communication is described as "awesome" by Dani, in contrast to later experiences in secondary school. Kelly notes that certain teachers who "get it" make a substantial difference to Neil's willingness and ability to attend. These pockets of relationally attuned, flexible support echo evidence that supportive school climates and reasonable adjustments can mitigate the negative impact of chronic pain on participation (Shiu, 2001; Lum et al., 2017).

The review discussed tools such as RAiISE Health Passports and Pain Concern resources that aim to support communication about chronic health conditions in schools. However, without systemic support and implementation, such tools risk becoming another layer of parental work. Building on trauma-informed practice in education (Bomber, 2007; Treisman, 2017), I argue for 'pain-aware schooling': a framework that treats chronic pain and fatigue as legitimate, fluctuating conditions that require specific knowledge, flexibility and relational care.

Potential core principles of pain-aware schooling include:

- Recognition of chronic pain as real and fluctuating. Staff need basic understanding of chronic pain and fatigue, including their invisibility and impact on cognition, mood and social engagement. Training should explicitly challenge myths that pain is "in the head" or that attendance problems reflect parental failure.

- Flexible, co-produced planning. Attendance and curriculum plans should be co-constructed with families (and where appropriate health professionals), reviewed regularly, and based on the child's particular needs rather than one-size-fits-all expectations.
- Practical accommodations. Rest spaces, exit cards, flexible deadlines, hybrid learning and responsive exam arrangements should be considered, recognising that capacity can vary day to day.
- Relational continuity. Tools like Health Passports can reduce repeated explanatory labour, but they require a named staff contact and clear communication pathways between home, school and health.
- Protection from punitive systems. Use of attendance letters and fines should be carefully considered in cases involving chronic health conditions, with explicit differentiation between disengagement and medically constrained attendance.

EP's have a key role in developing and embedding pain-aware schooling. At the individual level, EP's can facilitate conversations that make the "impossible dilemma" discussable, helping schools and families to design realistic, compassionate plans. At a systemic level, EP's can contribute to local guidance so that attendance and EBSA frameworks explicitly include chronic pain and fatigue. EP's can also offer training on pain, invisible disability and stigma, using anonymised narratives from studies such as this to ground policy in lived experience.

5.5 Family functioning, identity positions, resilience and "mad mothering"

The literature review drew on research documenting the impact of paediatric chronic pain on family functioning: lower cohesion, higher conflict, role strain and reciprocal

influences between parental responses and child outcomes (Lewandowski et al., 2010; Palermo and Eccleston, 2009). Qualitative studies describe parents experiencing loss of identity, social isolation and gendered expectations of caregiving, while also sometimes reporting relational growth and re-prioritisation (Ngo et al., 2022; Sullivan et al., 2025). The identity positions identified in this thesis provide a nuanced view of how these processes feel and are narrated.

Dani often positions herself as a protective carer and self-sacrificing carer, “babying” Leo and putting herself “on the back burner”, while also describing a maturing advocate identity shaped by learning to challenge professionals. Kelly presents herself as care coordinator and emotional container, managing multiple roles and suppressing her own distress. Maddy portrays herself as Faith’s “safe person” who also becomes the “punch bag” for her daughter’s pain and anger. These positions involve pride, love and moral commitment, but they also carry costs: exhaustion, guilt, isolation and a chronic sense of responsibility.

These identity positions can be read alongside critical disability studies on the figure of the "mad mother." Ryan and Runswick-Cole (2008) and Douglas and Runswick-Cole (2016) argue that mothers of disabled children are often problematised when they advocate strongly. However, while this conceptual framework originates in special education and disability contexts, the underlying mechanisms, the pathologising of maternal advocacy, the reframing of knowledge as emotion, the use of psychological language to negate legitimate concerns, are not unique to disability. Runswick-Cole et al. (2024) extend this analysis to "gaslighting" as a systemic operation within resource-constrained institutions, showing how mothers' knowledge claims are systematically undermined. In this thesis, I argue that similar dynamics operate for parents of children with chronic pain: when systems must manage

scarcity while maintaining legitimacy, advocacy is reframed as pathology and mothers are positioned as "difficult," "anxious" or "neurotic." As Douglas et al. (2021) argue, mothers who challenge 'regimes of ruling', the institutional norms of schools and hospitals, are frequently pathologised. When these mothers advocate relentlessly for their children, their 'knowledge' is reframed by professionals as 'neuroticism' or 'catastrophising'.

This process has been described as a form of systemic gaslighting, in which institutions manage their own inability to provide answers by reframing mothers' concerns as evidence of problematic relationships with their children. The 'professional parental capital' I identify acts as a partial shield against this process, allowing mothers like Kelly and Maddy to use the system's own language to defend their sanity. However, this shield is not available to all, and the pathologisation of advocacy remains a significant barrier to equitable support for children in pain

This intersects with epistemic injustice: when a mother's testimony is dismissed because she is perceived as, "over-anxious" or "in denial", she is wronged as a knower (Fricker, 2007).

The participants in this thesis exemplify these dynamics. Kelly's experience of being called "neurotic" and later asking herself, "am I crazy?" reflects the internalisation of professional dismissal. Dani's persistent advocacy, met with defensiveness rather than acknowledgement, fuels her battle narrative. Maddy's emotional labour, absorbing family distress whilst maintaining composure for systems that have minimised her concerns, reflects the particular burden placed on mothers to manage both their child's condition and their own emotional presentation. These responses can be understood less as individual pathology and more as patterned reactions to

repeated minimisation and denial within services: repeated minimisation and denial that leads parents to doubt their own perceptions.

From an EP perspective, these insights complicate simplistic readings of parental "anxiety" or "over-involvement". High vigilance, persistent questioning and strong emotion may be understandable responses to years of having one's observations doubted and one's child's pain downplayed. Labelling such responses as pathology without attending to the history of epistemic injustice risks reproducing the "mad mother" narrative. Instead, EP's can:

- Contextualise parental anxiety and advocacy within histories of dismissal and systemic failure.
- Use consultation to explore how parents have been heard (or not) over time, and how this shapes current interactions with school.
- Avoid pathologising language in reports that might contribute to blaming narratives and instead emphasise the structural and relational factors that have shaped parental behaviour.

The critique of resilience discourse in the literature review is relevant here. Traditional resilience frameworks emphasise individual traits and coping, risking celebration of endurance under poor conditions (Tugade and Fredrickson, 2004; Saetes et al., 2017). The participants in this thesis often appear highly "resilient" in outward functioning yet describe significant emotional strain and unmet needs. Their resilience is relational and resource-dependent, not an endlessly renewable personal asset. EP's should therefore treat resilience as a situated process and ask, "resilience to what, at what cost, and supported by whom?" when formulating and making recommendations.

Family-level implications for practice include:

- Incorporating siblings' experiences and couple relationships into EP formulations and feedback, rather than focusing exclusively on the identified child.
- Recognising identity positions such as protective carer and self-sacrificing carer and validating the intentions behind them while gently exploring alternative possibilities where these roles become overwhelming.
- Advocating for systemic supports (e.g. peer groups, respite, flexible employment policies) that can reduce the burden on families.

5.6 Pain, mental health, trauma and meaning-making

In the literature review I explored the biopsychosocial perspective on chronic pain, that is a perspective that emphasises biological, psychological and social processes that interact over time to shape pain experiences and disability (Eccleston et al., 2004; Gatchel et al., 2007). I also highlighted links between chronic pain, sleep disruption, low mood and anxiety, and the role of trauma and family stress in maintaining symptoms, particularly when pain is poorly understood or contested (Fisher et al., 2018). At the same time, I cautioned that psychologising pain, framing it as "just anxiety" or "in the head", can be experienced by families as delegitimising and blaming (Hyden, 1997; De Ruddere and Craig, 2016).

My interpretations suggest that the participants constructed complex, if sometimes conflicted, models that already braid together physical, psychological and relational elements. Maddy questions whether Faith's symptoms might be "a physical symptom of what's going on in her head", linking flares to stress, sensory overload and social strain, while insisting that the pain itself is real and not simply a psychological

reaction. Kelly situates Neil's pain and fatigue within a wider web that includes hypermobility, her own chronic pain, sleep difficulties, school demands and family history. Dani connects Leo's pain and flares to infection, treatment changes and stress, but also to systemic failure when screenings were delayed. Parents thus hold lay biopsychosocial formulations that are emotionally charged and shaped by prior encounters with services.

These accounts resonate with research suggesting that parents often adopt multi-layered explanations of children's symptoms that do not map neatly onto professional categories (Palermo and Chambers, 2005). Importantly, parents in this thesis are not opposed to psychological perspectives per se; they resist invalidating versions of psychological explanation. Maddy's neurodevelopmental framing of Faith's distress, and Kelly's recognition of Neil's anxiety and low mood, show openness to mental-health understandings. What they reject are narratives that appear to override or deny the embodied reality of pain, particularly when these follow earlier dismissal.

I suggest that Educational psychologists, positioned at the edge of health, education and family systems, are well placed to support more tolerable and accurate meaning-making. In practice, EP's can:

- Foster and facilitate joint formulations that validate the body. It seems vital to help schools and families develop a shared understanding where chronic pain is treated as a real, embodied experience. Even when the medical "why" is missing, anxiety or mood should be conceptualised as factors that interact with pain, rather than as standalone explanations that risk overshadowing the embodied aspects of children's experiences.

- The use of narrative methods should be considered, such as constructing timelines of pain, sleep and school events; mapping “good days” and “bad days”; or inviting multiple “versions” of the story (medical, school, family), to integrate perspectives and make implicit beliefs explicit.
- I suggest that schools need support to move away from either/or framings (“it’s purely medical” vs. “it’s just anxiety”) and show move towards both/and narratives that recognise complexity and uncertainty.

This pattern echoes the literature reviewed in Chapter 2, where parental distress and resilience frequently co-exist rather than forming simple opposites. The present narratives complicate this further, suggesting that what can look like “resilience” from the outside may, from a parental perspective, be experienced as costly, contingent and dependent on fragile systemic support

5.7 Carer-specific illness narrative typologies and systems theories

In the literature review I used Franks 2013 typology of restitution, chaos and quest to frame illness narratives, while acknowledging its limitations for parental accounts (Frank, 1995, 2013). Franks work, grounded largely in first person experiences of illness, does not fully capture the system facing and relational labour that characterises parental narratives. Caregiver illness narratives differ from patient accounts because mothers speak about a child’s symptoms while also managing how systems respond to the family (Kleinman, 1988; Knepper & Arrington, 2016). The NOI analysis I use in this thesis contributes to this gap by proposing a set of caregiver illness narrative modes tailored to mothers.

Across Dani, Kelly and Maddy, several recurrent modes emerged: battle/advocacy, burden–isolation, calibration, containment/holding, translation, and contingent hope. These differ from Frank's genres in that:

- Rather than just focusing on their internal feelings, these mothers focus the sheer labour of "system-facing." It's about the constant, often draining negotiation with health, school, and welfare services. In a sense, the "story" is as much about the bureaucracy as it is about the pain.
- The mothers narrate who they are, focussing on identity positions (e.g. protective, self-sacrificing, strategic) in relation to professionals and family members in front of them.
- The narrative arcs are 'messy, the is no clear direction. They are often 'in-between' rather than moving towards some kind of restitution There is rarely a clear end-point; instead, mothers live with ongoing management, flare-ups and partial, contingent gains.

I suggest there may be a need for more 'carer-specific' narrative typologies. A preliminary schema might include:

- Battle/advocacy narratives: I suggest this would be a common typology within illness stories. This narrative focuses on the stories of "fighting", 'battling', characterised by combative metaphors, repeated confrontation, small victories and ongoing struggle.
- Burden–isolation narratives: This typology relates to the ongoing struggle of being misunderstood, in feeling alone and fatigued. The plot moves toward accumulation of load rather than resolution.

- Calibration: I think of this as the "doing the maths" mode. It is very present-focused, where constant fine-tuning the details of daily life-calculating exactly how much energy Neil has for school or whether a weekend trip is worth the inevitable flare-up.
- Containment/holding narratives: Here, mothers narrate themselves as the emotional anchor. They are the ‘glue’ that holds the family together, the emotional container.
- Translation: This mode is all about making the invisible seen. It’s the constant, repetitive work of re-telling and reframing symptoms for different audiences-doctors, teachers, relatives, to make a child’s invisible pain "legible" to a sceptical world.
- Contingent hope narratives: These stories contain cautious optimism, in which hope is explicitly bounded (“for now”, “glimmers of light”), acknowledging ongoing uncertainty.

It is important to note that mothers move fluidly between these modes/typologies; they are not rigid categories but lenses that highlight different facets of parental narrative work.

For EPs, being able to recognise these modes can support more attuned consultation. For example, hearing a battle narrative as a response to years of unmet need and dismissal, rather than as evidence of a “difficult parent”, can shift the relational stance in meetings and reports.

The literature review also used Bronfenbrenner’s (1979) ecological systems theory to conceptualise how processes unfold across micro-, meso-, exo- and macrosystems, while noting limitations of this model (e.g. its tendency to underplay agency and

mechanisms). The present findings suggest the value of integrating Bronfenbrenner with family systems illness theory and with a more explicit focus on trust at the mesosystem level.

Rolland's (2005, 2025) Family Systems Illness (FSI) model distinguishes illness types by onset (acute vs. gradual), course (progressive, constant, episodic), outcome (fatal vs. non-fatal) and degree of incapacitation, and maps these characteristics onto family developmental tasks and coping demands. Episodic conditions, such as JIA and hEDS with flares, require families to live in a state of "between equilibrium and chaos" (Hodgson et al., 2024), repeatedly shifting between crisis and relative stability. This conceptualisation fits closely with the wave-like narrative forms identified for Dani and Kelly and helps explain the prominence of calibration and contingent hope narratives: families must constantly hold both the possibility of crisis and the hope of stability.

At the mesosystem level, research has highlighted how gaps in inter-agency working place additional burdens on families of children with complex chronic conditions (e.g. Antonelli et al., 2009; Rolland, 2025). The participants in this thesis describe precisely such gaps: repeating their stories to different professionals, receiving conflicting advice, experiencing unclear responsibilities and "falling between" services. These are not only practical issues; they erode trust between families and systems. Building upon the work of Lum et al. (2017), it is evident that such systemic failures in communication between health and education sectors transform parents into the "default bridge" for information, a role that necessitates the constant, exhausting retelling of their child's history to overcome the fragmentation of support.

Combining ecological theory, Rolland's FSI model and the present narrative interpretations suggests that EP's should not only map contextual influences but also attend to the concept of trust within the mesosystem: how consistent, transparent and respectful inter-agency relationships are, and how they are experienced by families. In practice, this means:

- Advocating for named keyworkers or coordinators for families with complex pain conditions.
- Encouraging joint meetings where parents do not have to "start from scratch" with each agency.
- Attending in consultation to the history of trust and mistrust between a family and local services and feeding this back (sensitively) into systemic discussions.

This systems-level focus on trust also connects back to the "mad mothering" work: when services respond to parental advocacy by problematising mothers rather than addressing structural problems, they not only harm individual families but also undermine the possibility of constructive mesosystem collaboration (Ryan and Runswick-Cole, 2008; Douglas et al., 2021).

5.8 Implications for Educational Psychology practice and research

The findings suggest several areas where educational psychology can make a specific contribution. Because EP's work at the intersection of school, family and wider services, they are well placed to attend to both the narrative and systemic dimensions of chronic pain. This includes helping schools to recognise how mothers' stories of pain and support travel across systems, and how institutional responses can either validate or undermine those narratives.

Drawing these threads together, several implications for EP practice and research emerge.

1. Narrative-informed, justice-oriented consultation

EP's should treat parental narratives as sophisticated, effortful constructions that reveal not only child needs but also systemic functioning. Recognising narrative labour, being alert to epistemic injustice and "mad mother" discourses, and actively validating parents' knowledge can help repair trust and improve the quality of joint problem-solving. EP's can incorporate explicit questions about when parents have felt believed or dismissed, and how this shapes current engagement, into consultation practice.

2. Pain-aware schooling as a systemic goal

EP's can support schools to move toward pain-aware practice: staff training on chronic pain; flexible, co-produced attendance and curriculum planning; practical accommodations; and careful, child-sensitive use of attendance enforcement mechanisms. EP's can embed awareness of chronic pain and fatigue within existing EBSA and inclusion frameworks, and champion third-sector tools (e.g. RAiISE Health Passports) while focusing on implementation, not just recommendation.

3. Family-level formulations and support

Formulations and recommendations should routinely consider siblings' experiences, parental identity positions and couple dynamics. EP's can help staff understand why certain parental behaviours (e.g. over-protection, intense advocacy) may be adaptive responses to chronic uncertainty and past dismissal. Where appropriate, EP's can signpost or support access to family-based interventions and peer support, emphasising that supporting the family system is central to supporting the child.

4. Complex biopsychosocial formulations

EP's can model nuanced "both/and" formulations that respect the embodied reality of pain while exploring psychological and contextual contributions. Narrative tools can be used to hold multiple meanings in play and to co-author more tolerable, shared understandings that avoid psychologising or purely biomedical reductionism.

5. Mesosystem trust-building and advocacy

EP's are well placed to work on developing trust within and between local systems: identifying patterns of fragmentation, advocating for keyworker roles and joint meetings, and feeding back to senior leaders about the cumulative impact of repeated retelling and inconsistent responses on families' trust and wellbeing. This might include contributing to multi-agency practice frameworks that explicitly recognise chronic pain and epistemic injustice.

Furthermore, the findings suggest three broad areas for educational psychology practice. First, narrative-informed consultation can be used to engage explicitly with parents' caregiver illness narratives, helping them to explore shifts between different ways of telling and to consider how these positions affect relationships with school and services. Second, work at the mesosystem level can focus on strengthening trust between home, school and health, for example, by reducing repeated retelling, clarifying responsibilities and supporting the development of shared, written plans that travel with the child. Third, recognising narrative labour as legitimate and effortful work invites EP's to validate this labour in meetings, to consider how school and service processes may add to or ease it, and to advocate for arrangements (such as key contacts, pain-aware policies and accessible information) that lessen

the need for mothers, or parents to constantly translate their child's experience for different audiences.

5.9 Theoretical contributions

I make three interlinked theoretical contributions within this thesis. First, it extends Franks 1995 illness narrative framework by proposing a set of carer specific narrative typologies that better capture the dynamics of caregiver illness narratives (Knepper & Arrington, 2016). Across the three narratives, participants move between battle/advocacy, burden-isolation, containment/holding, translation, and contingent hope modes, shifting emphasis as they speak to different audiences and manage different relational demands.

Second, I explore the concept of trust construction at the mesosystem level, extending ecological systems and family illness models by focussing on, not only which systems are present but how families experience the quality, consistency and relational tone of connections between them. Trust is eroded when participants must repeatedly retell their story, receive contradictory advice or encounter unclear responsibility; it is strengthened when there is continuity, coordination and named relational anchors.

Third, the analysis conceptualises narrative labour as a central feature of parental experience in chronic childhood pain: the cognitive, emotional and relational work involved in translating a child's embodied distress into forms that schools and services will recognise, while maintaining family identity and hope in the face of uncertainty. Thinking with narrative labour centres mothers and parents not as passive recipients of services but as active, strategic meaning-makers whose efforts are often invisible within systems.

Although the analytic focus here has been on chronic pain, the concepts of narrative labour, professional parental capital and mesosystem trust may be relevant to other long-term, less visible conditions where families find themselves explaining, justifying or defending their child's needs across settings. For educational psychologists, this suggests that attending closely to how parents narrate their experiences, and to the conditions that make certain stories easier or harder to tell, could inform work with a range of groups who navigate similar systemic and credibility challenges.

Chapter 6: Conclusion

6.1 Synthesis and Complexity

I began with what looked like a straightforward question about what it is like to mother a child living with chronic pain. The stories shared by Dani, Kelly, and Maddy show that nothing about this experience is straightforward. Their accounts move back and forth between crisis and adjustment, certainty and doubt, being believed and having to justify themselves again. These are not tidy stories of tragedy or triumph; they hold tension, they remain unfinished.

Across the chapters, one theme stands out. Mothering in this context involves constant work that few people see.

The role of these mothers is extensive; they interpret the pain of their child, attempt to translate it into acceptable language, repeat histories to new professionals. At the same time, they hold family life together while symptoms change without warning. This work is emotionally and cognitively exhausting as they attempt to juggle needs and manage relationships around them. This work is tiring and continuous, and it is strongly shaped by how services are organised rather than solely by family choice.

6.2 Diagnostic Visibility, Narrative Possibility and Equity

Diagnosis shapes whether a child's pain is accepted as real. Where there are clear markers and established pathways, parents can rely on an existing medical story. Where pain is less visible, parents must construct that story themselves and persuade others to listen. Kelly and Maddy describe having to explain and re explain their children's experiences, so they are not dismissed.

This difference is not neutral. It creates uneven access to recognition and support.

Two mothers brought professional knowledge from health or education into their parenting role. That knowledge helped them navigate systems and speak the language services expect. This raises a difficult question about families who do not have that background. Without it, the path is likely harder and slower, with greater risk that needs remain unnoticed. Educational psychology cannot ignore how strongly systems reward confidence with bureaucratic processes. Support must not depend on insider familiarity.

6.3 Schools as Sites of Friction and Possibility

School is where many tensions surface. Visible illness often prompts quick adjustments. Invisible pain can be questioned or reframed as anxiety. Participants describe a daily decision about attendance that feels impossible. Sending a child in may increase suffering, keeping them home risks academic and social loss.

Yet schools also show what is possible when they respond well. Positive examples demonstrate that flexibility, listening, and relationship building can shift the experience entirely. Practice described by participants points toward what might be called pain aware schooling. Recognition that pain fluctuates, plans developed together with families. Practical adjustments that change as needs change. Consistent relationships rather than repeated reassessment. Protection from punitive responses to absence.

This is less about new policy and more about cultural change. Schools need to understand invisible illness as a real constraint on participation, not a behavioural issue.

6.4 Family Identity, Narrative Positions and the Pathologising of Advocacy

Chronic pain reshapes family identity. Parents become carers, coordinators, advocates, and emotional anchors at once. Several spoke about placing their own needs aside or becoming the central organiser of care. These roles carry costs such as exhaustion, guilt, and a sense that personal identity has narrowed.

Persistent advocacy can be misunderstood. When parents must push repeatedly for recognition, professionals may interpret this as anxiety or over involvement. The accounts here suggest something different. Advocacy often reflects gaps in systems rather than personal difficulty. Recognising this changes how educational psychologists interpret parental behaviour and how they respond.

6.5 Resilience: Cost, Contingency and Systemic Responsibility

The concept of resilience is complex and can often obscure suffering or systemic failures. It can often be something that individuals or families are attributed with and show in the face of adversity. The parents here, show persistence and creativity to cope, but this is contingent on relationships and access to resources and/or support. Their capacity is not infinite.

Perhaps it is better to explore what families are being resilient to, and who is responsible for reducing that burden.

Focusing only on family strength risks overlooking the service structures that require such endurance in the first place. Educational psychologists need to support coping while also challenging the conditions that make coping so demanding.

6.6 Original Contribution to Knowledge

Across the thesis, I have argued that mothers of children with chronic pain are engaged in extensive narrative labour as they seek to make their child’s invisible

pain recognisable within education and health systems. This thesis contributes to knowledge by formalising that concept and linking it to diagnostic visibility, professional parental capital and epistemic injustice in everyday practice. It extends existing illness narrative theory by identifying carer-specific narrative typologies and by demonstrating how these are shaped by mesosystem trust, or its absence, across school–family–health interfaces. In doing so, it positions educational psychology as uniquely placed to work with narratives as a focus of consultation, systemic change and advocacy, rather than treating them as background context.

6.7 Limitations and Their Implications

This research draws on a small group of participants. The depth gained through narrative work limits the ability to generalise. Fathers' perspectives are absent. Families facing greater socioeconomic challenge or less engagement with services are not represented.

Some of these limitations were a result of difficulties in recruiting. The evolution of the study from an earlier, less successful recruitment attempt to the final design is itself part of the research story. It highlights how doctoral projects are shaped by the realities of access, timing and participant burden, as well as by conceptual aims. In my case, refining the topic led to a more coherent and ethically manageable project, but it also meant that some questions originally envisaged could not be pursued. This experience reinforces the value of flexibility, reflexivity and transparency about the contingencies that shape qualitative research in practice.

As noted in Chapter 3, two of the three mothers had professional or system knowledge that enabled them to draw on policy language, procedural understanding and networks when advocating. Families without such resources may face greater

difficulty accessing support, may use different narrative strategies, and may experience more acute forms of marginalisation. The findings should therefore be read as offering analytic insight into processes of meaning-making and system navigation, rather than as capturing the full range of experiences among all families living with paediatric chronic pain.

The study also sits within a specific UK context shaped by the National Health Service, the education system, and ongoing resource pressures. Experiences might differ elsewhere or under different policy conditions. Interviews capture what participants chose to share at a particular time. There was no observational or longitudinal element, and children's own voices were not included.

These gaps highlight where further work is needed.

6.8 Directions for Future Research

Future studies could include more varied family structures, wider cultural backgrounds, and parents with limited contact with formal services. Following families over time would help show how narratives shift as children grow and transitions occur. Research that tests pain aware approaches in schools could examine what helps them take root and what outcomes matter most to families.

Comparative work across different chronic conditions may also clarify whether issues such as diagnostic visibility and system navigation appear in similar ways elsewhere. Participatory designs that involve parents directly in shaping research questions would keep inquiry grounded in lived experience rather than professional assumptions.

6.9 Final Reflections: Obligation and Practice

This work reinforces a simple but demanding idea. Listening carefully to families is not optional for educational psychology. It is an ethical responsibility.

The mothers who contributed did so in the hope that their experiences might lead to change. That creates a duty to translate understanding into practice, whether through more flexible school responses, better coordination between services, or training that prepares professionals for work with chronic pain.

There is no neat ending here. Chronic pain does not resolve on schedule, and neither do the challenges surrounding it. Families continue to manage symptoms, negotiate support, and maintain everyday life within uncertainty. Systems continue to struggle with coordination and understanding.

But change can begin in small, practical shifts. Professionals who treat parental accounts as knowledge rather than bias. Schools that allow flexibility without suspicion. Services that reduce the need for families to retell their stories again and again.

And most importantly, parents of children living with chronic pain should be recognised as experts in their own experience and partners in shaping support. Their experiences of battling and fighting with systems are exhausting and lonely. The ‘work’ is multifaceted and too often unseen. Educational psychologists can be important partners and support, advocating and offering alternative narratives that can encourage real change.

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Appendix A-

Working Transcript- Dani- StEP's1,2, 3 and 6

1.	**Table 2: Dani's Story** Working Transcript – organized into segments with sjuzet underlined. Fabula and sjuzet overlap in *Italics*. **Simon T Dixon:** No, okie doki. Alright, okay so, can you share the story of when you first realised that your child was.. experienced chronic pain? What was that like for you and your family? Okay. Yes. **Dani:** So, Leo was three and half years old, ummm it was in the January er, *we were looking after my Mums dogs*, and we'd, Leo was always a bit, well we thought lazy, cuz even though he started to walk at 9 months old he didn't really like walking distance, so, like only walked around the village and stuff but obviously we didn't make him climb mountains or anything like that (chuckles), but still he'd always like ask for his buggy and want to be carried. He didn't really like walking a lot erm so when he was three and a half, we took him for a walk, we'd been for a walk, and he really used to kick off, like a toddler would. **Simon T Dixon:** Um uh **Dani:** We carried on the walk and then the next day his knee had all swollen up. So we're a bit like ooh, has he hit it? Because we'd been to Tigers, the play area as well. **Simon T Dixon:** Okay. Yeah. Yeah. **Dani:** So, we went there in the afternoon. So we were like,… **Simon T Dixon:** Yes. Yeah. Okay. **Dani:** So has he, you know, *being a typical boisterous boy*, has he hit it or done something? So we wasn't sure what had happened. Umm I thought him being a boy, we're not going to make any rash decisions to rush him to hospital. So the next day it was a little bit more swollen, well quite a bit more swollen and you could clearly see there was fluid on his knee. He was not putting pressure on it and wasn't walking properly. So, I took him to the doctors and they said there's a lot of heat coming from it, so we're a bit worried that it's an infection in his joint.	Key: - Fabula within move identified as Fab:..... - Identity Positions- Annotated in blue - Holistic Content- Annotated in green - Holistic-Form- Annotated in yellow **Fab:** Initial Symptoms and Uncertainty (Early Childhood) **Wave-like / Cyclical (Onset–Crisis–Stability–Recurrence)- (Please also see Move 3)**

	Simon T Dixon: Okay **Dani:** So, they sent us straight to the hospital with him. , erm we stayed in hospital. So, that was on the Monday. We didn't come out of hospital until the Friday… er with no, we didn't really have any answers. He'd had an MRI, he'd had erm fluid.. been put to sleep and had fluid pulled from it cuz they wanted to see if it was I don't know what they were looking for (shaking head). *They didn't really give me a lot of information* which that week was the worst week of my life, because you didn't know what was wrong with your baby, but *there was clearly something wrong.* but then they just put it down to a trauma that he'd obviously hit it and that, that was that.. *just try and make him rest,* which was a crazy to say to a three and a half year old that doesn't watch telly(chuckles) and just wants to kick a football **Simon T Dixon:** Yeah. Yeah. **Dani:** So, we got sent home and then we was meant to go back to see them I think two or three weeks *later just to see how he was getting on, erm,* but then we noticed that his ankle on his other leg was swollen. **Simon T Dixon:** I see. Yeah. **Dani:** Then when we went back to see the doctor, Mr. L who was brilliant, he was like, "Yeah, I think this could be	**-Reflective Parent** Experiential- Plot Holi Cont- Unknown, inconsistent information from health services
2.	arthritis." We were like, he's three and a half years old, how.. That's an old person's thing, we'd never really like, well never heard of it before. Erm.. So was a bit, like didn't really know what to think. Me and Paul were like, *""Right, okay."* So we then went to see a specialist and she obviously confirmed, "Yeah, he's got it in both joints of his knee, two joints of his ankle and also in his wrist." So then our journey then obviously started. **Simon T Dixon:** Mhm. **Dani:** So, Leo is 12, nearly 13 now and he's just had another flare up. **Simon T Dixon:** Okay.	Explaining naivety which later is contrasted to becoming more knowledgeable **Fab:** Diagnosis and Early Impact (Arthritis Confirmation) **Reluctant Traveler:**
3.	**Dani:** Even though his joints had calmed down once he'd had all his joint injections, he then went on to Methotrexate, which is like, well, the worst drug I think, Leo hated it, he was sick	

4.	all the time with it.. erm.. it then led on to other issues, Leo wouldn't eat, so then we had to go to a dietician because they thought he was anorexic, cos he *just couldn't keep anything down.* Erm..but I think the main thing with Leo is his eyes, so Leo, through juvenile arthritis, he then wasn't screened.. we.. erm.. looking back now, obviously, *you don't know anything, do you? You can only trust what a specialist is telling you. We knew nothing about arthritis and I think, at the time, myself and my husband, Paul, we were both, not in denial, but you don't, you don't want your kid to be broken, so, it was a bit like, we perhaps didn't ask the questions that we should have asked or we didn't research it because you don't want to research (shaking head) it because you research it and you get, like anything, if you Google you get horrific things*. Erm, so we were just trying to deal with what was happening at the time. But then, it then led to him having, I think he.. they didn't.. I don't know what happened and I don't think I've got the energy to ever try and find out what happened because (sigh) I do think that the NHS will probably all protect their selves, but Leo should have been screened for his eyes quicker than what he was. **Simon T Dixon:** Okay. **Dani:** Because then his uveitis was really bad, to the point that they had to like put him on nine drops a day of steroids to try.. **Simon T Dixon:** And when, when abouts was that, when they, when he, when they first realised that, you said that they should have screened them. **Dani:** So I think the screening they're meant to have, like four months, well meant to have straight after they've been diagnosed with arthritis. So Leo, he's under Northampton, but he was..he also got sent to Birmingham because at the… not 100% sure, I think so he's got Dr. K and Dr O, Dr K is obviously an adult doctor that deals with arthritis, but Dr. O is a pediatric doctor that has got a interest in arthritis. **Dani:** So together they make a specialist. **Simon T Dixon:** Okay. Yes. No. **Dani:** But Leo also had to go to Birmingham just because obviously they're a bigger, bigger hospital.	**Fab:** Challenges with Initial Treatment (Methotrexate and Side Effects). **Wave-like / Cyclical** (Onset–Crisis–Stability–Recurrence) **Identity in Conflict:** Holi-cont- relentless nature of the illness. Unpredictable and feeling letdown by services **Fab:** Uveitis and Missed Screening **Reflective Narrator:** Battle/fighting typology

5.	Erm..but then Leo should have probably got in straight away to go and see for his eyes as well to make sure his.. but we didn't know anything about this, like obviously, you don't know, you, you don't even think your kid could get arthritis let alone it go to his eyes, cuz you don't, that's not a joint is it?(shaking head) So you don't really put two and two together, but it wasn't until, I think, after his steroids had been done and he started on his medication when we went back to the specialist. I think it was actually my mom had read up about it, so my mom was like has Leo got to go for a screening on his eyes and they were a bit, oh yeah, hasn't he been? We were like, ""No, we wouldn't have known that."" So, so Leo then went for his eyes, like I say, his eyes were really swollen, had to have a lot of steroids. He then.. had cataracts in both eyes because of the intense, erm.. steroids in his eyes. But unfortunately, it then made his left eye not work anymore because that cataract was last to be taken out. Erm, it it made, it basically *his little brain just told him that eye doesn't need to work anymore*. Erm.. so that's like blurred vision, erm but then Leo's other eye that he had cataracts in, then he got Glaucoma. So only got 10% left of nerves in his good eye. **Simon T Dixon:** Yeah. Okay. **Dani:** Not his good eye, but it's his good eye vision (chuckle). **Simon T Dixon:** Okay. Yeah. **Dani:** So I think, *as much as it was awful to see Leo in pain at the beginning, cos he then was okay with his joints but it was like the medication that he was on was obviously horrible and it took ages to work out that Methotrexate wasn't for him*. So we then went on to Humira, which.. he fell in love with the nurse at X surgery, they couldn't have done enough for us. They were absolutely brilliant. because me myself and Paul didn't want to inject him. **Simon T Dixon:** Yeah. **Dani:** So they played around with his drugs, but then Humira has lasted quite a long time actually, until 6 months ago when they took him off to give him a break and hope that it didn't come back. But yeah, unfortunately it has come back, it came back in January and we've had to kind of start the process again with injections and *this time around it was a lot worse because obviously Leo is very much aware of being put to*	**Holi-cont- Good experience of nurse(inconsistent with others)** **Fab:** Treatment Evolution and Recent Flare-up **Mentally Strained Mother:** Holi-Cont- Unpredictable and ongoing concern that pain will return. Burden of the cycle of illness

6.	*sleep, having to have canulas in his hands and yeah, it wasn't a fun experience this time around at all*. so… **Simon T Dixon:** Yeah. **Dani:** And to see him in pain, to be able to talk about it. I think when they're little kids they're kind of relentless, aren't they? They just crack on and they do get on with it. But… Leo had a lot of tantrums, like, probably more than any other kid because he couldn't deal with what was going on. Erm.. Leo's also had to have counselling quite a lot, because especially as he's got older and he's gone to D [Secondary School], he can't control how he feels and yeah, it was a bit rubbish last year, we had a bit of a rubbish year with him and then it's hard on, like his older brother Bennie, cos he's two years older.. it. and I.. he doesn't get what's going, he he gets that Le obviously, like, this time around, he was like god yeah he, he's got a massive leg and poor kid, he feels for him but also that attention is on Leo a lot so it must.. **Simon T Dixon:** Yeah. **Dani:** be hard for Bennie to think and we have to constantly reassure Bennie, like 'he's not our favourite, he just needs us more', like he's never been our favourite, like we love you both the same and that's hard aswell… **Simon T Dixon:** How did think, er, so kind of. Did you feel like your relationship might have changed a bit when the diagnosis came and how do you think your kind of relationship might have changed or shifted kind of at that point? Okay. **Dani:** I think I'm more protected over Leo. **Simon T Dixon:** Okay **Dani:** There's a lot of like, Leo I'd say out of Leo and Bennie…Erm, Me and Bennie are more alike. So we laugh at the same things and whereas Leo I'm very protected over and I, I probably baby him a lot more than what like, *Bennie bless him, just cracks on and he's always had a shower himself whereas Leo (chuckling) I'm still like giving him his toothbrush in the shower him but Leo plays on that like he's got a wicked character*. And I think because of everything that goes on, like, but I do feel for Ben because I think a lot of people in general, like family members I feel like they give Leo more attention and I don't think that's fair. And so I feel like I overcompensate for Bennie in that way.	**Fab:** Emotional Impact on Leo and Sibling Dynamics Relational typology- convincing me that she is thoughtful around all of the families needs. Holi Cont-More protective over Leo and babies him, due to his condition. **Honesty and humour**

7.	**Simon T Dixon:** Yeah. **Dani:** So, as much as I do everything for Leo, *I overcompensate with Bennie, like, making sure he's ok, because I'd hate in years to come for Bennie to be like, 'oh, it was all about Leo when we were growing up'. Like, 'mom didn't care about how my exams were going'*, or, and that's what's been difficult as well this month because Bennie's had his mocks. **Simon T Dixon:** Mhm. **Dani:** *It was all about Leo and* er *I had to* like*... And I'm exhausted now. I'm so glad January is done*. Because that is another thing. *you're exhausted all the time because* you're constantly*, it's tiring having kids anyway, but when you've then got kids with additional needs, and it's lonely* like*, people don't get it,* like*, teachers don't get it*. Like*, the battle that I've had with them trying to get* like*, the rule for saying,* "" oo, your kids attendance is rubbish, but I felt like they didn't really help me."" … **Simon T Dixon:** Okay. What could, what do you think they might have been able to do differently? **Dani:** Well I just, things like *them passing me to pillar to post, like ""..you need to speak to his form tutor, you need to speak to this person.* ""Come on guys, like, I've got enough to deal with Leo and his medical like stuff, just one of you sort something out". **Simon T Dixon:** Yeah. **Dani:** *That's how I was getting frustrated with it to the point that I was a bit like, do you know what? He's not coming back in school until you've sorted something out. And then you'd get one of them say, could you call back on Friday to like, to make sure everything's in place? No, I shouldn't have to call, I'm trying to hold down a full-time job, look after my, like Bennie, like sort a house out. And I just think people don't realise, like, how much you like appointments you have to arrange*. And I'd say that me and Paul are quite equal, Paul is self-employed so it's hard with that as well because he feels a lot of guilt because he knows that I have to do a lot of appointments and stuff. **Simon T Dixon:** Yeah. Yeah. **Dani:** But it's like *I'm quite a control freak and I think Leo's illness has made.. me change as a person, massively change as*	**Fab:** Navigating Systems and Loneliness in Advocacy Holi Cont- Battle with teachers and school. Isolated- no one gets it.. Battle fighting typology Holi Cont- Inconsistent support from secondary school **Fighter/Advocate:**

8.	*a person cuz I never got people getting panic attacks and anxiety. Like, I've always been a whittler, but I've never had anxiety like I've had since everything's gone on with Leo*. **Simon T Dixon:** Okay. **Dani:** So obviously it's affected my mental health as well, as well as like. Paul is a bottler, he'll bottle everything up, so it's affected him as well. And I think sometimes we perhaps don't talk as much as what we should together because we don't want to upset each other. **Simon T Dixon:** Hmm, **Dani:** Which it it then, like I say it then becomes quite lonely because you can talk to your best mate, but they don't get it cuz they've got healthy kids that are fine and then if I talk to my mom or dad I feel like my mom's too close because that's her grandson as well, that I'm.. I feel like I don't want to say too much to her cuz she's a, *I'm quite, luckily I'm quite a hardish person* that I don't cry at everything *whereas my mom's quite emotional and she does cry at everything so then it's a bit like 'I don't want to come and talk to you now because* I can't deal with your emotions as well as my own', **Simon T Dixon:** Mhm.. **Dani:** So, it is, yeah, it is I think myself and Paul at first felt stupidly lonely, like, we felt like, 'why us?', I felt like, was it something that I've done. **Simon T Dixon:** Yeah. **Dani:** Like, is, did I do my, because I did do my pregnancy a little bit different cuz you are more relaxed with your second, so I'd have the odd glass of wine whereas with Bennie I was very ready… because he was my first I didn't touch alcohol, I di.., I ate everything that they told me to eat. Then when, I then was a little bit more relaxed with Le, as in I don't know, I'd perhaps have my steak like, not burnt to a crisp like you're meant to. I perhaps had it a little bit red or I had like, a tiny glass of red wine, probably twice in my pregnancy. You then blame yourself, you think it's got to be something I've done? **Simon T Dixon:** Do you do that now? Is that something that you've done kind of in the past and, or is something is ongoing for you? **Dani:** No, I don't anymore…	Pulsing effect: (Evaluative segment) being reflective of the impact- followed experiential Lonely/isolated narrative **Fab:** From Self-Blame to Acceptance Holi Cont- Parental blame and change to 'normal' parent experience.

	Simon T Dixon: Okay. **Dani:** Because obviously the specialists are like, 'it's nothing to do with you', cuz I'm quite open and honest, like I talk to the specialists and I did say to them is it something that I've done, like and I said I did this and they were like ' No, no it's noting to do with like, it's literally nothing to do with anything that you've done'. **Simon T Dixon:** Yeah. **Dani:** So at the beginning I did, I think I bottled it and I was like it's got to be something it's.. like, it's my fault, but and then I was like 'oh god', I used to carry like Bennie on my bump is it something I've done to his joints and I'm like no there's so many, like, like (chuckling), I think it was one of the specialists said people take heroin and their kids are okay, it's nothing that I've done. But yeah, so I don't know. I don't blame myself anymore. **Simon T Dixon:** You said it changed you as a person and you kind of said that I think you were talking about maybe experience more anxiety, **Dani:** Yeah. Yeah.	**Resilient Self-Reflector:**
9.	**Simon T Dixon:** in what, is there any other ways in which you feel like it might have changed you or can you tell me a bit more about it? **Dani:** Yeah, like I say I'm really anxious like with everything, like even to this time when Leo, we were actually going to Newcastle for Christmas and that's when he realises his leg was swollen.. Erm, yeah I don't know, *I think it just makes you a bit more of an overthinker but in like in everything* (Dog barks..) hold on, sorry stupid dog screaming. **Simon T Dixon:** (chuckles), no probs. **Dani:** So yeah, I think it just makes, *it makes me, like especially this time around, it* like, *overthink everything,* like *relationship, friends..* like, *just I think it's just made me a bit* erm*.. more anxious and a little bit less tolerant to people that are like 60 years old and saying, ""oo, this hurts."" I think yeah, like, my kids had it since he was three. He should never have had it, you should have this when you're old, not when you were kid and trying to get through life, so..* **Simon T Dixon:** Yeah.	Less tolerant of **Fab:** Enduring Anxiety and The Fear of the Future. Perpetuating cycle of flare up/illness **Anxious Planner**

10.	**Dani:** But yeah, I think I'm anxious as well cuz like I say, Paul bottles stuff up. So, it's it's, it's never put, like massive pressure on mine and Paul's relationships cuz I think we're quite good. We work as a team, we do talk about stuff that needs to be spoken about but. I think he struggles sometimes with me because I overthink everything and I whittle about everything. **Simon T Dixon:** Mhm **Dani:** So like, this time around I was like, am I doing the right thing? Like, I didn't know about his joint until we drove to Newcastle, erm and then Leo was like, ""Mom, just to let you know er, my leg hurts."" And of course, straight away I had tears in my eyes because I was like, ""Oh, God, no", like, I knew straight away what it was **Simon T Dixon:** Yeah **Dani:** so, just give the kid a break, but.. **Simon T Dixon:** Yeah, God… So when you were, when that happened, does it, did it take you back to a point in your life back to kind of previous experiences? Were you thinking about the there and then, were you thinking about the future? Where were you? What were you… **Dani:** *I always think of the future and I think that's one of my biggest anxieties is his future like, so we'll talk to Ben about like, what he's going to do for his career and stuff, but then when Le talks about it we're a bit like we've always been positive with him and we've never lied to him if he said to us like he said the other day do you think I'll be on injection for the rest of my life now. And I was like, erm, yeah you'll perhaps will Le, you'll perhaps do what you've done before, you'll have a bit of a break. But I'll always be honest with him if he asks me anything. I don't tell him obviously too much detail, but I'm always honest with him.* **Simon T Dixon:** Yep. **Dani:** Cos *it must be scary for him, like it must be.. he must.. but he's very honest and open, he'll tell you how he feels. We've always, like, made him talk to us, like never bottle stuff up. You've always got to talk. Like, there's always somebody out there that can help you and obviously we've shown him that by taking him to the [counselling] and him having like eight counselling sessions and he said he feels better about that as well.*	Talking about managing relationships across the family **Holi-Cont- trying to foster hope but with honesty.** **Honesty** **Fab:** Openness and Encouragement to Talk **Advocator for Mental Health:**

11.	**Simon T Dixon:** Okay, do you think that's helped him? Definitely… going for counselling, **Dani:** *Yeah…And he made me laugh cuz he said, ""Maybe you should go, Mom."" (chuckling) I was like, "" Yeah, didn't really I don't think of me Leo, I just think of you. So yeah…* **Simon T Dixon:** Is that something that you might consider? or… **Dani:** Erm, I have been, but when, er it first all happened, I think it was probably a few years after my work actually paid for me to go and see a counsellor. Erm, did it, *I don't think it helped cuz he's still got arthritis and still partially blind…. So, she can give me coping mechanisms for my anxiety…* **Simon T Dixon:** Mhm. **Dani:** ..which I, the thing is, like.. with me I see anxiety as a weakness, a massive weakness so I'm constantly fighting with myself, like come on you're all right, like just get on with it, *like so I always put myself, like any parent puts herself second,* well any good parent puts herself second. But I think I perhaps put myself too much on the back burner because I'm too busy trying to make sure like Le's okay and Le's happy and obviously Bennie's happy, Paul is happy. So, *I perhaps don't look after myself as much as what I should.* **Simon T Dixon:** Yeah. Has that, has that been all the way through? Has there been any changes in that or..	**Fab:** Parental Reflection and Self-Care
12.	**Dani:** No, I think when Leo's like, when Leo's had his time that he's okay, his eyes are settled, I settle, so less anxious. But it kind of goes to the back of your mind, doesn't it? Because looking at Leo, Leo is a normal kid, Leo does play football, Leo does go out with his mates. It's only when things crop up that you're a bit like, *like Halloween, Leo can't see in the dark properly. So, it's things like that that then make me feel a bit sad because I'm like oh, like I feel for him that his mates know that he can't see properly and that worries me because then I'm constantly like tracking his phone to make sure he's not like, lost and it's things like that that I wouldn't think twice about with if Bennie, like if Bennie went out and come back like it, I wouldn't , obviously I worry like a normal parent, but with Leo I find that it's quite intense and I have to stop myself from being like that.. because I don't want Leo to feel like he's different.*	**Self-Sacrificing Carer**

13.	**Simon T Dixon:** Yeah. Yeah. Erm.. Something you said, erm before was to you know, to look at Leo, you wouldn't know. **Dani:** Yeah. Yeah. **Simon T Dixon:** Is that something that you experience other people? Is that something you worry about with other people or is it something that other people don't quite understand? You said that as well. I don't know.. what you mean by that? **Dani:** Yeah, now I don't know what goes on at school, like I only know what my kids tell me but in the past, erm, I know that people don't know what to say to you but a few times, like I've been in when they were at primary school and people have been like, *"oh, well he looks all right"* and that like, that infuriates me. *And there, there is quite a few people now that I tend not to talk to because I just think, have you really just said.. "..*nah, I've just made it up about my kid*"*, so like.. **Simon T Dixon:** Was that friends or like, **Dani:** Erm, like no it's more like parents of other kids like people like, cuz I don't… if you're my friend, you know about my life, If you're not my friend, I don't, I don't broadcast anything like…if, if somebody.. I'm open and honest, if people ask me questions I'll answer them erm, but yeah, *I think sometimes when people say things like that, it's a bit* like, yeah, I don't carry him, like this time around, I've had carry him, I've had to put him in the bath, and it puts pressure on your body as well. And people don't see that side of it, people don't see what goes on in your house when he was on Methotrexate and I used to have to knock on my neighbour's door saying, ""We promise we're not killing Leo, we've just got to inject him tonight, or he's got to take his pills tonight, so, if you hear lots of commotion going on… it's just like one minute like trying to be like 'come on mate, it'll be all right, we'll buy you whatever you want', next minute like, '..we're going to call an ambulance if you don't take the tablets'. (Use of gestations and became animated, toned went higher) It's horrible cuz… but yeah, people don't see that, do they? Like, I think people just see.. and like with his eyes, cuz he just carries on with stuff.. it yeah, I don't. And even like the teachers, there.. Like Leo's got a partially sighted lady that goes in. She's not partially sighted, Leo is (chuckle)… **Simon T Dixon:** Yeah, yeah, yeah, yeah. **Dani:** .. and she go and she goes in and she's actually told C [school] off quite a few times because he's meant to have, like, a pass to leave early because of his sight. He's meant to have	**-Normalising Parent:** **Fab:** Managing Chronic Illness Impact Holi-Cont- Others don't understand. Hidden disability. **Fab:** Navigating Social Perception **-Powerless Advocate** Pulsing effect (Experiential) describing vivid high emotions events

14.	like a lift pass. He's meant to have a laptop and things like that. But I've never pushed it with them just because Leo is not unhappy. Leo hasn't said to me, "" oh, mom, I really need that. I can't see", and I think Leo would so I think some Yeah. **Simon T Dixon:** It sounds like he's, he wants to be like everyone else and he's quite resilient, but you say, it's like you say, but when you can't see these things, then they're hidden, aren't they? **Dani:** Yeah, yeah, and *I think Leo is a little bit like me, he comes across as if he doesn't care and he's quite hardcore and he'll just get on with it and nothing phases him. But then when he's obviously in the security of his own house, he… this is why he had to go to the Low Down, because he started to get a bit obsessive with one of his mate. Because his mate had shown him, like care and then, so then he wanted to cling on to him because I think he felt safe with him*. **Simon T Dixon:** Yeah. **Dani:** But obviously I check both my children's phone cuz while I still pay for the bills I'll be looking at their phones. **Simon T Dixon:** Okay. Yeah. **Dani:** And I'd looked at Leo and it was just constant, like are we still friends? It was very, he's insecure, but he's like that with football. So, at the beginning of the season, Leo plays rubbish because his confidence is not there. He'll come off the pitch and cry and say, ""I, I'm rubbish, I'm just so rubbish."" and he's a really good little footballer,… **Simon T Dixon:** Yeah. Mhm. Yeah. **Dani:** but his confidence is just.. and then at the end of the season he's one of their best players because his confidence is there and.. but Leo is like that his confidence is just not.. I think since going to the counsellor I've seen a different side of him. Erm, but, yeah it got that bad that we obviously.. well we didn't tell him off, we were just a bit like you can't be like that with people mate because you push people away if you're like too needy. And he came into our bed and was like just really upset and he, he didn't say he wanted to kill himself. I think his words were sometimes I just.. it's too much. I don't want to be here. And so like, obviously that's really tough to hear as the parent and… **Simon T Dixon:** Yeah. Mhm.	

15.	**Dani:** *we knew that we had to give him some kind of help which again with the, with the… with Northampton I feel like Dr.N, bless her, she said like, go to low down. But I find it really weird that a clinics with kids with chronic illness haven't got a counsellor like what I don't get that.. cuz our friends, their little lad's got type 1 diabetes*. **Simon T Dixon:** Okay. **Dani:** He said just call his specialist cuz her lad has counsellor like, for one type 1 diabetes they've got a counsellor they can go and talk to and Dr. N even said *I've been trying for years to try and sort this out but I just think it's mad kids with chronic illness should need someone to talk to*. **Simon T Dixon:** Yeah. **Dani:** *They should almost be offered that after a year of having it so that they can digest what's going on and then speak to somebody…. that…*	**Fab:** Managing Mental Health Crises **-Protective Carer** **Holi Cont- Dissapointed with healthcare**
16	**Simon T Dixon:** Do you feel like it's quite separate then and maybe that because you're going somewhere separate they might not have that specialist understanding of chronic pain maybe a counsellor and if there was somebody part of it might, do or is it just the fact that it's a kind of oversight that it's just not part of it? Mhm. **Dani:** Yeah. think they just don't think it's needed. But I just think it's madness. Like, you've got kids that are suffering on a daily basis with being different with having chronic pain. Obviously, like Leo it's a little bit extra because now his eyesight. You just think that part of a chronic illness team to have a counsellor to help the kids and to help the parents as well. Like, I say, us going into it, it was so lonely cuz you get given, like leaflets and like, things to… but I've always said if I came into money and I didn't need to work anymore, I would volunteer at Dr. N's clinics to speak to parents because you feel like lost, you feel like nobody understands you and Dr N can't be on call, can he? Every two seconds to answer your question. **Simon T Dixon:** Other than Dr. N, was there anybody that you felt maybe understood what gave you support? **Dani:** They gave us leaflets and we did go I think after like.. how old would he have been? I think after two years there was um.. CCAA..	**Fab:** Using External Support Networks and lack of healthcare provision

.	**Simon T Dixon:** What's that? **Dani:** They're um, like a charity that, like deal with like children with juvenile arthritis and they put on weekends and so we actually went to one of their weekends. **Simon T Dixon:** Okay. Yeah. Yeah. **Dani:** But because they're like charity and they're obviously wanting people to fund raise and stuff for them, they use a lot of that as their money, so you get it like discounted. So, like we went to the Peak District and that the boys went and did like, caving and potholing and all that stuff. And we, umm, me and Paul for two days we sat in a boardroom and they brought in somebody from the research, for a lot of arthritis, he spoke to us. they brought in a specialist to speak to us. Um.. and then a young lad that had lived from probably Leo's age at I think he was 23, 24. So, he spoke about him, which I thought was good. **Simon T Dixon:** Yeah, yeah,… **Dani:** Then Leo got to meet other kids that have got the same illness as him and… **Simon T Dixon:** yeah. Yeah, yeah. Yeah. **Dani:** Ben got to meet other siblings that haven't got anything wrong with them but going through, like, I think it.. the thing is my kids are at a bit of a difficult age now that I think Leo would benefit from it but Bennie is at that age that he probably wouldn't want to do it again, **Simon T Dixon:** Yeah. **Dani:** um but yeah, *as soon as we went to that, that made us feel better about it because it wasn't just us and actually there's loads of people that have got kids with chronic illnesses. So, it makes you then think, okay, maybe we're not the only ones that are on this path, like there's other people and like this lad had been traveling and everything, it didn't stop him. So, it was nice.* **Simon T Dixon:** It sounds like it gives you a bit of hope. **Dani:** Yeah. **Simon T Dixon:** Yeah. when you think about the future is it a challenge to see a kind of hopeful future? I know you said I do worry a lot about the future but can you find is the times where	**-Experienced Parent** **Fab:** Worries and Hopes for the Future **-Realistic Planner** **Hopeful**

	you think I mean it sounds like in that moment you could see other people and how they've dealt with chronic pain and their conditions is it really hard for you to look hopefully or is the times where you feel like actually, yeah.. **Dani:** Yeah. I mean it makes me sad, like I try not to think about his future too much… **Simon T Dixon:** Yeah. Yeah. **Dani:** because it does, No. **Simon T Dixon:** You don't have to talk about it if you feel…. **Dani:** No, no, no. I think with Leo it's not just his chronic pain, it's his sight. That's what scares me. **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. **Dani:** But a lot of it it now is down to his sight. **Simon T Dixon:** Yeah. Yeah. Yeah. **Dani:** Umm, and also things like.. having a baby, he'd obviously have to come off medication and then puts him at risk again. So, it's just, I just hope, I know everybody hopes that their kid finds somebody that they can, like get on with and marry but I just hope that he does find somebody that will understand him and look after him really like, understand that if he doesn't want to come off his drugs to have a baby, then.. that's what it is, or to understand that if he does come off his drugs to.. try for a baby, then he maybe, like, not be able to move because this time around, he couldn't, like put pressure at all on his leg. **Simon T Dixon:** Yeah. **Dani:** So, *it's hard, isn't it? I think things like that, is, yeah. I think that's the one thing that me and Paul probably struggle about speaking about. So, we live for the moment, like we want to take Leo places to see stuff like abroad and…* **Simon T Dixon:** Yeah.. **Dani:** *have a little bit of a bucket list for him, but obviously not a bucket list cuz hopefully he's not going to die (chuckles). It's just list of places to see and…* **Simon T Dixon:** Yeah. Yeah.	Cyclical plot- moving from past to future.

17 .	**Dani:** *without making it obvious why we're doing it*. **Simon T Dixon:** Yeah. Yeah. **Dani:** But yeah, I mean Leo, like h he's, he'd tell you what his future's going to be and I hope that's what it is going to be. **Dani:** He wants to be a barber. He wants to have kids. **Simon T Dixon:** Okay. Yeah. **Dani:** He's going to get married. Well, one minute he's having kids and getting married and then he's living with us forever. So kids and wife are not living with us (chuckles). **Dani/Simon T Dixon:** (laughing) **Dani:** Love him, but I don't want everyone living with me. **Dani/Simon T Dixon:** (laughing) **Dani:** So, but yeah it never phases Leo, so like, this time around the only thing that's phased him is that he's not been able to play football. And then I think it's building his confidence back up to playing football. **Simon T Dixon:** How do you, how do you help him with that confidence? You said a couple of times where, you know, you used the football as an example of, you know when he's not.. at the start the season he's not feeling very confident. How do you help him with his kind of self-esteem and feeling.. is the things that you do or. **Dani:** Yeah, I, *I mean I don't put my kids up on a pedestal, never have done, I think if you put a kid up on a pedestal, they then think the world owes them, so, we're quite, we quite equal with our kids, we'll praise them if they've done well but we don't go over the top with it. Like, they're both good at football but when they come off the pitch it's very much like, "well done mate you played well", not, "my god you were the best player on there", so we don't want to overcompensate for that either*. **Dani:** So um, and obviously you've also got that sibling rivalry there, that would have been there even if Leo was okay or not okay. They both be better than each other at football, so (chuckle). but Leo is a skillful little footballer. **Simon T Dixon:** Mhm. Yeah.	Realistic parent **Fab:** Supporting Confidence and Independence **-Balanced Parent**

18.	**Dani:** And we just say to him, ""Look, mate, at the end of last season, you got most improved because you played your socks off. you played like you play your brother and he does, and I think his friends are quite good with him, like he… but Le is, like I say, Leo is a bit of an odd one as in… *he wouldn't take anything from anybody if someone said to him you're rubbish at football he wouldn't think twice to fight him, like Leo is, he's got a fire in him that I think's a good thing so I've never knocked that out of him* **Simon T Dixon:** Yeah. **Dani:** cos I don't like it that he's hot headed, I'd prefer him to be more placid like Bennie is.. but I think Leo needs that because Leo's had a lot to deal with. **Simon T Dixon:** Mhm. Anything that might help him through **Dani:** Yeah, I think it will cuz I do think, like, like I say,…I don't think he'll let anyone walk all over him **Simon T Dixon:** Mhm. **Dani:** he knows who he is and.. but he just lacks in confidence sometimes.. which with school work he'll say I'm rubbish at that and we're like Le if you try hard that's all you can ask from somebody. **Simon T Dixon:** Yeah. **Dani:** Both my boys I say that too, all we wish for is that you try hard.. and I know that Leo suffers a little bit more that what Bennie does but we've never let him use that as an excuse either. **Simon T Dixon:** Okay. **Dani:** Leo says, like this week he did get away with it but that was only because sometimes if I feel a bit urgh I haven't got the energy to argue with him and I have to pick my battles with him. So this week he didn't go, he was meant to be going back to football training for half an hour just because he's obviously his muscles and that are all adjusting to walking properly again and he said that he didn't want to go because his leg hurts. Of course, *that he knows what to say to me*. So, I was like, " okay then, mate. I'll, I'll let the coach know." But, it turned out he didn't want to go because he thought he was rubbish and everybody would think he was rubbish. So, Paul does get a little bit cross with him in that way because he's	

19.	like, "Mate, come on. You can't let this stop you're not rubbish. **Simon T Dixon:** Mhm. **Dani:** "So next week you either go back to football or you retire" (laughs). Paul is very much like that's what's going to happen mate. And he went, "no, no I'm not retiring. I'll go back again". So sometimes he does use it.. he doesn't ever, yer, like I say, you wouldn't ever know that Leo's got something wrong with him, but he knows how to play it if he wants to play it, especially with me because he knows that I'm probably the weaker link out of me and Paul And like, if my anxiety is not in a great place, then… and I've always been honest with them with my anxiety as well, like I'm, I'm not a drama queen with it, but if I don't feel, they probably know me by now that if I feel a bit anxious or I'll just take myself and say, "Right, I'm having an early one." **Simon T Dixon:** Yeah. **Dani:** And I've always said that to Leo, if it gets too much and enough's enough, then you, you do what you've got to do. **Simon T Dixon:** And does that help? Do you think that that's something that he does do? Does he.. **Dani:** Yeah, I think like, Leo is a bit of a homeboy, he does like being at home. He's quite like every teenage kid at the minute loves being on an Xbox or a PlayStation. Um, so but we do try and stop not let him go into himself because that's when his dark thoughts come. **Simon T Dixon:** Yeah. **Dani:** So like, Leo has always, Leo is lazy with it as well though like, Leo will be playing football down in the living room with Bennie and fighting and then you say erm, "can you go and tidy your bedroom?" and he's like, " Oh, my joints are killing me" and you're like "haha no, no mate", He is, he is quite comical with it as well like, and he's learned to inject himself now, erm and the nurse was so proud of him. She was like, "I can't believe he's like, picked it up as quick as he has", **Simon T Dixon:** I can imagine, yeah. **Dani:** But this is what, what I mean by Leo (speaking with fondness). So, he's so brave. Injected himself first time. didn't, didn't even say, " my god, I can't do anything like that." But then a little bit of blood come out. He's like, "Oh no, I'm	**Fab:** Current Coping and Leo's Humour (Present Day)

20.	bleeding out." He's so dramatic, like, yeah, he's, he's a funny one. I think he copes with it... I think he's brilliant how he copes with it, like he makes me super proud all the time, **Simon T Dixon:** Is there, there a time…where you felt, can you think back, I mean, well you you've explained one of them… So it's a different question, I just, as I was talking I was thinking back to.. when.. how has it kind of changed in, you know, obviously him now and when he was younger? how has your kind of experience changed with him? **Dani:** I think, like when he was obviously little, he was so like, little [(dog walks in) Go away dog. Go lay down]. He was little and cute and it was like, your heart broke for him, like e was a little boy that it should never happen to, like. **Simon T Dixon:** Yeah. Mhm. **Dani:** You can't explain to him. You can't explain that he's got to be put to sleep again for, like the sixth time. So he obviously used to lose his mind and when he used to come out of anesthetic he was Hulk. He used to try and rip everything off. Blood test, oh my god, blood tests were the worst things that I had to do because he was abusive to (chuckle), I laugh now, but at the time like that my anxiety was really bad with bloods cuz he was just really abusive to the nurses cuz he was scared. He was petrified and, and that used to like, that crippled me. **Simon T Dixon:** Yeah. Yeah. **Dani:** But I think now that he's older, it's different because you can have a joke with him now like and you can explain things to him, like, don't get me wrong, this time around he was quite bad with cuz he obviously knew what me and Dr. O were talking about. He was very aware that he had to be put to sleep again, which I think he hasn't been put to sleep since.. just after lockdown, I think it was, he had to go to Moorfields and be put to sleep. So I had to stretch something in his eye of his glaucoma, erm, and he was fine then because he was older so he could deal with it a bit better but he wasn't, he hadn't been put to sleep for a very long time so I don't think he could remember, whereas this time he could remember.So that was, it was hard because it was frustrating for me and Paul cuz he wouldn't eat. So we went on the Wednesday and Dr. O said on the Tuesday she was doing the injections and he was just overthinking it, massively overthinking it. He had worked himself up, he wouldn't eat, to the point that on the day the	**Proud Mother** **Move:** Trauma of Early Childhood Medical Experiences -**Emotionally Vulnerable Mother** **Fab:** Growing Older: Communication and Humour

21.	morning obviously had to be near mouth. He passed out in the shower… **Simon T Dixon:** Mhm. God. Yeah. **Dani:** which was stupidly scary. Luckily, like I say, I mother him, so, (chuckle) I was in there with him and he said, "Mom, I feel funny." And I undid the curtain and next minute he just went. **Simon T Dixon:** Mhm **Dani:** So, that was quite scary to he'd got himself to the point that he hadn't eaten and was exhausted. **Simon T Dixon:** Mhm, yeah. **Dani:** But we're quite a jokey family, we like, we take the Mickey out of each other quite a lot, like. So I think Leo is probably like he is because of that, like we've never.. as much as I baby him, we've never pussyfooted around him. So we've never been like, "oo Bennie, don't do that to him because of his joints." Or if Le is going to fight with Bennie, then his joints are clearly okay to do that. So, we've never put him on a pedestal in that way with.	-Evolving Parent
22.	**Simon T Dixon:** So you don't want to create a barrier, like uh, erm, make kind of boundaries for him because you think **Dani:** No. **Simon T Dixon:** Yeah, okay. **Dani:** So, like I say, we've always joked with him and like this time around he was joking because he said that I'm a really rubbish carer cuz he said I'm really clumsy (laughing), there's a few times I'd put the blanket on him and went to push the puff in and like, knocked his leg and I was like, " my goodness, I'm so sorry. I'm not a good nurse Le," And he'd laugh.. So I think now he's older, you can joke about it more, like. **Simon T Dixon:** And does Paul do the same? **Dani:** Yeah.. Paul is a little bit more sensitive with it. So like, like I say mine and Bennie's personality is very similar to each other. Whereas I think sometimes Bennie's not learned there's a line and you don't cross it. Bennie pushes boundaries as in things that he says. And I think like I said to Bennie the other day, because Bennie's 15 now, so he needs to understand and	

	he was, I don't know how the conversation started, Bennie had said that Leo said what about if I don't wake up when he goes under anaesthetic. Leo had said that Bennie had said it, but things like that Bennie is.. you got to remember Bennie's still a kid so, he is grown up but he is still a kid, so things now I can explain to Bennie like, "mate when you joke about Leo's eyes me and dad don't always find the funny side of it because it's not funny and potentially he could go blind". So things like that and like he was obviously being a typical brother, "uh, Leo is fine. He's walking around on his leg. He's skyving". And I'm like, "mate, that's because he's like, I've given him the maximum Ibuprofen that he can take. He's pilled up to the eyeballs so that he's not in pain". But yeah, we… **Simon T Dixon:** Was… was there a time where you sat him down, Bennie and explained it and how did you do that or when you said that you went to the camp. Was that a time where it was explained to him? how do you kind of talk him through everything, cos, you know, through his ages? **Dani:** Erm, like I said we're honest with both of them, so if Ben asked a question like, "Will Leo go blind one day?". **Simon T Dixon:** Yeah. **Dani:** we say to him, well, that I don't think he'll be blind as in close your eyes I can't see anything blind, but yeah potentially he could not be able to look at a book, or.. because if his eyesight goes in his good eye his other eyes, like if you've got cream in your eye, so it's blurry. Urm and the same with Leo, if Leo asked a question, we're not medically trained we can't give him all the answers that he wants or needs. But I've always said to Leo,… "Have you got anything that you want to ask Dr. O?" I've never hid anything from either of them. **Simon T Dixon:** Yeah. Mhm. **Dani:** Like, when they ask questions, I've never, and we are perhaps are a bit harder on Bennie as in, when they're taking the mick out of each other, Leo will always, cuz Leo's tiny. Bennie hasn't got anything on him either, but he'll use the, "you're fat" and Bennie gets angry and I'm like but Bennie you're not fat mate there's nothing.. **Simon T Dixon:** Yeah **Dani:** on you, whereas you calling him blind is more of an insult, but then like I say they've got a mate that's diabetic and they all take the mick out of each other.	Returns to telling a story about managing sibling relationship- Feels important for Dani to convey a protective yet, thoughtful stance with Bennie as this is mentioned throughout. **Fab:** Parenting Two Siblings with Unequal Needs **-Educator** **Fab:** Honest Communication and Emotional Modelling

	Simon T Dixon: Yeah **Dani:** So I think, Leo does, like Leo does joke about it, but Leo will joke about it on his terms. He knows when someone's gone too much that he then doesn't like it anymore. And he is quick to say, that'll do now and Bennie does normally, normally, depending on what mood is in (chuckles). He does stop, but yeah, I think we've never actually sat them down and said this is what's happening. This is what's going to happen. **Simon T Dixon:** Mhm. **Dani:** Erm, I got told… by… I think it was a doctor, I can't remember who I was, or it might have been the counsellor that I saw cuz when we used to have L*eo's appointments, if something bad happened, I wouldn't ever cry. I drop Leo off and then I'd go and cry. And they were like, "No, you can't do that. if something's happened, he knows it's happened. You not showing emotion is showing him that he can't show emotion."* And they were like, "You don't want that, do And I was like, "No, but I just, I wouldn't want to see my mom cry." So that's why I tried to protect him by not crying in front of him. But like, now like, and It really upsets him if he thinks that me and Paul are upset about something. I think that probably hurts him more than his joints hurt him. If he thinks that me and Paul are	-Transparent Mother
23	worried about him and *we just explain to him, "you're a child,* **Dani:** this shouldn't be happening to you, me and your dad would give you our eyes, our joints, like we would take it off of you in a heartbeat if we could. So, he, I think Leo is very supported by us. But it's just sometimes a bit annoying that me and Paul then don't feel supported sometimes **Simon T Dixon:** Mhm. Yeah. How, you've said that a couple of times, that you, the support, you feeling lonely and I just yeah,	
24.	what do you see that changing? **Dani:** Yeah, because I, I dare to stick up for what I know now. I think I didn't know anything before. This was all, we were going into it blind, like excuse the pun, erm, we were going into it blind. We didn't have a clue, we didn't really want to know about it either. I think we kind of maybe buried our heads a little bit, cos **Simon T Dixon:** Yeah **Dani:** and even now I'm on a Facebook, juvenile arthritis Facebook thing and *even like, now, when, when Le is going good I don't want to read about other kids. And, er, as harsh as that sounds I don't want to.. know what could happen or to,*	**Fab:**

25.	*I think so a few times I have took it off but obviously this time around when Leo's then been bad again I have opened it back up again and like, I've reached out to like people, there's a few people that are on there that have come on new and I've messaged and said if I've been going through this now for like.. nine years now*, so, if you ever want to talk or ask any questions, then please private message me, like, but that's what I mean… *If I had the money, I would love to say to Dr. O, I'd do, I'd do like basically your aftercare, because that's what it is, isn't it?* **Simon T Dixon:** Yeah. Yeah. Yeah. **Dani:** I get that she's only got a set time that she can see people, so, she perhaps can't tell people. And also, as much as doctors are caring, their kids are healthy, well you, you don't know that, but I'm pretty sure that her kids are healthy and got nothing wrong with them. So, actually, they're treating the child, but they don't really care about the parent, I'd say.. I just, *Birmingham you get a lot more support, but I think that's because it's a massive hospital.* **Simon T Dixon:** Okay **Dani:** So, they've got volunteers walking around giving out the CCCA card saying… **Simon T Dixon:** Okay. **Dani:** *if, you've got them and they'll come up and ask you,* like*, how you are, how are you feeling? And that's another thing a lot of people ask about your kids which* obviously *that's what you want them to do.* **Simon T Dixon:** Okay. Yeah. **Dani:** But *I do think people forget about you. Like, like I say, I've got, my friend's got two kids now with type 1 diabetes, she just had the second one, and I'll always ask how she is first and then I'll ask about the kid because..* **Simon T Dixon:** Do you think that that would you have done that previously before you had children? Yeah. **Dani:** Probably not, because I think you look at things differently, don't you? Like, I think like, I've felt this time around there's a few of my friends that have known that Leo's been in hospital and they haven't even messaged you. That makes me then question. *And I feel like I've probably got a*	Peer Support and Seeker Community **-Empathetic Peer** **Fab:** Desire to help and systemic frustrations. **-Aspiring Advocate** **Fab:** Feeling forgotten and isolated **-Invisible Carer** Isolated and burdened-feeling misunderstood

23 cont.	*smaller circle now of friends because of how people have made me feel.* **Simon T Dixon:** Yeah **Dani:** And then you have, to, then, that's what I mean by questioning myself because then you're trying to constantly look outside the box and think would you have said that if he wasn't poorly.So it's hard, like you find that you're battling with yourself quite a bit, like, I think you battle with yourself anyway as a parent to think, " god, am I a good parent? Am I doing the right things?" **Simon T Dixon:** Mhm. Even harder when you've got that extra pressure of your kid not being very well. **Simon T Dixon:** Mhm. **Simon T Dixon:** And it sounds like you, erm, in offering support to others, is that something that in turn kind of may help you as well? **Dani:** Yeah, I think so, like, there's this lady that we met on holiday, erm, when we were in Greece and we'd just been on that weekend and… **Simon T Dixon:** Yeah. Yeah. **Dani:** we' bought Leo a er, CCAA, erm, top and the little girl started talking to him in the pool but he come out of the pool and she was like, I think she's Greek and we were like, "that's okay mate you can still play with her even if you don't understand her". And then her mom come like, walking over to us and we were like, "oh god, what's Leo done?" Because Leo is that kid that someone cries, you're like, "What's Leo done?" (chuckles) erm, and they were Scottish. (shared laughter) **Simon T Dixon:** Okay. **Dani:** They weren't Greek. And we, me and Paul started laughing and like, she looked at us, as if to say, "So, what you laughing?" And we were like, "We're so sorry. Le didn't play with your little girl because he come out and said she was Greek." And obviously she laughed. She went, " no, just Scottish. **Simon T Dixon:** (Laughing)	Moving through Isolated and transformative type of narratives Holi-Cont- Parental doubt/burden)

24 cont.	**Dani:** But her little girl had got it. **Simon T Dixon:** Okay. **Dani:** So she said, "Has your little lad got juvenile arthritis?" And we were like, "Yeah." We were like, "How the hell does she know?" **Simon T Dixon:** Okay. Yeah. **Dani:** But we forgot that obviously he'd had that top on, erm.. I've got a bit of a connection with her, like, well like this time around when it all happened and I couldn't get hold of anybody because it was Christmas. **Simon T Dixon:** Mhm. **Dani:** Um, I actually messaged her and said, "What do you do with Leila when she flares?" **Simon T Dixon:** Yeah **Dani:** ..Because Leila, bless her, she's off of the drugs, on the drugs, off of the drugs, so I, *I messaged her and she was like, " no, you should really be able to just drop into the ward,"* which is not the case in the general, but, but…. so yeah, it's nice to and like you say, I like it when people say, "How do you deal with this? Like, I, *I like to think that something good comes with something so rubbish.* **Simon T Dixon:** Mhm. **Dani:** So yeah, I do like, like I say, I'd love to volunteer and help people, but at the minute with full-time work and two kids that still needing me and a house to clean, a dog to walk, like football to go to, I haven't got the time, really to do or help anybody. So, I need to.. **Simon T Dixon:** Well, you've got life, haven't you? **Dani:** yeah, I need to keep myself afloat. (sigh/chuckle). **Simon T Dixon:** Yeah. If there's jobs out there that, that you could do, kind of full-time jobs that were like support, that would be ideal, wouldn't it? But like you say there's nothing there is there. **Dani:** No, but I do think that that's what Northampton maybe lacks a little bit. you get diagnosed and then it's like, "Okay,	**-Empathetic Peer** Transformative- Quest type narrative **- Aspiring Advocate:**

26.	see you later, here's the drugs, here's some pamphlets you can go and talk to.. but it's not really explained a lot to you. **Simon T Dixon:** You just left on your own to kind of explore… **Dani:** Yeah. yeah. And it's Yeah. **Simon T Dixon:** how, um, it sounds like kind of you go through an exploration and of you know, you, you don't know anything about this thing and then all of a sudden you go whaaat. "I didn't even know this was a thing", **Dani:** Yeah.	
27.	**Simon T Dixon:** Yeah, so so… when, when Leo went to school, how did that then, did you find yourself having to explain a lot to people and then, how did, was there anybody particular in school that you had a relationship with? And how was that at primary school? And then what was it like going to secondary school? **Dani:** Yeah, I mean Primary school were awesome like the Head Teacher, like, he loved Leo, he knew exactly what was wrong with Leo, **Simon T Dixon:** Okay. **Dani:** Yeah, he, he was really good, like if Leo ever had to, like have operations, he was like, like, no pressure, like.. to come back when he's 100% and feeling 100%. Obviously with, *also with like the medication that Leo was, well is on now as well, it lowers their immune system.* **Simon T Dixon:** Yeah. **Dani:** So then, he was really, like *they were all really good at saying, "Oh, such and such." Because Leo never had chickenpox.* **Simon T Dixon:** Yeah, okay. **Dani:** So the word chickenpox used to like, *fill me with dread…* **Simon T Dixon:** Okay. Yeah. **Dani:** because obviously he'd have to go into hospital for a week if he had it because he'd have to go on a drip.	Holi cont- Good experience of Primary school. **Fab:** Positive Primary School **Informed Mother** **Fab:**

26 cont 28.	**Simon T Dixon:** Mhm. Yeah. **Dani:** *So that like, really filled me.. anytime anyone said chickenpox literally my heart dropped.* **Simon T Dixon:** Mhm. Yeah. **Dani:** And I think I perhaps said it in front of Leo probably one or two.. and I think he knew the panic about it,..so then he then looked at kids with chicken pox like they've got the plague (chuckle). **Simon T Dixon:** Yeah. **Dani:** So a little bit like, "Oh, Le, no, you don't need to be like that. It's okay." (chuckle) **Simon T Dixon:** Yeah. Yeah. Mhm. **Dani:** It's just," but I think it worried him maybe because.. he knew it had worried me. **Simon T Dixon:** Yeah. Yeah.	Experience Anxiety over Chickenpox **Vigilant Caregiver**
29.	**Dani:** but yeah, um, but yeah like, Primary School was brilliant, like, they were really good. They kept in contact with me constantly if anybody was poorly *or if they all had, like the flu spray they knew that Leo had to be off for that*, for a few days like and, you know, they were brilliant. XXX (Secondary school).. probably not so much. I don't think they communicate, I don't think they communicate enough, but then I may be in the wrong as well, cos maybe I've not checked on everything that they've, because I think they tell Leo what he was going to get, I've never really questioned if he's got it or not and Leo's never said anything else either. So it wasn't until this time round.. when the lady went in for his eyes that she was, Leo come home and she had sent a letter saying basically, *"I've given the school a bit of a telling off because Leo should had all this in year seven, we're now in year eight".* **Simon T Dixon:** Mhm.	Fighting with school **Fab:** Disappointment with Secondary School **Frustrated Advocate**
30.	**Dani:** Um, yeah, it wasn't until she had kind of said about it and even then *I said to Leo, "Are you bothered that you haven't got these?"* like, and he was like, *"No." He said, "Not really. It doesn't stop me doing anything."* So, I think as long as it doesn't stop Leo doing anything, I don't get involved in it, because Leo has got to fight his own battles as well. Leo, like, as much as he's got this illness, which is awful, I can't do	

31.	everything for him. He's got to grow up as well because doing him any favours by babying him. **Simon T Dixon:** Mhm. Yeah. **Dani:** And I'd say this, which is really annoying September cuz he's in year eight now. I kind of stepped away a little bit, a bit like, *"come on Le, you got to get up and get in the shower yourself. You got to get your lunch ready. Bennie does all this, so you need to do it as well"*. But then obviously January has now set us back a little bit **Simon T Dixon:** Yeah. **Dani:** ..because we've gone back into me babying him and helping him and him getting um, in the habit of asking Alexa to announce for me to bring a drink up and everything else for him (chuckles). So yeah. **Simon T Dixon:** That's inventive, isn't it. **Dani:** (both laughing)	**Fab:** Encouraging Leo's Independence **Empowering Parent:**
32.	**Dani:** Yeah, got him an Alexa dot for Christmas. *We're like that is going out the window if he doesn't keep announcing to us. Honestly, it's driving us insane. (animated- rolls her eyes)* **Simon T Dixon:** It used to be a bell, didn't it not an Alexa? (chuckles) **Dani:** Yeah. Yeah. **Dani:** But yeah, I'd say that XXX Secondary school frustrated me, this, they, *I felt like when I needed the help*, they weren't there.. and that just adds more pressure and frustration and anxiety really. And, but again there's, I don't know if they don't realise that that's the case, but my mom has a fit at me because she says, *"if you feel like that why don't you write an email and tell them how you feel"*. **Simon T Dixon:** Who would you send it to? **Dani:** I don't know, but that's why I don't do it because I can't be assed to try and find out who. **Simon T Dixon:** Yeah. Yeah. **Dani:** I mean, I just,I can't be bothered with it and I think even to the point of the whole thing with Dr O, um, we actually put	**Fab:** Dani babying Leo and Leo taking advantage **-Light-Hearted but Frustrated Carer** Battling and fighting narrative **Fab:** Frustration with Secondary School **-Emotionally Exhausted Advocate**

	in a complaint about Dr. O. um just because her secretary was really rude. **Simon T Dixon:** Okay. **Dani:** She, she basically told me to, "chill out" one time and I was like, "chill out".. *I'm in admin. I've worked in an office all my life and I wouldn't even speak to my customer about a bit wood about like tha*.. so I've got an ill kid and you're telling, yeah, that just didn't, *I think that was the last straw*, um, so we did go through, um, is it PALS, isn't it? and… **Simon T Dixon:** Oh yeah. Okay. **Dani:** ..has been so much better since, (intonation rises) but it shouldn't take that, that's another frustration. **Simon T Dixon:** Yeah. Yeah. Mhm. **Dani:** It shouldn't take the person who screams louder to be seen quicker or, to have a better relationship, like, every kid that goes through that door and every parent that tries to call through to them have a nice response, because before you've even made that call you're anxious, you're stressed, you're upset. So you should have somebody on the phone that can speak to you with a proper phone manner.. **Simon T Dixon:** Yeah.	**Fab:** Formal Complaint to PALS **-Empowered Complainant** Growing confidence in advocating- showing a transformation
33.	**Dani:** .but again they perhaps haven't got ill kids. They're not doing it out of an interest, are they? They're doing it out of that's what job they're doing because they can earn money and they like to do it for a living. So yeah, I think that's like, it's frustrating along the way with certain things that and… how you get spoken to, you think I'm not this crazy mom that the kids got a little sniffle and I'm demanding to see a doctor, my kids's actually got something, but, and then it makes you doubt yourself. **Simon T Dixon:** Yeah. **Dani:** I often think, "Oh god, am I being dramatic? Like, do I need to call him?" And I'm like, (heightened emotion, speaks quicker) "No, I do need to call him. His leg's massive. Of course I need to call." **Simon T Dixon:** Mhm. Yeah. **Dani:** And then I feel like sometimes they can talk down to uou, so you're a bit like, "oh yeah." And like you back down,	

34.	whereas now I don't. So this time around I, I spoke to the. And I'm never rude to anybody, but I'm more firm now. **Simon T Dixon:** Yeah. **Dani:** So the secretary this time told me, well she, she's not back in for another four days. So I just said right okay that's fine, I said what I'm going to do then is take him down to A&E, "oh, no no no don't do that don't do that they don't". So I feel like before I would have just been like okay I'll speak to you on Tuesday… **Simon T Dixon:** Yeah. **Dani:** whereas now I'm not doing that. I've got a kid that's in a lot of pain, that can't move, that's stopping him from going to his school, stopping me from going to work, so, "no actually, that is your job so you will see them". (animated/frustrate tone), but.. **Simon T Dixon:** Yeah, **Dani:** I wasn't like that. **Simon T Dixon:** And, no, and why do you think that is? **Dani:** I don't know **Simon T Dixon:** What's kind of happened that means that he can be more assertive? Yeah. Yeah. **Dani:** Like, like, erm my uh, getting older and realising I can stick up for myself and stick up for somebody without being rude but getting my point across. **Simon T Dixon:** Yeah. Yeah. **Dani:** I don't like confrontation… I don't like.. Like my mom is a lot more ballsier than what I am. She'll say how it is. She'll get to the point and she'll get it sorted. Whereas I'm not like that, I don't like confrontation. Paul doesn't like talking on a phone. So we're screwed with Paul when it comes to phones (chuckles). He's like, "I can't, I can't ring, I'm not talking". **Simon T Dixon:** Yeah. Yeah. **Dani:** Paul is very good if he's face to face. **Simon T Dixon:** Yeah.	**Transformational typology- sticking up for herself- finding her voice.** **Fab:** Standing Up for Herself **-Maturing Advocate**

35.	**Dani:** So, we had a bit of a problem with the eye people when Mr. F retired and Paul very much like,*" I'll take him in and I'll be seen by the person that I'm meant to be seen by".* **Simon T Dixon:** Yeah. **Dani:** Yeah, so very good. Again, not rude, but very.. **Simon T Dixon:** Yeah. **Dani:** ..to the point, whereas I'm not like that, like, I'm just like, okay, I'll sit in the waiting room for four hours until you see me. (smile/slight embarrassment?). **Simon T Dixon:** Mhm. **Dani:** But I have, like I say, I have, I'd say the last few years and I think it may be a little bit to do with age a little bit more to, that I've got more experience now and I understand and you see other people, like proper kicking off, that actually I'm not doing any of that… **Simon T Dixon:** Yeah. **Dani:** but I'm not sitting here for 4 hours either. **Simon T Dixon:** Yeah. **Dani:** So I think I've just, I think I've just probably matured with it and don't take.. as much rubbish **Simon T Dixon:** Yeah. **Dani:** as what I used to probably take.	**Fab:** Reflecting on Personal Growth **- Grounded Self:**
36.	**Simon T Dixon:** Yeah. Yeah. You said earlier, urm, about because, because he takes Methotrexate, Urm **Dani:** Mhm. **Simon T Dixon:** ..his immune system's not as good, has there been times where you've really like, other than kind of the chickenpox and at school, is, has there been times where you've been really worried about that? **Dani:** Urm, no, it is just the chicken pox. Obviously when the whole COVID thing happened that was a little bit scary cuz they were obviously saying kids that or people that are	**Holi Cont- Dani describing growing in resilience and confidence**

	vulnerable, so that that was quite scary. But weirdly enough Leo then got Covid, we all got Covid **Simon T Dixon:** Yeah, okay **Dani:** ..and Leo was the only one that was fine. So we were all, we all tested positive, me and Paul were in bed, Bennie was rough. Leo I think had a sore throat and just felt a bit, meh but temperature like wasn't blazing like they said it would or.. **Simon T Dixon:** How did it feel when you first got, you know when you took those tests? **Dani:** Oh, Leo was dramatic as hell, (imitating deliriously) "*I'm going to die, I'm gonna." cuz that's all he'd heard, that people like him will die, and we're like, "mate you haven't even got a temperature you're fine"…* **Simon T Dixon:** Okay. Mhm. Yeah. **Dani:** but again it was a, like we laughed at him because it, he was being dramatic and we're very quick to pick him up on if he's being dramatic. There's feeling crap and like, we don't ever want him to feel in pain or anything like that, but there's also being dramatic, which Leo can tend to do. **Simon T Dixon:** Mhm. **Dani:** So Leo has always got something wrong with him... always, if it's his hair hurting or he's too squabbbly, or, he hurt *his finger the other day and we're like, "Come on, mate." but then when it comes to the big stuff, he's really brave.* **Simon T Dixon:** Yeah **Dani:** He, he's odd like that, like he's really brave when it comes to anything like being put to sleep, like his blood now, he just watches them put the needle in. He's so brave with things like that but then, if he tripped and hurt himself, he would be the *biggest drama queen going.* **Simon T Dixon:** Is he like that when he's playing football? **Dani:** You what? **Simon T Dixon:** Is he like that when he's playing football? **Dani:** Oh no, no	**Fab:** COVID and Leo's Resilience **Relieved mother** **Fab:** Leo's Dramatic vs Brave Duality **-Observant Mother**
37		

	Simon T Dixon: oh,oh	
	Dani: *He's a bit of a nutter on the pitch (chuckles).* Yeah. Yeah. He doesn't take, he'll mark the biggest player on there.	
	Simon T Dixon: Yeah, it's interesting, isn't it? different context. Yeah.	
	Dani: But yeah, anything, like we now say to him, *Leo bore off, as if you haven't got enough wrong with you,* (Both chuckling)	
38.	**Dani:** like, we've got to that point with him now, that like, he'll say something, we're like, oh when did we go, oh *when he went for his injection to learn to do it, I think he'd wound himself up a bit and had a headache.. but he then makes me cross, because I'm like mate, "you're nearly 13 years old, you know where the iburprofen is go and get a tablet and take one, why like, you can do that yourself, but you're not helping yourself".*	
	Simon T Dixon: Yeah.	**Fab:** Frustration with Learned Helplessness **-Devoted Parent**
39.	**Dani:** We'll do anything for Leo and obviously I was doing a lot for him in January because Paul got up early in the morning, so.. I'd be like showering him before I went to work early, so I'd have to lift him in the bath. And I would literally do anything for my boys, but when they don't help themselves, it frustrates me. And Leo sometimes can tend to not help himself with stuff.. and it's a bit like, "Come on, mate. You've got this, you can do this".	
	Simon T Dixon: Is that, is there erm, is there um any pattern to that? Is there like times where you're like, "Okay, I get It's happening at this time." Or have you not ever noticed it's there, or is it just whenever?	
	Dani: *Leo is just lazy, so it is,* (both chuckle), *honestly is the most laziest kid going.* He, he just, he did, yeah, he's just, he'd let me probably still spoon feed him.	
40.	**Simon T Dixon:** Ah, ok.	
	Dani: *He's not embarrassed by it either.* Bennie had his friend around the other day, bearing in mind they're 15, so two years older, school years than Le, and um he come in, he was like, "Mom, can you come and cut my sausages up?" This was in front of Bennie and his friends and I was like, I would never dare to do that in front of my big brother's friends (chuckling). I was like, "That's embarrassing, Leo." I was like, "Yes, I can,	**Fab:** Leo's Laziness **-Affectionate Mother**

	but it's embarrassing." And then later on Ashton was like, " can Leo have a chewing gum?" And I was like, "Yeah, mate. He's nearly 13." I said, "I can see why you're confused, though, that he can't cut his own sausages." **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. **Dani:** But yeah, *Leo is just lazy and he's not embarrassed of it.* Like Leo,… **Simon T Dixon:** So, what does Bennie say? **Dani:** *Bennie just ignores him because he knows that he's lazy.* **Simon T Dixon:** Oh really, so he's just.. **Dani:** Yeah, yeah, he just rolls his eyes, as if to say really mate. But … **Simon T Dixon:** Yeah. What's their relationship like? **Dani:** Oh, oh they fight. **Simon T Dixon:** Okay. Yeah. **Dani:** They love each other. But yeah, they're just Bennie, Leo, em, *he's quite laid back,* he's quite a laidback lad*, he's quite chilled.* Whereas I'm pretty sure Bennie borderline ADHD, like he's constant, always has been, like as a little baby **Simon T Dixon:** Yeah. Yeah. **Dani:** Because they're only two years apart. So, when we first had Le, Bennie loved him *to the point that I used to have to hide Leo* to put him to sleep so that he could literally sleep without Bennie.. Ben, Bennie used to Bennie gave Leo acne as a baby cuz he constantly touched his face. **Simon T Dixon:** Okay. **Dani:** So he's always loved him, like If you're in a room with both, Bennie's got to be touching him. If it's strangling, he might be strangling him, but he's always got to be touching him. Yeah, they just love, he Bennie loves him, *but there obviously sometimes can be a little bit of resentment there* maybe, but I think that's because he's a bit like, *"ur, Le gets away with everything"* and we're like, *" He doesn't, mate", he actually doesn't get away with everything*, um but obviously as a big brother, you feel like you're getting, like you're hard	**Fab:** Normalizing Leo's Laziness **- Impartial Mediator:** **Fab:** Sibling Relationship Dynamics **Protective Parent:**

41.	done by. I think Bennie forgets all the money that gets spent on him and all the times that he's been took to Spurs and Le hasn't gone or he's gone to the (local football team), but this is Leo's first time back since December because he's not been able to stand up properly. **Simon T Dixon:** Ah, okay. **Dani:** He's not wanted to go out in the cold, so again, like we say to Bennie, *you got to remember all them times that you've gone with dad and he's not been able to go*... So, but no, they have, they've got a nice relationship. I love it, you hear them sometimes and they'll be playing, well, I don't love it because they sound like they're coming through, but they'll be playing basketball together or they're on, like the PlayStation together, but it doesn't normally last long, you know like half an hour of laughing then the next 10 minutes scrapping him because someone said gone out line and said something (chuckling), but yeah, they're typical brothers. But Bennie is, I don't think Leo needs protecting, so Bennie's never really had to, *Leo is probably more protected over Bennie than Bennie is over Leo*. **Simon T Dixon:** Oh, really? **Dani:** Yeah. **Simon T Dixon:** How's that? What is it, can you give me an example of that? **Dani:** Well, I think like I say, Leo would stick up for anyone, like even if he had to fight the biggest man, he'd stick up for anybody. Umm, whereas Bennie, he's a bit like me, he doesn't really like confrontation, like even if his own friends are arguing, Bennie, there's been a lot of times that *Ben's just come home and you're like, "What's the matter, mate?"* And he's like, *"Oh, such and such were arguing, I can't bother with it." he can't be bothered with anything like that.* **Simon T Dixon:** Yeah. **Dani:** But no, there's been, like obviously going, when we lived in (Village) they all played out together and there's been a few times that Bennie's perhaps done a dirty tackle on someone and they've gone, like gone for Bennie and Leo's like. **Simon T Dixon:** really okay. **Dani:** oh, yeah, *Leo would never let anyone touch Bennie…* Where I think the other way around I don't think Bennie would	

42.	ever see him get hurt but he probably wouldn't want to get involved. **Simon T Dixon:** Yeah. **Dani:** Yeah, so *if it's an argument, he wouldn't probably wouldn't get involved. Whereas if Bennie was having an argument, Leo would get involved.* **Simon T Dixon:** Yeah. **Dani:** *Leo would make it beeline to make sure that he sorted it out for his brother.* **Simon T Dixon:** Yeah. Is he like that with his friends as well? **Dani:** . Yeah, *Leo very loyal and protected* when he's mate and… **Simon T Dixon:** Yeah. … **Dani:** very very *protected over me.* **Simon T Dixon:** is he? Okay. **Dani:** Yeah. **Dani:** Oh yeah, they're like, Bennie is, *me and Bennie often play fight and muck about and if he hears us play fighting he's straight in there,* and I'm like, *"Leo I can handle"* (chuckles), *I sometimes say to him, "keep out of it because it's nothing to do with you when"* like other people have, he's been told a few times that *we love it that you're protective, but you have to, but there's a line,* that you don't need to protect anybody, like, sometimes you have to protect yourself, don't you? **Simon T Dixon:** Yeah, where do you think that comes from? **Dani:** I don't know, I'm a bit of a lioness with both of them. I'll, I'm not one of those parents that's like, " my kids." "No, not my Bennie and Leo". I'm very much like, *"them two are absolute little gits".* And I know that they are, but I know that *they're both nice hearted boys* as well. *I wouldn't ever let anyone speak bad of either of them.* And obviously, like and I *think as a family we're quite protective of each other, like, Paul would never let anybody badmouth me* or, like the same as I think we're all very protective but I don't know. Leo, *Leo as a little kid's always been a bit of a mommy's boy* but he'd never say, if you said to him Leo, "Are you a mommy's boy or	**Fab:** Leo's Protective Nature **Nurturing Realist:** **Fab:** Parental Perspective on Emotionality

43.	a daddy's boy", he'd say, "I don't know, both of them, I love them both the same". **Simon T Dixon:** Mhm. **Dani:** He's very like, *If he's in a room,* he'll be like, *"Love you, mom." And if Paul is in there, he's like, "I love you, Dad. Love you, too, Dad."* he'll never think. He doesn't like you to think. And I always wind him up, like the other day, *he was at my mum's house and mum said, "I'll bring him back." And he said, "Oh, no. I don't want to go back." So, I joked, I was like, "That's fine. If you want to stay at grandma, no, no, okay, I'll come back."* (chuckling and smiling, speaking with fondness). He's quite easy to say something and *he'll be like, "No, no, I won't do that then."* But yeah, now he's always, he's actually, when they were little, when he was obviously a bit bigger that he could like move and come to me, *he used to try and push Bennie off of me quite a lot* **Simon T Dixon:** Mhm. Okay. **Dani:** yeah, *he was more jealous of Bennie, he didn't like Bennie cuddling me that*. But Bennie winds him up now. **Simon T Dixon:** Okay. **Dani:** He'll come and cuddle me and he'll say, *"she was my mom first".* (both laughing) **Simon T Dixon:** Does he get that as a joke, like the humour in that because it sounds like he's Yeah. **Dani:** Yeah. Yeah. But *he'll still try and fight Bennie off me.* But yeah, but like, they do, they do. *He's got a good little sense of humour, Leo has.* Yeah, um, like I say, he's um, he's probably, *he's a lot more with his emot(ions)* and I don't know *if that's because what's happened to him has made him* like that, but *Leo is very an emotional kid.* If, like, Bennie still laughs now, *but when we watched the film when they were little and a frog died,* Leo literally sobbed the whole way through the film and… they take the mickey out of him now (chuckling) and say, " *You remember when we watched that film with the Frog".* He is quite an emotional kid, but I like that about Leo because actually, *like I say to Bennie, just because you don't have the emotion like he does, that's not a bad thing.* **Simon T Dixon:** Yeah.	**Supportive Parent:**

44.	**Dani:** It's like a boy crying, it's different if a boy cries, well if anybody cries at anything. But Leo has got quite an emotional side to him... *He's got a rage side to him which I think comes from probably pain and and.. that's like when he's a kid it was hard to know if he was just a hot head or if he's in a lot of pain* and that's why he's acting out. **Simon T Dixon:** Mhm. **Dani:** But *now he's older and he can talk about it, you can see that a lot of that happened from he's in pain or he's scared,* like *a lot of it comes from being scared and not..* and not *feeling that on the day he could have said what he wanted to say.* So he gets raged rather than, but like I say with the counsellor he, I don't know what, cuz I said to Leo, *"Look I'm not allowed to come in with you. You've got to go in by yourself, um, and whatever you and (the Counsellor) talk about, I don't need to know about".* I said, *"you don't have to feel that you got to relive it or talk about it. But if you want to talk about it you also can.* So, I don't actually know what was said in there. *A few times he'd come out and say, "..all we've talked about is football this week."* And then you're a bit like, " *okay*." But like my friend said, He was probably talking about football to try and then get something else out of him. So, erm, but whatever he did, *it seems to have made Leo a happier person,* so. **Simon T Dixon:** Mhm. Okay. **Simon T Dixon:** Is that something that's going to continue? Okay. **Dani:** cuz again, that's charity as well, I think, isn't it? Lowdown. So, he had eight sessions, I think.. yeah, eight sessions. But he come to the agreement with (the counsellor) that, that was enough so, urm, like (the counsellor) *said if you ever need to come back just obviously refer him back to us and cuz it's self-referral anyway,* so. But yeah, like I say, we.. **Simon T Dixon:** How does that make you feel about that? About having the kind of option of going back? **Dani:** Yeah, it takes a massive.. **Simon T Dixon:** Yeah. **Dani:** That day that he come into the bedroom and was like, "I sometimes don't want to be here anymore". And me and Paul panicked, like, because we're not counsellors, *we can be truthful with him, we can talk to him, we can ask him how he*	**Fab:** Counseling and Mental Health **Concerned Pragmatist:** Relational typology- encouraging Leo to talk and not 'bottle things up'

	feels, but we're not trained in the way that, and *actually we're too close to the situation. So, sometimes he doesn't like to say stuff because he don't, he doesn't want to upset me*. And he, and a while ago to me, he said to me, he said, "Oh, but I don't want to upset your mom*." I was like, "Mate, I'm your mom. It doesn't matter if you upset me.* It is what it is, like I'm big girl. I cope with it, I would never want you to bottle stuff up, so you must always tell us". But obviously it did help, because he, the first session I went in with him when they were like asking him questions and stuff, and he didn't really answer the questions. He was a bit, he sunk into his seat and he kept looking at me. **Simon T Dixon:** Yeah. **Dani:** He didn't want to answer truthfully because he didn't want to upset me. And obviously, like *I said to him*, "That's the whole reason why they don't let adults go in the room with you because they don't want you to hold back on how you feel". So, I think he probably does hold back on some stuff as he's got older, but that's only because he just doesn't want to upset me or Paul. But, I'd like to think if he was truly… like worried about something or something really hurt, then he would tell us, he wouldn't bottle it up. **Simon T Dixon:** Do you feel that there's some things that he will talk to you about, some things he won't? Is there kind of like, an obvious separation of those things or is it just sometimes you feel like you might not? **Dani:** No, I think actually, I think with Leo he is probably too truthful. **Simon T Dixon:** Yeah, okay. **Dani:** Sometimes you're a bit like, *but he's always been like that, like as a little kid he'd come in and say, "I've just punched Bennie, he's crying. he would be like, "He punched me first, he was out there, I punched him, and what"?* **Simon T Dixon:** Yeah. **Dani:** and, he, he's always been like and… like *he'll come home from school and I'll say, "'You've got a detention, what's the detention for?" And he'll say, "oh, because.." and he's quite happy to tell you. Whereas Bennie is a bit more cagey with stuff, especially girls. Whereas Leo will come home be like, " I've got this girlfriend." Or, "This girl dumped me today, but I don't care because I'm going out" like, he's very truthful*. But I'm like that with my mom and dad. My mom's	**Fab:** Truthfulness and Honesty **Holi-Cont- Encouraging Leo to be truthful and to talk.** **Transparent Parent:** Use of Humour and honesty are important to her- return to the her values around these.

45.	*always said, "Dani, sometimes as a teenager, me and your dad used to cringe because it's too much information, you don't need to be that truthful* (chuckling). Like, *"taking the whiskey from the top, we don't need to know about that"*. (Both laughing) **Dani:** Yeah, I think Leo is, I'd like to think that he's obviously going to big school now, *he, he's going to try stuff and do stuff, isn't he?* But like, *he did say the other day, "oh, my friend was vaping and I tried some." And I was a bit like, "Mate, come on, don't go down that path." I said, "It's silly." He said, "Nah, nah, nah. I wouldn't, I'm not going to do it."* But again, he's truthful, he'll tell you that he's done it and I love that about Leo. I love it that he's not.. like, that he wouldn't, but he also knows he's on medication, so he knows that like, he can't have piercings or when it comes to it he'll have to come off a medication to have a tattoo or, so he knows drinking alcohol maybe won't be the best thing to do. Because *we always joke and say we've made you into quite a good druggy Leo*, you can inject, you can pop. we obviously joke with him, but like *he's always said, "Yeah, but I'd never do any of that because I already take enough drugs."* **Dani:** So he's quite, he's quite an honest little boy. I think, I think he's, I don't ever have to worry that he wouldn't tell me the truth and stuff. **Simon T Dixon:** Umm, does he, do you feel like… he is that to deal with a stuff as a child that, you know, most people well, would never have to kind of cope with or deal with, but also if they did it would probably be later on. You see what I mean? Or even if it's something different, it's very young to experience these things, isn't it? As you have to grow up quickly?	
46.	**Dani:** Yeah, I just think this world's cruel, isn't it? I think before you're 25, you shouldn't have to go through any cancer or anything like that, like, you should be allowed to have a bit of your life before anything happens, but that's not how life is it? *And Leo's saying is, "life's a b****, but it is what you make it"*, like. **Simon T Dixon:** Where's he got that from? **Dani:** cuz *we've always said to him* like*, "Life's crap, mate, but you got to make it what you make it*". Like yeah and like, so *as a kid he's already said that, I've actually got that tattooed on the back of my leg. Life's a b****, but it is what you make of it'* (proudly exclaims this). Cuz he does make it to	**Fab:** Childhood Hardships and Resilience **- Proud Mother**

47.	what he wants it to be. It's stopped him, but it hasn't stopped him. **Simon T Dixon:** Yeah. **Dani:** I think it's made Leo the quirky little guy that he is now. **Simon T Dixon:** Mhm. **Dani:** because he has had to put up with like, more than, and my pap got to the age of 94 and it used to make my pap sad… **Simon T Dixon:** Mhm. **Dani:** because *he was like, "I've never had anything wrong with me, like he's a ten year-old little boy and he's been through more than I've ever been in my 90 years of my life",* and the same with me and Paul, like Paul has had stuff happen like his mom dying, like his dad not being a part of his life. But like he said, he's never had to put up with anything as extreme as what Le has had to. But like I say, I'm so proud of that kid, he is my little superhero, he is a hero.. because he gets on with it, don't get me wrong. I say he gets on with it, he doesn't always get on with it. Like, sometimes, like anybody *it gets too much and he has a little outburst of, "I hate this life". "Why is this happening to me?" "*Why can't I just be like all the other kids?" *And then the next day he cracks on, he gets on.* **Simon T Dixon:** Yeah. Yeah. **Dani:** He goes to school and he's fine*... But that's why we live every day as it comes* cuz.. because you don't know what's going to happen next. Do you? We could go to another eye appointment and they could say that his eyes are more damaged.. *or these drugs might not work that he's, he's only just took, started taking them*, they might not work. We might have a longer journey there than what we think we're going to have with it. It might not be plain sailing like it was last time with his joints. But, *I think Leo is very much, he just takes it as it comes and then he deals with it.* **Simon T Dixon:** Mhm. **Dani:** I think as a parent it's harder (sighs), like, *because things like the drugs that he's on, you get told that the,* like *if you're giving him these drugs then* actually *he could be more prone to getting child cancer or kids like adult cancer. You're getting told that knowing that you're pumping your kid with these chemicals that yes, they're getting him through day-to-*	**Fab:** Parental Anxiety and Fear **Resilient Supporter:** Holi-cont- Leo painted as a resilient and adaptable. **Fab:** Impact of Vision Loss on Leo

48.	*day life, but actually in five years time it could give them cancer.* I think as an adult it's a lot harder to deal with, *kids are resilient, they bounce back, they get back on with it again, don't they? Whereas a parent. worries, don't they? You see more into what could happen in his future and like especially now with his eyes like.* Leo just sees his eyes as they are and it wasn't until he went for that counseling session and it really upset me I had to like, turn my face away from him because he, she asked something about his sight and he said, "ah yeah", *I think she said can you remember ever seeing Leo properly and he went, "oh yeah." He said, "Um, I was watching the Aristocrats, that was the last time that I could see properly." And that* like, that *killed me because. I was like, 'Oh my god', I didn't, I didn't, you don't think of things like that, like why would you ever ask him that?* **Simon T Dixon:** Yeah. **Dani:** Like, *why would I ask him that? I wouldn't, whereas obviously she knew what to ask.* **Simon T Dixon:** Yeah. **Dani:** But yeah, *that I said to mum that killed me because I was* like *I honestly didn't think he could remember seeing.* **Simon T Dixon:** Yeah, **Dani:** So *that's why I thought it's never been that much of an issue to him because he's never known any different, but he obviously did know different.* **Simon T Dixon:** Hard, isn't it, that's... **Dani:** Yeah. **Simon T Dixon:** Like you're saying it must be challenging when you talk, kind of about that responsibility as being a parent and that's like a, such a heavy weight, isn't it? **Dani:** Yeah. **Simon T Dixon:** You know, because like you, I think there's a few things you've talked about which made me think of, um, yeah that responsibility being a parent, but also kind of, not, you know, you're put in this position where you don't know what the best thing is and as you say you're not a counsellor. **Dani:** Yeah. No.	**Emotionally Burdened Parent:** **Fab:** Parental Responsibility and Isolation

	Simon T Dixon: You're not a medical professional and you know, you're a parent and all of these decisions you're making. **Dani:** Yeah. Yeah. **Simon T Dixon:** You don't know what the right right or wrong thing, and is that what makes you feel a bit lonely? **Dani:** Yeah, I think and I think *that's what beats you up a little bit because things like knowing that you're giving him these drugs so that he can live a normal life and… so they could go blind but potentially you might be stopping him from having kids.* **Simon T Dixon:** Yeah. **Dani:** cuz *drugs could make him infertile or…like that, that you could prevent him from having a higher risk of getting cancer* **Simon T Dixon:** Yeah. **Dani:** especially if he then got that in mind and Chris's lives when we were still alive, you'd go back to the beginning of blaming yourself,… **Simon T Dixon:** Yeah. Yeah. **Dani:** But there's and you know, that you're being irrational about that because you know that there's nothing else that you can do. **Simon T Dixon:** Yeah. **Dani:** But you still, it doesn't matter, does it? Like, you're there to protect your kids, but you can't protect them. **Simon T Dixon:** Yeah. Yeah. because that the normal parenting role you go through those things to such a massively lesser degree but you still have those thoughts about things don't you about how it impacts but then for the things that it's just so unfair isn't it that you got those things that nobody can really advise you on can they? **Dani:** And you've got no control over it. **Simon T Dixon:** Yeah.	Self blame at the start of the journey- Transformative by relating that to present day assertiveness **Isolated Parent:**

	Dani: You've got no control to say, well obviously you have, you could say, no, we're not giving him these drugs because we're going to try, I don't **Dani:** know, CBD oil or whatever. But… **Simon T Dixon:** Yeah. Yeah. **Dani:** why would you do that? *Your kids in chronic pain, you're not going to argue with somebody that's going to tell you,* and you can clearly see the results in him being okay on them. **Simon T Dixon:** Yeah. **Dani:** And *especially now with his eyesight, we can't gamble with anything,* so, anything that they tell us that we've got to do, we've got to do. **Simon T Dixon:** Yeah. Yeah, yeah, yeah. **Dani:** It's as if like, I know you don't have full control as a parent anyway, like your kids can go out and take cocaine. You haven't got control over that, have you? **Simon T Dixon:** Yeah. Yeah. **Dani:** But from a three-year-old, you've got that control. **Simon T Dixon:** Yeah. **Dani:** You've got control of what your kid puts in their mouth, what, like you have got that control. Whereas that has been away from me and Paul, we've got to do what they tell us to do. **Simon T Dixon:** Yeah. Yeah. **Dani:** Like, *we've got to take him for his blood test to have him stabbed with a needle that he can't stand*, and you feel like, because, I did say to Leo as he got, when he got older. I said, "Did, you, did you ever, like obviously you're little so you can't really remember, but did you ever blame me and dad for like?" Because you kind of.. like what is that kid thinking, that like my parents are letting these people stab me or letting them.. **Simon T Dixon:** Yeah.	Holi Cont-Parenting role is not 'normal'.

	Dani: I think that's a horrible part of it as well, cuz thinking God *your kid must think "why, why are my parents not protecting me?"* **Simon T Dixon:** Mhm. Yeah. **Dani:** *"Why are they letting me get stabbed by a needle or be put to sleep or be put on a massive machine that scares the crap out of me?"* **Simon T Dixon:** Yeah. Yeah. Yeah. **Dani:** It's things like that think you've got no say over. You got to let them do it. **Simon T Dixon:** Yeah, yeah. **Dani:** So yeah, I think like, yeah, I think it's like I say, *it's lonely and it's hard work,* like it is. Like don't get me wrong last year with sound there was nothing wrong with him, well there is something wrong with him, but he wasn't in pain he got on with life, his sight was fine, everything was calm *it's always calm before the storm isn't it*,(chuckle) so… **Simon T Dixon:** Yeah. Yeah. **Dani:** And I think that's another thing like people used to say to me, *"God you're going on holiday, why don't you just, just enjoy it or like, just get excited about it"*. But then a part of me, I can't get excited about it because if he gets chickenpox? Then we can't. Then what about if his joints flare or it's things like that, isn't it? I think that's changed how we look at things. *** [Sorry, I'm looking for my charger there.]- Dani was running out of battery.**** **Simon T Dixon:** No, it's alright. **Dani:** [I was just looking for my charger and it weren't there.] **Simon T Dixon:** No worries, no worries. **Simon T Dixon:** When did you get your tattoo? **Dani:** What? What? Sorry. **Simon T Dixon:** When did you get the tattoo? **Dani:** When	Transformative narrative- Initially naïve, now adapting to possibility of a flare up and its impact. "Calm Before the Storm"

	Simon T Dixon: Yeah. **Dani:** Um, I don't know, when did I get that one? I got that one last year. **Simon T Dixon:** Okay. Yeah. **Dani:** I've got other ones on my leg but they're all like, for the boys. I've got two tiger cubs fighting, *cuz that's all they do.* (both laughing) **Simon T Dixon:** Cool. **Dani:** And then I've got their flowers and stuff of their date of birth like the birth flowers and that. So,… **Simon T Dixon:** Okay. Yeah. **Dani:** and then I said to Leo like, when we're on holiday, cuz he obviously always says it, now he's older he says it **Simon T Dixon:** Yeah. **Dani:** and I said should I get that tattooed on me? He said, "Yeah". **Simon T Dixon:** Has Paul? **Dani:** Has Paul? He's, Paul has got load of tattoos, **Simon T Dixon:** Has he? **Dani:** Paul's are not as.. mine are more meaningful, Paul has just got tattoos (chuckles). **Simon T Dixon:** Okay. All right. Yeah. … **Dani:** Well, he's got a Spurs badge, that's meaningful to him. (chuckles) **Simon T Dixon:** nice. **Dani:** And he's got the boys names and that. So, **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. But nothing as, you know.. I think that's amazing to have that tattoo and it is meaningful, isn't it? But I just, I think, would you have had that before any earlier? You don't think you were in a place	
49.		

	where you could have done, or, why wouldn't you have had it before? **Dani:** *No, because nothing's happened, obviously I've had cramp grandparents died and stuff like that.* **Simon T Dixon:** No, sorry, I meant earlier in your journey I guess and kind of Leo's life or.. **Dani:** *No. Because at the beginning we thought that would be it, he'd have his joint injections, yes it's crap, he's got to stay on these drugs, but, I don't think we knew that this journey would then carry on into his teenage years.* **Simon T Dixon:** Yeah. **Dani:** I think it's one of those things but again nobody tells you anything, they treat him at the time. **Simon T Dixon:** Yeah. **Dani:** So nobody tells you that, *well in 5 years we're going to take him off his drugs because nobody knew about his eyes so then he had to stay on the drugs longer.* **Simon T Dixon:** Mhm. **Dani:** *So yeah, it feels like from when he got diagnosed to about four years ago, it's been one thing after another*. So you think that *things are okay and something else happens, then, and then it get and then something else happens. So then when like people say to you,...* you got to think positive, it's like, I don't think I'm a negative person, by far. Like, *in my work journey and everything, I've always been the hyperactive person, but then, and people have always said, "Jesus, Dani, I never knew that your son was poorly."* And I was like, *"What? Cuz I'm not rocking and crying in a corner, like". Life goes on, you have to get on with it.* **Simon T Dixon:** Yeah. **Dani:** And, but that is why that saying is so relevant to anything like, because life is a b****. People do die, people do get cancer, people.. like, but life goes on, you've got to make it. You can't say, "My dad left me at the age of two, so now I'm going to be horrible to everyone." Or, "I've been diagnosed with this horrible thing, so now I'm going to be an arrogant, horrible person because life owes me". Life doesn't owe you anything.	**Resilient Parent:** **Fab:** Affirmation & Hope

	Simon T Dixon: Mhm. **Dani:** *And that's how we've always been with Leo. "This may happen to you, mate, but it's not an excuse to like, be.. horrible.. or be bitter towards other people.* **Simon T Dixon:** Mhm **Dani:** Like, just cuz someone else is healthy and okay, it like, you can't then be bitter towards people that are okay, can you? **Simon T Dixon:** No. **Dani:** And also, someone's always got it a lot worse, and Leo knows that. There's a little lad that's just been diagnosed with a really rare leukemia. **Simon T Dixon:** Mhm **Dani:** And *Leo even said himself the other week, "I'm so glad that like, mine's just my joints".* So Leo's not like, he's not silly hisself, *he knows that people have got it a lot worse.* **Simon T Dixon:** Mhm **Dani:** But it doesn't make your situ,.. like people, *when people say, I can say that, but if someone says that to me, I'm a bit like you're not in my situation and so, how do you know how I feel?* **Simon T Dixon:** Yeah. Yeah. **Simon T Dixon:** Is there anything else you want to add or anything else you want to say? **Dani:** Um, I don't think so, like I say. I think like, *throughout the whole journey, Leo's been a little pro. He's just got on with it, um, it's made Leo who he is.* I think *as parents it was lonely but then.. like I think me and Paul have done well because you see a lot of parents,* don't you? *If their kids are ill or got something wrong they do tend to split up and stuff.* **Simon T Dixon:** Mhm **Dani:** Don't get me wrong, we're not perfect couple, but, and *we both have had our times that probably one of us has thought, " god, I don't know if I can cope with you any longer." But I think that we do quite well as a family to keep everybody upbeat and not let it win.*	**Teamwork- narrative of strength and relational resilience.** Maintaining hope and continuing to 'fight

50.	So, and that's what we've always said to Leo, *"Don't let it win, Leo". It's not who you, you're not the illness. So, I know it stops him sometimes, but we try our hardest not to let it stop him.. doing anything and in the future, hopefully not letting it stop him do anything that he wants to do.* So, **Simon T Dixon:** Mhm, What feels really important has come across so, so much is although looking into the future is really difficult and kind of anxiety provoking for you, you kind of really want him to, to have hope in the future and you have hope for him in the future and you're kind of part of him growing up. And you're building him into somebody who's going to be able to cope and I think you've got quite a good idea of what a parent is generally, but and navigating all of this is like, you're doing an amazing job and it's like, just the way that you've been talking through it, it felt like you've been talking about um, the real struggles and how unfair kind of life can be, but throughout all of it, it's like this real hope that actually, 'but I'm resilient and I'm going to get through this and so is he and he's going to grow up and he's going to be able to do things and, you know, even if he can't, he's going to be able to cope with not being able to do those things'. **Dani:** Yeah.	
51.	**Simon T Dixon:** And that's really come across, without taking away the struggle that you've been through, you know, and are still going through. But I think just take a bit of kind of pride in what you're doing because yeah, you, you know, I'm sure people tell you that, but I think sometimes you forget, you forget it and just kind of go away thinking I'm doing a really good job. You know.	
52.	**Dani:** Yeah. Well I like to think, well I hope I am, I hope I do Leo proud like he does us proud, so, I'd like to think if you interviewed Leo, Leo would be like, "Yeah, my mom and dad support me, like I've got the support that I need." So, I'd like to think that anyway, you never know with Leo though, he could come out with anything (chuckles). **Simon T Dixon:** Really? Yeah. **Dani:** So yeah, *he's thrown me and Paul under the bus when we haven't actually done anything like with specialists before,* and you're like, I'm surprised the social hasn't knocked on my door, *but obviously they know that he's just a kid with a very good imagination.* (laughing) **Simon T Dixon:** Yeah.	**Reflective Parent:** **Fab:** Mutual Recognition **Reflective Parent**

	Simon T Dixon: He's er, you speak so fondly of like, his little intricacies and like little kind of bits about him that you kind of, his quirks, do you know? "And that's Leo".	
53.	**Dani:** Mhm. **Simon T Dixon:** And it's like endearing, you're not kind of yeah allowing, you're, you're not oblivious to that and you're not allowing, all the conditions and everything to be his identity. It's like you're kind of like, yeah, but that, that's him. Do you know what I mean? He's got that humour and he's got the you know. It's , you know, you speak really fondly of him and that really comes across as well.	**Projecting herself as honest and 'to the point'** **Fab:** Humour & Reality Check **Real/Grounded Parent:**
54.	**Dani:** Yeah, *well I don't always* (smiling). **Simon T Dixon:** Obviously you're human yeah **Dani:** Yeah. that's it. Well, we laugh at work cuz a few of the lads at work have got boys and they're like, *" we love you, Dan, because you don't put on Facebook, we had such a lovely day with the family. You're very to the point that your kids are asses."* (chuckles). *I thought, "Well, they're boys." Of course they are.*	**Fab:** Fondness & Acceptance **- Loving, Accepting Parent**
55.	**Simon T Dixon:** Yeah. Yeah. **Dani:** But yeah, they're not, they're not. *They have their faults*, but I'd like to think that we've raised them to be good kids. *But only the future will know that I suppose, won't it?* You can only have so much control. **Simon T Dixon:** Yeah, but, yeah. As parents, you can do what you can do **Dani:** That's it. **Simon T Dixon:** you know you do your best, but like you know. **Dani:** You can only have so much control, can't you? **Simon T Dixon:** Yeah. That's it. **Dani:** Even though *when they start going clubbing, I think I'll have to get my clubbing shoes back on and go out with them, (both laughing) go and spy on them.* **Simon T Dixon:** That's if there's any clubs open.	**Fab:** Honest Parenting **- Realistic Parent:** **Fab:** Uncertainty & Hope **Hopeful and Resilient Parent:** **Fab:** Parenting Control Limits **Adaptive Parent**

56.	**Dani:** Yeah. **Dani:** Nothing will be, will it? **Simon T Dixon:** Yeah, I don't think so. **Dani:** The way Northampton's going. **Dani:** I'll be going to house parties with them instead. That's the new thing. House parties. **Simon T Dixon:** No, I'm sure they'll invite you to the house parties. **Dani:** Make friends with the next door neighbours. Can I come in? **Simon T Dixon:** They look through the window. (both laughing) **Simon T Dixon:** Did you want to add anything else or… **Dani:** Yeah. No,… **Simon T Dixon:** do you feel like you want to say anything else? **Dani:** I don't think so. I think I've covered everything that's happened and… **Simon T Dixon:** Okay. **Dani:** yeah. No,… **Simon T Dixon:** And are you happy with everything you've said? you don't feel like you have no worries about anything you've shared. **Dani:** I don't like to bad mouth like the NHS. **Dani:** I know that they're under pressure and stuff like that, but *unfortunately that is our story and yeah,...* **Simon T Dixon:** It's important and… I don't think yeah, it's important that you're able to tell a story. that's what your experience is and that's how you make sense of your	**Fab:** Sharing & Confidentiality Reflective

	experience. And you're not the only person that feels that way. … **Dani:** yeah, yeah,… **Simon T Dixon:** there is a lot of pressure on all sorts of services at the moment, isn't there? … **Dani:** yeah. That's the thing. **Simon T Dixon:** and you talked about school as well. **Dani:** Right. **Simon T Dixon:** And you think, but people need to hear and that's what I'm hoping, we hope that, with doing things like this, it's only a little thing, isn't it? But maybe something comes of it where people listen a little bit and people hear the story and then it kind of, people get a better understanding of what it's like to be a parent. it might be in your little context… **Dani:** Yeah. Yeah. **Simon T Dixon:** but like you said if you want to help other people in your position as well and it's only by telling people your story that that can happen can it really no.. **Dani:** That's the thing. Even if one person, Yeah. Yeah. And that's the thing if, I like, you don't expect anybody to get fired or anything like that. But if it could help another family to realise, I don't have to put up with that or I don't have to you should stick up for what's right. **Simon T Dixon:** Yeah. Yeah. **Dani:** I'm not saying be rude or demanding but stick up for yourself and make sure your kids got the best care, because anybody else would, wouldn't they? **Simon T Dixon:** Yeah. I think like I said at the start and all the way through is that nobody will be able to be identified, there won't be schools and I won't, locations of things so it wouldn't be Northamptonshire, I wouldn't talk about Northampton and so Dr. O,…I say Dr. O won't look at it and…be like, "That's Leo." Yeah, nobody would so don't go away with any anxiety or worry about actually what happens if something, because it's completely confidential. It's completely and…	

57.	**Dani:** Yeah. Yeah. **Simon T Dixon:** utterly nobody would know and at the moment there is a possibility that in the future like I say it could be that it gets shared in different places but at the moment it would only be my supervisor and a few people from other universities two or three who assess it and look at it so at the moment you wouldn't… **Dani:** Yeah. Yeah. Okay. **Simon T Dixon:** but you wouldn't know it was and you wouldn't be able to identify Leo, or anybody in the family, anybody you've talked about or.. everybody will get changed and the location won't be mentioned so they couldn't identify anybody, so that isn't something for you to go away and worry about but the only thing I'd say is that, I think I wrote it in the pack was just to consider Leo when he gets older if he might want read if he goes, " when you had that interview or whatever, if you told him or Are you happy that he could then read what you said?" **Dani:** Yeah. Yeah, I've not said anything in it that I wouldn't say to him, so. **Simon T Dixon:** Okay. if you feel like you you've told me everything, you told your story and then Are you happy or is there anything else you want to say? **Dani:** I don't think so. **Dani:** No. Okay. **Simon T Dixon:** So the next stEP'sare that I'll go away and kind of, as I mentioned at the start was I'll have a look at the recording. I'll listen to it a few times. I go through it there's a particular order and way that I'll do that to analyse it through a kind of a narrative approach which then I'll come back to you like I say and we can talk through what I've written and how I've made it into a kind of story it made it into something I'll come back to you and see if you're happy with that and just to make sure that you feel that I've understood **Dani:** Yeah. **Simon T Dixon:** or I haven't got anything really wrong. and then if you're happy, then it will go forward. I'm going to stop the recording, but I'll just hang on. How do I do that? There we go. stop recording.	**Fab:** Consent Closure & Next Steps **Thoughtful Narrator:**

Appendix B-

Dani- Extract of table of transcript segmented into moves, summary of 'move',

identified Fabula and Sjuzet* and Identity Positioning in each 'move'

'Move' number	'Move' name	Fabula within 'move'	Sjuzet within 'move'.	Identity positioning	Supporting quotes
1.	**Initial Symptoms and Uncertainty (Early Childhood**)	Leo was three and a half years old. He had always disliked walking long distances. After a walk, he 'kicked off' like a toddler. The next day, his knee was swollen. They had also been to a play area (Tigers) that afternoon. Dani observed clear fluid on his knee and he wasn't putting pressure on it. Dani took him to the doctors. Doctors noted heat and worried about a joint infection. They sent him straight to the hospital.	Through the Sjuzet it gives us an insight into Dani's internal world, how she made sense of early warning signs, medical uncertainty, and the emotional turbulence of not knowing what was wrong with her child. It includes humour, self-reflection, and expressions of confusion or distress. *"Leo was always a bit, well we thought lazy..."* *"obviously we didn't make him climb mountains or anything like that (chuckles)"* *"we're not going to make any rash decisions to rush him to hospital."* *"that week was the worst week of my life..."*	**Reflective Parent:** Dani reinterprets Leo's early behavior (disliking walking) through the lens of pain rather than laziness.	"we thought lazy, cuz even though he started to walk at 9 months old..." - "obviously we didn't make him climb mountains or anything like that (chuckles)" - "we wasn't sure what had happened... we're not going to make any rash decisions" - "they didn't really give me a lot of information which that week was the worst week of my life" - "just try and make him rest, which was crazy to say to a three and a half year old that doesn't watch telly (chuckles)".

		Leo stayed in the hospital from Monday to Friday. He had an MRI. He was put to sleep and had fluid pulled from his knee. Doctors concluded it was trauma and advised rest. 14. Leo was sent home.	*"which was crazy to say to a three and a half year old that doesn't watch telly (chuckles)."*		
2.	**Diagnosis and Early Impact (Arthritis Confirmation)**	Dani noticed his ankle on his other leg was swollen. They went back to see Mr. L (doctor). Mr. L suggested it could be arthritis. They went to see a specialist. The specialist confirmed Leo had arthritis in both knee joints, two ankle joints, and his wrist.	This 'move' is rich in reflective tone, particularly as Dani confronts the unexpectedness and confusion around her son's diagnosis. The phrase, "that's an old person's thing" carries embedded social assumptions. Her speech is non-linear and emotional, marked by hesitations, corrections, and shared language ("we were like"), suggesting a collective	**Reluctant Traveler:** Frames the diagnosis as the start of an unwanted "journey" that fundamentally shifts the family identity.	- "we was meant to go back... just to see how he was getting on..." - "his ankle on his other leg was swollen" - "he's three and a half years old... that's an old person's thing" - "we'd never really like, well never heard of it before." - "our journey then obviously started"

			processing with her partner. *"we was meant to go back..."* *"we'd never really like, well never heard of it before."* *"our journey then obviously started."*		
3.	**Challenges with Initial Treatment (Methotrexate and Side Effects)**	Leo started treatment with Methotrexate. Leo experienced sickness with Methotrexate. Leo wouldn't eat and they went to a dietician.	"Erm... but I think the main thing with Leo is his eyes..." "Looking back now, obviously, you don't know anything, do you?" "We were both, not in denial, but you don't want your kid to be broken." "We perhaps didn't ask the questions we should have asked." "You research it and you get... horrific things." "I don't think I've got the energy to ever try and find out what happened." "I do think the NHS will	**Identity in Conflict:** Struggles with the tension between trusting medical professionals and feeling guilty for not pushing for answers sooner.	- "You don't want your kid to be broken." - "We perhaps didn't ask the questions that we should have asked." - "You Google you get horrific things." - "I don't think I've got the energy to ever try and find out what happened." - "Leo should have been screened for his eyes quicker than what he was."

			probably all protect their selves."		
4.	**Uveitis and Missed Screening**	Leo developed uveitis in his eyes. Leo was not screened for his eyes immediately after arthritis diagnosis. His uveitis became severe. He was put on nine steroid drops a day. Leo was under **** doctors but also sent to *** Hospital. Leo developed cataracts in both eyes due to steroid use. The last cataract was removed from his left eye. His left eye stopped working. Leo developed Glaucoma in his other eye. He now has only 10% left of nerves in his "good" eye.	Through the sjuzet, we witness Dani's emotional vulnerability and regret as she revisits moments of ignorance and trust. She openly expresses the helplessness of not knowing what to ask or expect, the lasting consequence of delayed screening, and the weight of "what if." She illustrates how knowledge came too late, initiated by her mother's curiosity rather than proactive medical oversight. There's palpable sadness in her realisation of the permanent damage, frustration at systemic gaps, and deep fatigue.	**Reflective Narrator:** Looks back at the tragedy of Leo's vision loss with a mix of regret and hard-won insight into systemic failures.	- "Leo should have been screened for his eyes quicker than what he was." - "We knew nothing about arthritis... not in denial, but you don't want your kid to be broken." - "You don't even think your kid could get arthritis let alone it go to his eyes...that's not a joint, is it?" - "My mom was like, has Leo got to go for a screening on his eyes? And they were a bit, oh yeah, hasn't he been? We were like, 'No, we wouldn't have known that.'" - "Cataracts in both eyes... his left eye not work anymore...his brain just told him that eye doesn't need to work." - "Only got 10% left of nerves in his good eye."
5.	**Treatment Evolution and Recent Flare-up**	Methotrexate was determined not to be suitable for him.	The sjuzet offers a mix of timelines: Dani recounts the	**Reflective Narrator** (as above)	- "It was awful to see Leo in pain at the beginning..." - "Methotrexate

		They switched his medication to Humira. Humira lasted "quite a long time." Six months ago, Leo was taken off Humira for a break. His arthritis "came back" in January (current year). They had to restart injections and procedures. Leo has had counselling multiple times, especially since secondary school.	painful earlier days of trial and error with medication and contrasts it with the more recent relapse. There is a blend of past and present, as she reflects on the emotional toll for Leo and herself. Her narrative threads grief, guilt, growth, and humour (e.g., Leo “fell in love” with the nurse). She discusses not only Leo’s suffering but the broader family context, especially how the illness reshaped parental roles and mental wellbeing.		wasn’t for him...we then went on to Humira..." - "They couldn’t have done enough for us... brilliant." - "We didn’t want to inject him." - "This time around...it was a lot worse because Leo is very much aware of being put to sleep... having to have canulas." - "I think Leo’s illness has made me change as a person, massively change." - "I never had anxiety like I’ve had since everything’s gone on with Leo."
6.	**Emotional Impact on Leo and Sibling Dynamics**	Dani is more protective over Leo than Bennie (older brother). Dani feels she overcompensates with Bennie due to Leo receiving more attention. Bennie had mock exams this month, worried that she doesn’t give him enough time.	Through the sjuzet, Dani paints a picture of tension between care and fairness. Her storytelling is marked by self-reflection, chuckles at Leo’s cheeky nature, and visible empathy for Bennie. She illustrates the emotional gymnastics of parenting a chronically ill child while	. **Mentally Strained Mother:** Openly admits to the profound exhaustion and anxiety that comes with watching a child suffer.	- "He's not our favourite, he just needs us more." - "I probably baby him a lot more... Leo plays on that, he's got a wicked character." - "I'd hate in years to come for Bennie to be like, ‘oh, it was all about Leo when we were growing up.’" - "I'm exhausted now. I'm so glad January is done." - "It's tiring having kids

			trying to protect the sibling from feelings of neglect. Her internal conflict and fear of long-term impact on Bennie are central to this move.		anyway, but when you've got kids with additional needs, and it's lonely..."

Appendix C-

Dani- Extract of Stage 4- Categorical Content, including table of themes.

		Coding
1.	**Simon T Dixon: No, okie doki. Alright, okay so, can you share the story of when you first realised that your child was.. experienced chronic pain? What was that like for you and your family? Okay. Yes.** **Dani:** So, Leo was three and half years old, ummm it was in the January er, *we were looking after my Mums dogs*, and we'd, Leo was always a bit, well we thought lazy, cuz even though he started to walk at 9 months old he didn't really like walking distance, so, like only walked around the village and stuff but obviously we didn't make him climb mountains or anything like that (chuckles), but still he'd always like ask for his buggy and want to be carried. He didn't really like walking a lot erm so when he was three and a half, we took him for a walk, we'd been for a walk, and he really used to kick off, like a toddler would. **Simon T Dixon:** Um uh **Dani:** We carried on the walk and then the next day his knee had all swollen up. So we're a bit like ooh, has he hit it? Because we'd been to Tigers, the play area as well. **Simon T Dixon:** Okay. Yeah. Yeah. **Dani:** So, we went there in the afternoon. So we were like,… **Simon T Dixon:** Yes. Yeah. Okay. **Dani:** So has he, you know, *being a typical boisterous boy*, has he hit it or done something? So we wasn't sure what had happened. Umm I thought him being a boy, we're not going to make any rash decisions to rush him to hospital. So the next day it was a little bit more swollen, well quite a bit more swollen and you could clearly see there was fluid on his knee. He was not putting pressure on it and wasn't walking properly. So, I took him to the doctors and they said there's a lot of heat coming from it, so we're a bit worried that it's an infection in his joint. **Simon T Dixon:** Okay **Dani:** So, they sent us straight to the hospital with him. , erm we stayed in hospital. So, that was on the Monday. We didn't come out of hospital until the Friday… er with no, we didn't really have any answers. He'd had an MRI, he'd had erm fluid.. been put to sleep and had fluid pulled from it cuz they wanted to see if it was I don't know what they were looking for (shaking head).	Making sense of Leo early childhood and difficulties with walking. Leo as lazy Initial symptoms normalised Gender stereotype Uncertainty with Leo's health

They didn't really give me a lot of information which that week was [redacted], because you didn't know what was wrong with your baby, but *there was clearly something wrong*, but then they just put it down to a trauma that he'd obviously hit it and that, that was that.. *just try and make him rest*, which was a crazy to say to a three and a half year old that doesn't watch telly(chuckles) and just wants to kick a football

Scary, unknown

Simon T Dixon: Yeah. Yeah.

Frustrated with lack of information

Dani: So, we got sent home and then we was meant to go back to see them I think two or three weeks later just to see how he was getting on, erm, but then we noticed that his ankle on his other leg was swollen.

Simon T Dixon: I see. Yeah.

Dani: Then when we went back to see the doctor, [redacted] he was like, "Yeah, I think this could be arthritis." We were like, he's three and a half years old, how.. That's an old person's thing, we'd never really like, well never heard of it before. Erm.. So was a bit, like didn't really know what to think. Me and Paul were like, *""Right, okay."* so we then went to see a specialist and she obviously confirmed, "Yeah, he's got it in both joints of his knee, two joints of his ankle and also in his wrist." So then our journey then obviously started.

Worst week of life, scary.

Initial signs of something more serious

Simon T Dixon: Mhm.

Dani: So, Leo is 12, nearly 13 now and he's just had another flare up.

Simon T Dixon: Okay.

Good experience of Dr.

2.

Dani: Even though his joints had calmed down once he'd had all his joint injections, he then went on to Methotrexate, which is like, well, the worst drug I think, Leo hated it, he was sick all the time with it.. erm.. it then led on to other issues, Leo wouldn't eat, so then we had to go to a dietician because they thought he was anorexic, cos he *just couldn't keep anything down.*

Start of journey, confirmed swelling in joints

Erm..but I think the main thing with Leo is his eyes, so Leo, through juvenile arthritis, he then wasn't screened.. we.. erm.. looking back now, obviously, *you don't know anything, do you? You can only trust what a specialist is telling you. We knew nothing about arthritis and I think, at the time, myself and my husband, Paul, we were both, not in denial, but you don't, you don't want your kid to be broken, so, it was a bit like, we perhaps didn't ask the questions that we should have asked or we didn't research it because you don't want to research (shaking head) it because you research it and you get, like anything, if you Google you get horrific things*. Erm, so we were just trying to deal with what was happening at the time.

3.

But then, it then led to him having, I think he.. they didn't.. I don't know what happened and I don't think I've got the energy to ever try and find out what happened because (sigh) I do think that the NHS will probably

Settled but then took a new drug (worst drug).

4.	all protect their selves, but Leo should have been screened for his eyes quicker than what he was. **Simon T Dixon:** Okay. **Dani:** Because then his uveitis was really bad, to the point that they had to like put him on nine drops a day of steroids to try.. **Simon T Dixon:** And when, when abouts was that, when they, when he, when they first realised that, you said that they should have screened them. **Dani:** So I think the screening they're meant to have, like four months, well meant to have straight after they've been diagnosed with arthritis. So Leo, he's under Northampton, but he was..he also got sent to Birmingham because at the… not 100% sure, I think so he's got Dr. K and Dr O, Dr K is obviously an adult doctor that deals with arthritis, but Dr. O is a pediatric doctor that has got a interest in arthritis. **Dani:** So together they make a specialist. **Simon T Dixon:** Okay. Yes. No. **Dani:** But Leo also had to go to Birmingham just because obviously they're a bigger, bigger hospital. Erm..but then Leo should have probably got in straight away to go and see for his eyes as well to make sure his.. but we didn't know anything about this, like obviously, you don't know, you, you don't even think your kid could get arthritis let alone it go to his eyes, cuz you don't, that's not a joint is it?(shaking head) So you don't really put two and two together, but it wasn't until, I think, after his steroids had been done and he started on his medication when we went back to the specialist. I think it was actually my mom had read up about it, so my mom was like has Leo got to go for a screening on his eyes and they were a bit, oh yeah, hasn't he been? We were like, ""No, we wouldn't have known that."" So, so Leo then went for his eyes, like I say, his eyes were really swollen, had to have a lot of steroids. He then.. had cataracts in both eyes because of the intense, erm.. steroids in his eyes. But unfortunately, it then made his left eye not work anymore because that cataract was last to be taken out. Erm, it it made, it basically *his little brain just told him that eye doesn't need to work anymore*. Erm.. so that's like blurred vision, erm but then Leo's other eye that he had cataracts in, then he got Glaucoma. So only got 10% left of nerves in his good eye. **Simon T Dixon:** Yeah. Okay. **Dani:** Not his good eye, but it's his good eye vision (chuckle). **Simon T Dixon:** Okay. Yeah.	Instable, can't relax Guilt Tired and disempowered Frustrations with the NHS More drugs and Uvietis worsening Missed screening. Unsure of what to do/feels guilty

5.	**Dani:** So I think, *as much as it was awful to see Leo in pain at the beginning, cos he then was okay with his joints but it was like the medication that he was on was obviously horrible and it took ages to work out that Methotrexate wasn't for him*. So we then went on to Humira, which.. he fell in love with the nurse at X surgery, they couldn't have done enough for us. They were absolutely brilliant. because me myself and Paul didn't want to inject him. **Simon T Dixon:** Yeah. **Dani:** So they played around with his drugs, but then Humira has lasted quite a long time actually, until 6 months ago when they took him off to give him a break and hope that it didn't come back. But yeah, unfortunately it has come back, it came back in January and we've had to kind of start the process again with injections and *this time around it was a lot worse because obviously Leo is very much aware of being put to sleep, having to have canulas in his hands and yeah, it wasn't a fun experience this time around at all*. so… **Simon T Dixon:** Yeah. **Dani:** And to see him in pain, to be able to talk about it. I think when they're little kids they're kind of relentless, aren't they? They just crack on and they do get on with it. But… Leo had a lot of tantrums, like, probably more than any other kid because he couldn't deal with what was going on. Erm.. Leo's also had to have counselling quite a lot, because especially as he's got older and he's gone to D [Secondary School], he can't control how he feels and yeah, it was a bit rubbish last year, we had a bit of a rubbish year with him and then it's hard on, like his older brother Bennie, cos he's two years older.. it. and I.. he doesn't get what's going, he he gets that Le obviously, like, this time around, he was like god yeah he, he's got a massive leg and poor kid, he feels for him but also that attention is on Leo a lot so it must.. **Simon T Dixon:** Yeah. **Dani:** be hard for Bennie to think and we have to constantly reassure Bennie, like 'he's not our favourite, he just needs us more', like he's never been our favourite, like we love you both the same and that's hard aswell… **Simon T Dixon:** How did think, er, so kind of. Did you feel like your relationship might have changed a bit when the diagnosis came and how do you think your kind of relationship might have changed or shifted kind of at that point? Okay. **Dani:** I think I'm more protected over Leo. **Simon T Dixon:** Okay **Dani:** There's a lot of like, Leo I'd say out of Leo and Bennie…Erm, Me and Bennie are more alike. So we laugh at the same things and whereas Leo I'm very protected over and I, I probably baby him a lot more than what like, *Bennie bless him, just cracks on and he's always had a shower*	Inconsistencies with Healthcare Onset of Glaucoma Emotional impact on Dani Potentially eluding to frustration with prolonged Methotrexate use. But good experience of a Nurse. Leo more aware, but needing to adapt Describing Leo's understanding and tantrums at

6.	*himself whereas Leo (chuckling) I'm still like giving him his toothbrush in the shower him but Leo plays on that like he's got a wicked character.* And I think because of everything that goes on, like, but I do feel for Ben because I think a lot of people in general, like family members I feel like they give Leo more attention and I don't think that's fair. And so I feel like I overcompensate for Bennie in that way. **Simon T Dixon:** Yeah. **Dani:** So, as much as I do everything for Leo, *I overcompensate with Bennie, like, making sure he's ok, because I'd hate in years to come for Bennie to be like, 'oh, it was all about Leo when we were growing up'. Like, 'mom didn't care about how my exams were going'*, or, and that's what's been difficult as well this month because Bennie's had his mocks. **Simon T Dixon:** Mhm. **Dani:** *It was all about Leo and* er *I had to* like*... And I'm exhausted now. I'm so glad January is done.* Because that is another thing. *you're exhausted all the time because* you're constantly*, it's tiring having kids anyway, but when you've then got kids with additional needs, and it's lonely* like*, people don't get it,* like*, teachers don't get it.* Like*, the battle that I've had with them trying to get* like*, the rule for saying, "" oo, your kids attendance is rubbish, but I felt like they didn't really help me.""* … **Simon T Dixon:** Okay. What could, what do you think they might have been able to do differently? **Dani:** Well I just, things like *them passing me to pillar to post, like ""..you need to speak to his form tutor, you need to speak to this person. ""Come on guys, like, I've got enough to deal with Leo and his medical like stuff, just one of you sort something out".* **Simon T Dixon:** Yeah. **Dani:** *That's how I was getting frustrated with it to the point that I was a bit like, do you know what? He's not coming back in school until you've sorted something out. And then you'd get one of them say, could you call back on Friday to like, to make sure everything's in place? No, I shouldn't have to call, I'm trying to hold down a full-time job, look after my, like Bennie, like sort a house out. And I just think people don't realise, like, how much you like appointments you have to arrange*. And I'd say that me and Paul are quite equal, Paul is self-employed so it's hard with that as well because he feels a lot of guilt because he knows that I have to do a lot of appointments and stuff. **Simon T Dixon:** Yeah. Yeah. **Dani:** But it's like *I'm quite a control freak and I think Leo's illness has made.. me change as a person, massively change as a person cuz I never got people getting panic attacks and anxiety. Like, I've always been a*	first, because of his age. Balancing Needs of the Leo and Bennie Impact on family functioning, difficult for both Leo and bennie Differences in how Dani parents. Overcompensating when parenting Bennie Unseen Demands & Parental Burden Describing the emotional impact of parenting a

	whittler, but I've never had anxiety like I've had since everything's gone on with Leo. **Simon T Dixon:** Okay. **Dani:** So obviously it's affected my mental health as well, as well as like. Paul is a bottler, he'll bottle everything up, so it's affected him as well. And I think sometimes we perhaps don't talk as much as what we should together because we don't want to upset each other	child with additional needs Battle with School syatems

Table 3: Coding Notation

Typical boy.. . – Sjuzet is underlined
When both fabula and Sjuzet- *Italics*

Subtheme key:

Initial concerns & Diagnostic Uncertainty
Navigating Healthcare Systems
Experiences of Educational Systems
Information Gaps & Medical Communication Deficits
[redacted]
Parental Guilt and Burden of Decision-Making
Isolation and Lack of Understanding
Personal Growth and Assertiveness
Coping and Stress-Management Strategies
Balancing Needs of the Leo (ill child) vs Bennie (well sibling)
Sibling Relationships and Processing
Shifting Parental Identity
Parental and Family Protective Instincts
Strain on Marital and Family Relationships
Leo's Adaptability and Bravery
Normalising a Different Way of Life
Fostering Independence Amidst Vulnerability
Seeking and Valuing External Support Networks
Finding Hope and Maintaining Perspective
Empowerment and Advocacy

Theme	Subtheme	Associated Codes
Theme 1: Navigating Uncertainty in Diagnosis and Systems	Initial concerns & Diagnostic Uncertainty	⍰ Making sense of Leo early childhood and difficulties with walking ⍰ Leo as lazy ⍰ Initial symptoms normalised ⍰ Gender stereotype ⍰ Uncertainty with Leo's health

Theme	Subtheme	Associated Codes
		? Scary, unknown ? Worst week of life, scary ? Initial signs of something more serious ? Start of journey, confirmed swelling in joints ? Onset of Glaucoma ? Realisation that he was in a flare-up ? Settled but then took a new drug (worst drug) ? More drugs and Uveitis worsening
	Inconsistencies with Healthcare Systems	? Frustrated with lack of information ? Frustrations with the NHS ? More drugs and Uveitis worsening ? Missed screening ? Inconsistencies with Healthcare ? Onset of Glaucoma ? Potential frustration with Methotrexate use ? Underwhelmed Healthcare systems (no counselling support) ? Frustration with healthcare system ? Concerned about Leo's immune system and vulnerability
	Experiences of Educational Systems	? Battle with School systems ? Unhappy with school system ? School system not meeting Leo's needs fully ? Good experience of Primary, Headteacher relational and understanding ? Inconsistencies with Schools ? Overwhelm navigating systems, feeling unsupported
	Information Gaps & Medical Communication Deficits	? Frustrated with lack of information ? Underwhelmed Healthcare systems- should be a counsellor attached to pain clinic ? Frustration with healthcare system
Theme 2: Emotional and Psychological Impact on Parents	[redacted]	? Emotional expression ? Experiencing high anxiety ? Emotional exhaustion and tiredness ? Dani's emotional struggles during flare-ups

Theme	Subtheme	Associated Codes
		⍰ Emotional & Mental Health Impact on Parents ⍰ Dani reflecting on the long-term nature of chronic illness ("No magic wand") ⍰ Constant worry / Impact on daily life/planning ⍰ Difficulty experiencing joy ⍰ Emotional distress (parental burden)
	Parental Guilt and Burden of Decision-Making	⍰ Guilt ⍰ Unsure what to do/feels guilty ⍰ Reflecting on Self-Blame ⍰ Guilt over treatment choices ⍰ Potential long-term consequences (infertility, cancer) ⍰ Forced painful interventions ⍰ Loss of parental autonomy / forced compliance ⍰ Limited treatment options / trust in medical advice
	Isolation and Lack of Understanding	⍰ Experiences of Isolation & Lack of Understanding ⍰ Loneliness of parenting a chronically ill child ⍰ Frustration with unsolicited advice/lack of empathy
	Personal Growth and Assertiveness	⍰ Personal growth and understanding mental health ⍰ Personal growth and assertiveness ⍰ Narrative as validation & advocacy ⍰ Empowering other parents to advocate
	Coping and Stress-Management Strategies	⍰ Parents' strategies for managing stress & anxiety ⍰ Using jokes and humour to manage stress ⍰ Humour as coping mechanism (Paul's humour differences) ⍰ Managing stress with humour ⍰ Resilience & practical coping ⍰ Life philosophy: acceptance & personal responsibility
Theme 3: Family Dynamics and Changing Parenting Roles	Balancing Needs of the Leo (ill child) vs Bennie (well sibling)	⍰ Balancing Needs of Leo and Bennie ⍰ Overcompensating when parenting Bennie ⍰ Impact on family functioning

Theme	Subtheme	Associated Codes
	Sibling Relationships and Processing	Impact on family/sibling relationship Sibling relationship impacted by illness Reflecting on early sibling relationship Strong sibling relationship Sibling relationship-teasing Comparative suffering between siblings
	Shifting Parental Identity	Honest about parenting boys Proud in her parenting Looking to the future ("clubbing" with them)
	Parental and Family Protective Instincts	Leo's protective instincts (over mum) Concerns over Leo's protective instincts Parental and family protective instincts Child's reluctance to share to protect parents
	Strain on Marital and Family Relationships	Strain on Marital Relationships Maintaining marital/family cohesion amidst stress
Theme 4: Resilience, Adaptation, and Looking Forward	Leo's Adaptability and Bravery	Leo's adaptability and bravery Leo more aware, needing to adapt Brave but dramatic Fearless Fluctuating coping Child as "hero" Illness shaping child's identity
	Normalising a Different Way of Life	• Normalising a different way of life • Normalising differences in life • Living day-by-day
	Fostering Independence Amidst Vulnerability	Fostering independence despite vulnerability Empowering child & fostering autonomy Instilling resilience in child
	Support Networks & Seeking Help	• Seeking support (CCAA charity) • Good experience connecting with other families • Meet another family with JIA • Reflecting on support network
	Hope, Coping and Resilience	Reflecting on hope from others

Theme	Subtheme	Associated Codes
		Maintaining a positive outlook Perspective-taking & gratitude Fear of treatment failure Uncertainty of progression
	Advocacy	Narrative as validation & advocacy Empowering other parents to advocate Parental pride in Leo and self

Appendix D-

Dani- Categorical-Form analysis

Move 16-	
Simon T Dixon: Yeah. when you think about the future is it a challenge to see a kind of hopeful future? I know you said I do worry a lot about the future but can you find is the times where you think I mean it sounds like in that moment you could see other people and how they've dealt with chronic pain and their conditions is it really hard for you to look hopefully or is the times where you feel like actually, yeah.. **Dani:** Yeah. I mean it makes me sad, like I try not to think about his future too much… **Simon T Dixon:** Yeah. Yeah. **Dani:** because it does, No. **Simon T Dixon:** You don't have to talk about it if you feel…. **Dani:** No, no, no. I think with Leo it's not just his chronic pain, it's his sight. That's what scares me. **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. **Dani:** But a lot of it it now is down to his sight. **Simon T Dixon:** Yeah. Yeah. Yeah. **Dani:** Umm, and also things like.. having a baby, he'd obviously have to come off medication and then puts him at risk again. So, it's just, I just hope, I know everybody hopes that their kid finds somebody that they can, like get on with and marry but I	

just hope that he does find somebody that will understand him and look after him really like, understand that if he doesn't want to come off his drugs to have a baby, then.. that's what it is, or to understand that if he does come off his drugs to.. try for a baby, then he maybe, like, not be able to move because this time around, he couldn't, like put pressure at all on his leg. **Simon T Dixon:** Yeah. **Dani:** So, *it's hard, isn't it? I think things like that, is, yeah. I think that's the one thing that me and Paul probably struggle about speaking about. So, we live for the moment, like we want to take Leo places to see stuff like abroad and…* **Simon T Dixon:** Yeah.. **Dani:** *have a little bit of a bucket list for him, but obviously not a bucket list cuz hopefully he's not going to die (chuckles). It's just list of places to see and…* **Simon T Dixon:** Yeah. Yeah. **Dani:** *without making it obvious why we're doing it*. **Simon T Dixon:** Yeah. Yeah. **Dani:** But yeah, I mean Leo, like h he's, he'd tell you what his future's going to be and I hope that's what it is going to be. **Dani:** He wants to be a barber. He wants to have kids. **Simon T Dixon:** Okay. Yeah. **Dani:** He's going to get married. Well, one minute he's having kids and getting married and then he's living with us forever. So kids and wife are not living with us (chuckles). **Dani/Simon T Dixon:** (laughing)	**Analogy**: "Bucket list" evokes terminal illness; Dani uses it ironically. **Deintensifier**: "Not a bucket list" immediately softens the emotional weight. **Humour**: Chuckle signals discomfort and deflection; helps her manage fear. **Using language as an emotional regulator**: Balances seriousness with lightness; avoids overwhelm. **Enactment**: Dani performs Leo's imagined future using direct speech. **Hopeful projection**: Presents Leo as agentic and optimistic. **Intensifiers**: "Wants," "going to" reinforce certainty and ambition. **Contradiction using humour**: Contradiction between independence and dependence. **Humour**: Laughter diffuses tension; shows affection and realism. **Relational tone**: Shared joke with interviewer builds intimacy. **Boundary-setting**: "Not living with us" signals parental limits with warmth.

Dani: Love him, but I don't want everyone living with me. **Dani/Simon T Dixon:** (laughing) **Dani:** So, but yeah it never phases Leo, so like, this time around the only thing that's phased him is that he's not been able to play football. And then I think it's building his confidence back up to playing football. **Simon T Dixon:** How do you, how do you help him with that confidence? You said a couple of times where, you know, you used the football as an example of, you know when he's not.. at the start the season he's not feeling very confident. How do you help him with his kind of self-esteem and feeling.. is the things that you do or. **Dani:** Yeah, I, *I mean I don't put my kids up on a pedestal, never have done, I think if you put a kid up on a pedestal, they then think the world owes them, so, we're quite, we quite equal with our kids, we'll praise them if they've done well but we don't go over the top with it. Like, they're both good at football but when they come off the pitch it's very much like, "well done mate you played well", not, "my god you were the best player on there", so we don't want to overcompensate for that either.* **Dani:** So um, and obviously you've also got that sibling rivalry there, that would have been there even if Leo was okay or not okay. They both be better than each other at football, so (chuckle). but Leo is a skillful little footballer. **Simon T Dixon:** Mhm. Yeah. **Dani:** And we just say to him, ""Look, mate, at the end of last season, you got most improved because you played your socks off. you played like you play your brother and he does, and I think his friends are quite good with him, like he… but Le is, like *I say, Leo is a bit of an odd one as in… he wouldn't take anything from anybody if*	**Deintensifier**: "Never phases Leo" downplays emotional impact. **Contrast**: Football becomes the only disruption—normalising illness. **Resilience framing**: Leo positioned as emotionally robust. **Analogy**: "Pedestal" metaphor critiques overpraising. **Moral positioning**: Dani frames herself as fair and grounded. **Cultural discourse**: Challenges idealised parenting norms. **Sibling rivalry**: Normalised through humour. **Humour**: Chuckle marks affectionate teasing. **Intensifier**: "Wouldn't think twice" shows impulsive confidence. **Identity construction**: Leo framed as fiery and determined. **Contrast**: Dani prefers placidity but values Leo's assertiveness.

someone said to him you're rubbish at football he wouldn't think twice to fight him, like Leo is, he's got a fire in him that I think's a good thing so I've never knocked that out of him **Simon T Dixon:** Yeah. **Dani:** cos I don't like it that he's hot headed, I'd prefer him to be more placid like Bennie is.. but I think Leo needs that because Leo's had a lot to deal with. **Simon T Dixon:** Mhm. Anything that might help him through **Dani:** Yeah, I think it will cuz I do think, like, like I say,…I don't think he'll let anyone walk all over him **Simon T Dixon:** Mhm. **Dani:** he knows who he is and.. but he just lacks in confidence sometimes.. which with school work he'll say I'm rubbish at that and we're like Le if you try hard that's all you can ask from somebody.	**Moral affirmation**: Leo's self-assurance is celebrated. **Resilience framing**: Dani positions Leo as emotionally strong. **Enactment**: Quoting Leo's self-doubt adds emotional texture. **Deintensifier**: "Just lacks" softens the concern. **Supportive parenting**: "If you try hard..." shows encouragement over perfection.

Move 40-	Notes
oh, yeah, *Leo would never let anyone touch Bennie…* Where I think the other way around I don't think Bennie would ever see him get hurt but he probably wouldn't want to get involved.	**Intensifiers**: "Never," "make a beeline" emphasise protectiveness.

Simon T Dixon: Yeah. **Dani:** Yeah, so *if it's an argument, he wouldn't probably wouldn't get involved. Whereas if Bennie was having an argument, Leo would get involved.* **Simon T Dixon:** Yeah. **Dani:** *Leo would make it beeline to make sure that he sorted it out for his brother.* **Simon T Dixon:** Yeah. Is he like that with his friends as well? **Dani:** . Yeah, *Leo very loyal and protected* when he's mate and… **Simon T Dixon:** Yeah. … **Dani:** very very *protected over me.* **Simon T Dixon:** is he? Okay. **Dani:** Yeah. **Dani:** Oh yeah, they're like, Bennie is, *me and Bennie often play fight and muck about and if he hears us play fighting he's straight in there,* and I'm like, *"Leo I can handle"* (chuckles), *I sometimes say to him, "keep out of it because it's nothing to do with you when"* like other people have, he's been told a few times that *we love it that you're protective, but you have to, but there's a line,* that you don't need to protect anybody, like, sometimes you have to protect yourself, don't you? **Simon T Dixon:** Yeah, where do you think that comes from? **Dani:** I don't know, I'm a bit of a lioness with both of them. I'll, I'm not one of those parents that's like, " my kids." "No, not my Bennie and Leo". I'm very much like, *"them two are absolute little gits".* And I know that they are, but I know that *they're both nice hearted boys* as well. *I wouldn't ever let anyone speak bad of either of them.* And	**Identity construction**: Leo as fierce, loyal sibling. **Moral framing**: Loyalty is valorised. **Enactment**: Recreating dialogue builds narrative intimacy.

obviously, like and I *think as a family we're quite protective of each other, like, Paul would never let anybody badmouth me* or, like the same as I think we're all very protective but I don't know. Leo, *Leo as a little kid's always been a bit of a mommy's boy* but he'd never say, if you said to him Leo, "Are you a mommy's boy or a daddy's boy", he'd say, "I don't know, both of them, I love them both the same". **Simon T Dixon:** Mhm. **Dani:** He's very like, *If he's in a room,* he'll be like, *"Love you, mom." And if Paul is in there, he's like, "I love you, Dad. Love you, too, Dad."* he'll never think. He doesn't like you to think. And I always wind him up, like the other day, *he was at my mum's house and mum said, "I'll bring him back." And he said, "Oh, no. I don't want to go back." So, I joked, I was like, "That's fine. If you want to stay at grandma, no, no, okay, I'll come back."* (chuckling and smiling, speaking with fondness). He's quite easy to say something and *he'll be like, "No, no, I won't do that then."* But yeah, now he's always, he's actually, when they were little, when he was obviously a bit bigger that he could like move and come to me, *he used to try and push Bennie off of me quite a lot* **Simon T Dixon:** Mhm. Okay. **Dani:** yeah, *he was more jealous of Bennie, he didn't like Bennie cuddling me that*. But Bennie winds him up now. **Simon T Dixon:** Okay. **Dani:** He'll come and cuddle me and he'll say, *"she was my mom first".* (both laughing) **Simon T Dixon:** Does he get that as a joke, like the humour in that because it sounds like he's Yeah. **Dani:** Yeah. Yeah. But *he'll still try and fight Bennie off me*. But yeah, but like, they do,	**Enactment**: Quoting Leo's speech adds immediacy. **Emotional tone**: Warm, affirming; shows family closeness. **Deintensifier**: "Never picks sides" softens potential conflict. **Humour**: Playful teasing; laughter signals affection. **Enactment**: Recreating dialogue builds narrative intimacy. **Emotional modulation**: Lightens tone after serious reflection. **Sibling rivalry**: Physical enactment of emotional competition. **Humour**: Delivered with fondness, not criticism. **Enactment**: Quoting Bennie's teasing adds realism. **Humour**: Shared laughter marks emotional safety. **Narrative rhythm**: Moves from tension to playfulness.

they do. *He's got a good little sense of humour, Leo has*. Yeah, um, like I say, he's um, he's probably, *he's a lot more with his emot(ions)* and I don't know *if that's because what's happened to him has made him* like that, but *Leo is very an emotional kid*. If, like, Bennie still laughs now, *but when we watched the film when they were little and a frog died,* Leo literally sobbed the whole way through the film and... they take the mickey out of him now (chuckling) and say, " *You remember when we watched that film with the Frog"*. He is quite an emotional kid, but I like that about Leo because actually, *like I say to Bennie, just because you don't have the emotion like he does, that's not a bad thing*.	**Affirmation**: Dani values Leo's humour as part of his resilience. **Identity framing**: Leo's emotional expressiveness is embraced. **Intensifier**: "Literally" heightens emotional impact. **Emotional vulnerability**: Leo's sensitivity foregrounded. **Retrospective humour**: Teasing as emotional processing. **Shared reference**: "The Frog" becomes symbolic shorthand. **Family bonding**: Humour used to navigate and normalise emotion. **Moral positioning**: Validates emotional diversity. **Parenting philosophy**: Acceptance of difference.

Appendix E-

Kelly- Working Transcript- StEP's1,2, 3 and 6 of NOI

Move	Transcript	Key: - Fabula within move identified as Fab:..... - Holistic Content- Annotated in green - Holistic Form- Annotated in yellow - Identity Positions- Annotated in blue
1.	**Simon T Dixon: Yeah. So, okay, So, let me just ask you. (cough) So, if you could share your story that when you, kind of first realised that your child was experienced chronic pain and what that was like for you and your family, just kind of tell me your story, I guess.** **Kelly:** Okay. yeah, that's fine. So, I've got an older son, So um, George is 12 nearly 13 and Neil is um 9 nearly 10, um So George came, bless him, came first obviously. He didn't walk till he was um, much older. So he was 21 months when he walked, normally it's sort of, well age and stage, I know	Fab: Harry born Fab: Harry delayed walking Fab: Oliver born

	it varies but it's generally one, isn't it? *So he was a lot older when he walked,* um, So he bum shuffled everywhere, um, So when Neil came along um, I just, quite, he um, also bum shuffled everywhere, *So I kind of just thought actually these are similar, er this is how it works*. However, no one else in my family at the time um, had the same experience, because sometimes it goes through doesn't it? families as such. *at the time, and it didn't seem to affect him in any other way, um.*	Fab: Oliver also bum shuffled Normalising bum shuffling- comparing to brother IP: Observant mother
2	**Kelly:** Um, George when Neil was a baby um, George had um, he, his thumb. we were out shopping in Matalan and his thumb locked, just did a complete lock um and I really struggled to kind of move it to get it out of a lock, um, So I thought that's a bit strange, So we went to the, and then over time it just continued to happen, So we went to the GP, got referred to rheumatology, and *she said, "oh, he's hyper mobile*, So he's over flexible," um and checked all of his joints and things and that was it really, it was kind of just that one off, um, he's got Hypermobility, um, and he'll just be over flexible. *So, I just thought that's okay.*	Fab: Thumb lock in Matalan Fab: GP referral Fab: Rheumatology visit/Diagnosis given. IP: Trusting parent; early system-user Early experience, search for answers
3.	And then when Neil um, just really struggled to walk, So he was really late, So he didn't walk till he was two and a half, very much old er um, and which is.. all sort *of impacts*, you probably, in the sense of he bum shuffled, So whenever we went anywhere we could hardly get him out of the buggy, because obviously there's not many places that you can go to that you can let a child just bum shuffle. **Simon T Dixon:** Okay. **Kelly:** So, *he was in the buggy*, obviously, um *for periods of time or I carried him everywhere*. So I, bless him, *I probably carried him till he was about five (chuckled),* I mean, *and everyone would say to me, "really Kelly, should you still be carrying him now..", you know, " at this age" and I'm like, "what can I do". And then the whole buggy thing was an issue, with regards to the buggy only goes up to the three,* doesn't it*? It's kind of like what do I do next? Do I, kind of, get the next buggy up or, um. And it's kind of that sort of conversation of , if we're going on short journeys shall I just pick him up and carry him, and um.*	Fab: Oliver struggles to walk Fab: Reliance on buggy. Fab: Kelly carries Oliver until age 5 Questing self, holding on to 'normal IP: Protective mother; resourceful planner
4.	So we went under a pediatrician at about 18 months I think, So we did go under a pediatrician and sort of said, you know, I feel like there is something probably more here, **Simon T Dixon:** Okay. **Kelly:** *he's over flexible, So he didn't sit very much late, So fine motor, gross motor, really late.*	Fab: Pediatric referral Fab: Bowel issues start at 6 months

	Simon T Dixon: Okay. **Kelly:** But then not only that, he had bowel issues from a baby, So, as soon as he hit six months, he had bowel issues from a baby, was on medication, and none of our family had any sort of constipation or anything in that sense. So, we kind of thought, *this seems to be something else that seems to added into the cycle of that, um and as he got older, we had wetting issues, So he would wet, So obviously then, that, the two were sort of connected* um, together. So we went under, um *the hospital to see how, what could we do, and I was sort of saying to the pediatrician I think there is something more here*	Fab: Wetting issues linked IP: Concerned parent; emerging advocate Added complications and symptoms. Unknown.
5.	**Simon T Dixon:** Okay. **Kelly:** they did do a um they sort of thought cerebral palsy, **Simon T Dixon:** Okay. **Kelly:** to start off with. So we had a MRI scan and he had blood tests, *but when you've got a little one that's only 18 months and you're having to do blood tests (chuckles),…* **Simon T Dixon:** Yes. Yeah. **Kelly:** it's quite horrific, it is, *even though I got the numbing cream*, er. *However, when they're little, it's a bit easier to when they get older (chuckling)…* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *because they kind of don't know what's going to happen.* However*, I would say it probably affected him in his trust with professionals,* because he sort of, *saw a hospital as a place where pain happens*, **Simon T Dixon:** associates the two. Yeah. **Kelly:** yeah, not anything good happens. So we did have to have the blood test done, er, and that is just hard, isn't it? because you're, you're holding somebody's, obviously *two other members of staff there* and you're going through that and it's just horrific, isn't it? *To be so little and to have that sort of feeling really, um. But thankfully it came back and that wasn't the case,* **Simon T Dixon:** Okay. **Kelly:** *but, we were still like what is it, you know we're still on this road* **Simon T Dixon:** Okay.	Fab: Pediatrician suspected (Cerebral Palsy) Fab: MRI and blood tests, Fab: Neil associates hospital with pain Fab: CP ruled out IP: Vulnerable parent; empathetic observer

6.	**Kelly:** um. The paediatrician, I have to say was not very empathetic, **Simon T Dixon:** Really? Okay. **Kelly:** at all, um, thank goodness *he's now retired,* which I think that's the most positive, um that's happened (chuckling), um , we did not, um, he he, just, *he just said on numerous occasion, I've got worse children than him basically, you know, yeah, um, that you're neurotic,* you know, you are, you know in a sense, you know, um, and the, I'm just *with regards to appointments, you know, So that constant chasing of an appointment to see a paediatrician,* um, *if I didn't constantly chase it just wouldn't happen and I really fear for other children who are going through a similar pain issue* **Simon T Dixon:** Yeah. **Kelly:** *that if their parents haven't got the knowledge of a system or the self-esteem and confidence how that, you know, how that affects that child, that must be really difficult,* um. So it was, *the frustration was huge*, really. My husband did come, um to the appointment, um, but the last one I saw him at, um I just couldn't even engage with him, I just, he was just, you know, *none of the Carl Rogers, none of the old empathy and the genuine* (chuckling, animated), none of that malarkey going on at all,	Fab: Ongoing appointments (Chaos- Inconsistent and dismissive professions) Fab: Pediatrician dismisses concerns Hol-Cont- Systemic and Professional Failure Fab: Kelly chased appointments constantly IP: Frustrated advocate; professional insider Hol-Cont- Advocacy and leadership Using her own 'specialised' professional knowledge, but concerned for others without this
7.	So um, and then we recently saw another paediatrician, So he retired and then we obviously, we had COVID and… **Simon T Dixon:** Yeah. Yeah. **Kelly:** then nothing was happening, you, know, and then they had no paediatricians um, or they had some but had no waiting list, So we saw one last year, we saw one and Neil um came along and he's like eight at the time. So we walk into the appointment *and she's like, you know what you here for today, sort of thing, talks to me and I'm like, "Talk to him he's the one we're here for he's the one who's struggling". (Animated. High pitched)* **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** *Just the frustration of that interaction even with the young person*, you know, *as he's got older he's fully aware of what he's going through,* **Simon T Dixon:** Yeah. … **Kelly:** he's very… *he knows* his um, *his strengths, he knows what he struggles with*, um *but it's just that constant look at you to say what's sort of going on* really, um So that was last February and then um, we went private in the end because um, we didn't get anywhere really, to be honest.	Fab: Paediatrician retires Fab: COVID delays Fab: New paediatrician not child focussed, talked to Kelly not Neil

	There was just a back and forward, I'd asked to be referred to rheumatology in (retacted), that's where you would be referred to*. however, she was very much like, "oh I've tried to refer somebody today, but they wouldn't take that, So I don't think they'll take yours." And I'm like, I don't mind the other person, it was about me, it's not child focused, you know, it's not child focused.* **Simon T Dixon:** Yeah. **Kelly:** *There is no child focus around this,* um, *So it was very much she just didn't understand*. She was walking um, and I said to her, *"you know he really walks in, he turns his foot over and she's just like,* you know, *just like,* "what's the matter?" *just looking at him like, "what's the matter" and you're like, I, "surely you can see" you know (laughing) um. So I was leading, and I have, So all this time, I've led his care really, So I've been that person to coordinate* **Simon T Dixon:** Yeah **Kelly***: care constantly* um*, without being the expert*, which is quite a worry*, So Google is an expert really (chuckling) So you're googling things which isn't appropriate at all um, and can be quite worrying as well,* um but I'm leading *and I'm saying he, we need to do this test and we need to do this test and we need to do this test. That shouldn't be the case, you know, there should be somebody, well the pediatrician should coordinate that care um, but I'm asking the questions to them, you know, um, which is a worry and it it shouldn't be something that is um, that is done all the time.*	(End of Chaos/Beginning of Quest- Going private) Fab: Referral to rheumatology blocked Hol-Cont- Advocacy and leadership Fab: Kelly self-coordinates care IP: Decisive advocate; child-centred parent
8.	So we went privately last year to Leicester and he's had a diagnosis of Ehlos Danos syndrome. **Simon T Dixon:** Yeah. **Kelly:** So a form of hypermobility, um, So he, um, So yeah, So basically, God love him, he has all of the flexible side of things, So his whole body is, So he's a little scarecrow, God love him, in that sense, um. But then also he has his bowel, So his bowel, um, is over.. So overflex, but then he's about a, um no, no sorry, his bladder is over flexible, his bowel is under flexible. So it's not stretchy enough, basically. But, then he also has um, really thin skin, So he got bruising, **Simon T Dixon:** Okay. Yeah. **Kelly:** *So he gets bruised quite easily. Um, sprains and that sort of things he gets um quite easily um as well, So there's quite a, but nobody saw him as a whole per.., no one saw him as a whole issue really in that sort of sense. Everybody kind of, um, was just picking their points,* you know, part, *part of him, but not seeing as the whole, So and the interaction we had with the pediatrician when you pay privately, it's very different (chuckling)*	Fab: Private consult Fab: Comprehensive evaluation Fab: Ehlers Danos symptoms listed (End of Chaos/Beginning of Quest- Diagnosis given)

	Simon T Dixon: Yeah.	Fab: Diagnosis delivered Hol-Cont- Systemic and Professional Failure Fab: No holistic assessment before, private is more child-focussed. IP: Hopeful mother; knowledgeable consumer
9.	**Kelly:**. So as you can imagine (high pitch, chuckle) um, they were lovely to Neil, they were chatting with him getting to know him, really interested in what I was saying, *took the whole* sort of um whole *eight year, nine years that we've had through and um So it was a very different um, So it was a very different experience really.* **Simon T Dixon:** And was that almost instantly in the first appointment that you had? **Kelly:** *Yeah. Yeah. Yeah. Which is shocking, isn't it?* **Simon T Dixon:** Yeah. Yeah. **Kelly:** Yeah. So, particularly around, he's been in a under a *Paediatrician since he was 18 months and then we've got nowhere until he's like, nine. So, yeah. And he was like, "No, completely agree with you",* you know, did a few sort of tests and things and he said, you know that's um and that's what it is. And then in the sense of, you know, you just feel, thank god, thank god we've got a diagnosis, which is terrible isn't it? But i always knew there was something **Simon T Dixon:** Yeah. Yeah. **Kelly:** But um you felt actually just listened to, *I think in the sense that actually somebody did listen and I'm not crazy.* I think it, you start to think am I crazy? You know, you start to think yourself, I think I might be cra..(chuckling) I think I might be thinking something that's not here **Simon T Dixon:** Yeah **Kelly:** and *having to really check yourself out with* that as well, and do you think that that was that, as well.	Fab: First private appointment Fab: Tests relief-based plot. observations were accurate Fab: Confirmation and relief IP: Validated advocate; relieved mother Holi-Cont- Emotional and psychological toll
10.	**Simon T Dixon:** And do you think that, maybe, you mentioned it previously was maybe that first pediatrician you saw, probably kind of, played into that a little bit, what	

	you're worried about and then when you're leading it can you just see their gait? Can you see the way they walk? **Kelly:** Yeah, yeah. **Simon T Dixon:** So, it feels that you described something that felt a bit lonely, like you're on your own almost with it? **Kelly:** *Yeah. Yeah. Yeah. Yeah. Definitely. Yeah.* That they're just not being heard is that sort of side of things, isn't it really? Yeah. So that's that tricky um. **Simon T Dixon:** Okay. **Kelly:** And I'm, um, *So my role, like professionally is to be somebody who's very supportive.* So I really struggle… Then, when I come across a professional who's not giving me what I feel I should be having or what that my child should be having. **Simon T Dixon:** Yeah. Yeah. **Kelly:** When them interactions don't happen in that same way, I find that quite difficult because I think where are your skills here? You know, "Where are your ethics? Where are your values and why are they not transferring onto my son?" You know, in that sense it's quite yeah **Simon T Dixon:** Absolutely. Absolutely. **Kelly:** So that's tricky… however there's been some professionals that you know, I feel have listened over time but er.. quite vast, not, not, not So many so…	Fab: Recall of isolation Holi-Cont- Emotional and psychological toll Fab: Link to professional role Fab: Recall poor interactions Fab: Contrast with rare good professionals IP: Reflective professional; empathetic parent
11.	**Simon T Dixon:** Yeah, that's just, So, So is that now, kind of where you are at now? **Kelly:** So yeah, that's where we're at now. So yeah, that him, he has the diagnosis. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So now, we're, So it's a constantly kind of where we're at now? So obviously, he's year four. *So now we're prepped for secondary school, um So it's kind of, a like, where's the school that's going to meet his needs? in that sense, um, So that's, and that's a tricky* ***Simon T Dixon:*** Yeah. **Kelly:** scenario, because *we've got an older child in a school,* um and it's kind of like *will they go to the same school or actually is another school better for him to go to and actually then how will that affect them as siblings if we do choose to move him. So the luckiness with Neil is that, um, academically he's doing really well so…* **Simon T Dixon:** Okay. **Kelly:** *which is great, So he's got a strength there. The sport side of things*, God love him, he really struggles with… **Simon T Dixon:** Yeah, of course. Yeah. Yeah. **Kelly:** *which is understandable,* isn't it? So it's kind of like do we send him to the grammar or do we look to go to the grammar, which his other brother doesn't go to, or um.. do	Fab: Neil in Year 4 Fab: Prep/considering secondary school options. Fab: Neil strong academically

	we not and put them together, you know, in that sense because you've got a sibling then potential, one's gone because they're academic, one is gone potentially because we didn't think that, So it, and, and that to me in an psychology side of things, I feel uncomfortable with **Simon T Dixon:** Yeah. Yeah. **Kelly:** *the constant thoughts of.. around yeah am I doing the right thing*? I think all the time, is this, have I made the right um choice there? Or actually, it's it's yeah yeah, it's tricky, isn't it? *really to think about his own well-being, for him, yeah,* ***Simon T Dixon:*** *Yeah. Does that play out in other areas as well?* ***Kelly:*** *but if I was child focused I'd just think of him and I think yes the grammar is a good idea, however we have got another sibling and that would be hard for them, So it's yeah,* that's where I'm kind of at, yeah.	Fab: Kelly doubting her self and decisions. IP: Thoughtful planner; child-focused parent
12.	**Simon T Dixon:** If you think of the kind of impact on family, I suppose. Are you constantly thinking of how that impacts and your decisions? Yeah. **Kelly:** Yeah, yeah. *So all the time,* So anything really, *So the weekends we'd be very mindful that we do an activity potentially in the morning and then Neil could have* time to come back and rest, um for the afternoon, where you see George's got loads of energy, So, *it's very different,* So you see*, he's got a different form of hyperbility, So he's got all the energy in the world.* **Simon T Dixon:** Yeah. Yes. **Kelly:** *So that is a challenge because of that*, you know, and he's very good. So he knows, you know, and he understands. Um, obviously he comes with that alSo, for you know, frustration. We went away to Billund, we did um, Legoland last year. **Simon T Dixon:** Yeah, okay, cool. **Kelly:** Um and um, he ended in a wheel, *we had to put him in a wheelchair at the end of the day,*	Fab: Weekend activity pacing Fab: Differences in sibling energy levels IP: Adaptive caregiver; sibling-aware parent
13.	*because, So we do a scaling, So you talk about the coping strategies.* **Simon T Dixon:** Yeah. **Kelly:** So, *Neil has a scale of 1 to, 0 to 10 in a day and then* um, *he will, he'll tell me if, w here he's going*. So recently we went to a walk from, from our house, um to um… just to the forest, which isn't that far, but he said to me "I'm on a 3 now", So, *but by the time we were heading home, which is like we need to rest, need to sit down kind of thing. (animated and nodding head)* **Simon T Dixon:** Yeah. Yeah. **Kelly:** But then when we were in Billund, *he was like,* "I'm on a minus, I'm on a minus one*". And it's like, "Oh my dear god",* um and that was probably the worst I'd ever seen him really. So, he did get in a wheelchair and him and I George thought it was hilarious because he'd not been in one before (chuckling). **Simon T Dixon:** Yeah. Yeah.	Fab: Wheelchair at Legoland trip (Quest- Learning coping mechanisms) Fab: Neil reports pain levels by scaling

	Kelly: *So there was quite a funness around it*. However, I don't think it would be all the time. And it's, it's a funny effect, isn't it? *Because my mom and dad were there and my sister, um and it was absolutely fine. But I think they're mindful of what other people think* **Simon T Dixon:** Yeah. **Kelly:** *when he's in a wheelchair as well,* and um, the thought, So when he was little and he couldn't walk, my mother-in-law took him out and somebody made a comment like, "Why has he not got any shoes on?" And *she didn't say, "cuz he just can't walk, she didn't say anything because she.. just didn't know what to say* **Simon T Dixon:** Yes. **Kelly***: in that sort of sense, So it affects everybody else*, doesn't it? And it's, having that understand, everyone else to have the understanding, um.. as well, which not everyone does because they don't have, they don't understand where he is	Fab: family adapts accordingly. Fab**:** Family conscious of perception Fab: Kelly's Mother-in-law was not sure how to talk about Neil's conditions. Holi-Cont- The invisibility and social suffering of illness IP: Responsive parent; pain-aware advocate
14.	, I think, you know, like he'll get invited to parties, um, So like rock climbing is not obviously his thing, God love him **Simon T Dixon:** Yeah. **Kelly:** So I kind of *have to say, but he loves the food (chuckles), he loves the food and he loves a party bag, um, So I kind of have to say, "Oh, do you mind if he has, do you know what I mean, he comes for the food or come for the party bag", some people are cool with that, some people are, are like, "No that's obviously took up a space, or something, because you know, you're not paid for the",* you know, which is tricky isn't it and he's watching then everyone else and he's not taking part… *So for him self-esteem and wise that's not nice, but it's kind of like,* does he not go at all or does he go? So *it's them, even them choices of do go midway or do we not go midway?* Um, which is a hard yeah a hard thing to do. Um, yeah, So other people's understandings.	Fab: Neil invited but can't participate fully; Fab: Party adaptations Fab: Social tension. IP: Social gatekeeper; esteem-sensitive parent
15.	**Simon T Dixon:** Yeah. Yeah. I think that's always the way, isn't it? And in terms of the pain element to kind of conditions. **Kelly:** Mhm. Yeah. **Simon T Dixon:** Um, can you talk a bit more about that? Can you talk about how they, how they experience that and in in what ways and when that might happen? **Kelly:** Yeah, So mostly it'll be, So um it'll be fine in the morning, So he's all good to get up to school and goes to school, *but then after school he's shattered like he is*	Fab: Pain-free mornings, fatigue after school

	absolutely done. So, So he will, we don't do any after school activities. So, he has to get picked up at three at quarter past and **Simon T Dixon:** Okay. **Kelly:** we're lucky, me and my husband can work that between us. Not everybody else would be, which would be really hard if he had to go to an after school club… **Simon T Dixon:** Yeah. Sure. **Kelly:** *cos, because that he couldn't do that. So literally he comes home and he's done really. So, it will be a, I'm on the sofa, I'll read a book, you know, he'll play Roblox or, …* **Simon T Dixon:** Yeah. Yeah. **Kelly:** you know, watches YouTube or whatever, um, but he loves sort of reading um, So *he can do that and then that's it really, but he might come home from school and not, because he's had to concentrate and he's very good in that period of time that he will then come home and he'll be shattered,* like, sort of thing.	Fab: No after-school clubs possible Fab: Neil rests at home; reads or plays Roblox. IP: Routine-builder; energy-sensitive parent
16.	So when in school, they had, I think they were doing balance bikes and he had a whole morning of balance bikes and, sort of, nobody said and he came home and he was like not happy, very dysregulated (loud chuckle), very dysregulated *and it was like, "what is going on here", like "what's happened" and*, um, he said he'd done it all morning *and nobody had thought that's probably too much for him.* So I kind of had to go in and say, *"Oh can he have a break in between?" Or, actually, "two hours is far too much". Um,* the same with PE, So PE school, he's now doing it in a whole morning for two hours, **Simon T Dixon:** Yeah. **Kelly:** which is quite a lot for him, um, but no one said that, you know, and it's kind of that sort of, *So you have to kind of say, "Well actually that probably a bit too much".* You know, he's learning the ukulele at the minute and it's hurting his fingers, um really sore because his fingers are really flexible, So, *I just spoke to them yesterday that could he pad that time out.* So you're constantly kind of having to say, which I find quite frustrating that they're not thinking actually that might be really difficult for them, for him indivi, So that person that child focused time, um is more tricky.	Fab: Overexertion from balance bikes Fab: PE and music cause pain; Using professional knowledge and analyses the school's failure to communicate Fab: Ukulele causes finger pain Fab: Kelly requests adjustments.

		IP: Educational advocate; pain-aware parent
17.	So he, So he'll exp. Handwriting, So *any handwriting activities, he's experienced long pain*, um, *so we can't write for long which we're in year four,* so we're okay, but what about when we get older, So it's always that older future thought of exams and all them things, So we've, I've asked now and he's doing touch typing at school **Simon T Dixon:** Yeah. **Kelly***: So the hope that he will then touch type then when he gets older, however schools are very focused on handwriting,* they are obsessed with handwriting (chuckling). Um, and I don't know why because we don't write that much anymore, um, So we touch, we type everything but that's the curriculum that's incorrect, do you know what I mean? *And we're not adapting to children with send sort of needs* really, um, So even with that I'm having to lead, So every aspect, so health and education you're always constantly leading with the care. So, you know, *he's coming home and telling me, but he will not say, so he will not tell them because he doesn't like to.* **Simon T Dixon:** Yeah, Yeah. **Kelly:** So he'll say to me, so then I have to go in and then sort of say so. Anything sports day he really doesn't like sports day, as you can imagine finds that really difficult and he's separated from peers, so that means he's different to his peers. *Assembly, he has to sit on a chair, so because he can't sit on the floor he finds it really uncomfortable to sit with cross legs, his body, he's always moving his body, so his pain in his body.* *00:25:00* **Kelly:** God love him. *He just can't sit still really.* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *He's constantly fidgeting just to get a comfier spot.* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *So if we sit in the cinema, he won't just sit in the cinema. God, he's moving around because he just can't get comfortable in his own.. body. And then he's on medication So for his bladder* and… his bowel.	Fab: Pain during handwriting; Fab: school agrees to touch typing (Quest- Accepting and adapting to ED) Hol-Cont- Advocacy and leadership Fab: Avoids telling teachers pain Fab: Neil's differences and challenges in everyday activities IP: Forward-thinking parent; system challenger More symptom and concern
18.	**Kelly:** So we were under the doctor's So from six months really.. and *that time.. didn't get probably till last year did we actually get that regulated* which is a large amount of time So we tried lots of different medications, Umm, went through the hospital, went through school nurse, we went	Fab: GP switches meds;

	through specialist school nurse, *So you're telling your story every single time to a new person doing new things and…* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *then with this bladder and bowel we had to do all*, of I don't know, *but if you go into the continents team, you have to do three days of, Umm, how much they've weighed, how much they pooed, what it looked like. You got to measure everything.* So, you were doing that every six weeks. I mean, that is intrusive for him and his body and… (Voice pitch became higher and inclinated. **Simon T Dixon:** Absolutely. Yeah. **Kelly:** you know, that sort of thing. *then you got to get him take the medication. You know, now the GP,…* **Simon T Dixon:** Yeah. **Kelly:** *you know, he's been fine*. The GP wanted us to move away from a liquid oxybutynin to a tablet because they're much cheaper obviously, Umm, So we have moved and he's been fine. *That's the first tablet he swallowed, he's only little but the expectation is that he'll swallow it and it'll be fine, but that's not always the case is it? We've managed to do it. So he takes that medication but they brought in a new medication.* I don't know if you know, *Senicott which is for his bowel.* Umm, as we went through the change, Umm, *within Britain they couldn't get any,* So locally we couldn't get any in Pharmacies So they prescribed us another medication So a different one. However, God love him *he absolutely exploded I mean it was just the most horrific. (Tone became inclinated and spoke quicker/with purpose*) You know, and to deal with that it is, just So you *imagine the pain in your stomach and…* ***Simon T Dixon:*** *Yes. Yeah.* **Kelly:** *then having to deal with that.* He was at school. God love him as well. *And that's just uncomfortable with everybody else,…* So, He does get pains in his stomach, Umm, and that we're not sure if that's from the medication. Yeah. Or that's him being painful, Umm, as well. So anything that over exerts his joints, he will get pain with. we can't walk very far. So, he will be in pain for…	(Searching for the right medication) Fab: severe bowel reaction. IP: Medical manager; empathetic carer Holi-Cont- Emotional and psychological toll
19.	**Kelly:** cont…*if we went on a walk, he would be in pain he'll be crouching and holding himself*. So, *he often Umm, scooters*. So, he has a scooter and we have a trike. So, we bought a trike for him, Christmas before. So, the three… **Simon T Dixon:** Yeah. Yeah. **Kelly:** because his balance, God love him. *he hasn't got a good core.* So, his core, God love him, is really difficult. So, *you can't hold on a bike. And as you're probably aware, with children with SEND, everything's expensive. So, you can't just buy a bike.* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *You have to buy a trike and then you're spending a fortune to buy a trike to have a bike*. in a sense of the government side of things. *it's just not fair for parents with regards to that side of things, the costings*. So, the pain is just always there. I would say Simon if you asked him *he's not aware of the pain* I don't think and… **Simon T Dixon:** Okay. Yeah.	Fab: Trike purchased due to poor core strength. Acceptance and integrating adaptive activities, trike etc IP: Resourceful parent; financial realist

20.	**Kelly:** He, umm, so I said I was going to talk to you today *and he said, "why are you talking to him about pain, what are you talking to him for"* and I said "About" right okay because he's lived with it in a sense I quite like it because he's none the wiser. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So *he doesn't know…what a body without Ehlers-Danlos would have and as you spoke earlier on.* I've got rheumatoid arthritis. **Simon T Dixon:** Okay. Yeah. **Kelly:** So, I got rheumatoid arthritis when I was 27, so I knew my body before. **Simon T Dixon:** Yeah. **Kelly:** *which was lovely,* and I know my body now, *which isn't as nice.* So, I've got a difference of pain. **Simon T Dixon:** Yeah. Yeah. **Kelly:** However, *he has never known,* which I kind of feel that's quite nice in that sort of sense that he doesn't know any different. and that he's living in a world that's his world that Yeah. **Kelly:** He's none the wiser really. But yeah that's more with regards to observation I think .	Fab: Neil unaware of pain-free baseline; Fab:Kelly compares with her own experience. IP: Reflective mother; pain-normaliser
21.	**Simon T Dixon:** What do you think his perception of pain is? How do you know what he kind of said, " I don't know if he knows that he's in pain." So, tell me a bit more. How do you know that he's in pain then? 00:30:00 **Kelly:** Yeah..It's more through observation I would say, but, so *if we walk he'll say I'm tired. He will say sometimes his joints are pain. they he wouldn't say pain. He'll say they hurt.* ***Simon T Dixon:*** *Yeah. Yeah.* **Kelly:** We have had So, his joints do click out. So they do pop out of place and that does hurt. **Simon T Dixon:** Yeah. **Kelly:** So, at school that has happened in his hip and his knee and his shoulder *and actually the trampoline often does that* which is not a good sort of thing because we have to be very careful on the trampoline. **Kelly:** Umm, and then swimming sort of helps that. So, *he will set, but he just pops it back into place.* It is very bizarre, but a joint can pop out *and he'll just move it around and he'll click it back into place. and then off he trots. He's very resilient,* thankfully. **Kelly:** *So he does bounce back.* So if he falls over and he cries, we know something's really happened and there's been a big issue because if not he'll fall over and he'll just get back up again. Yeah. **Simon T Dixon:** Yeah. you mentioned when he plays a recorder and his hands start to hurt I guess it's that at his age as well there's limit it's limited isn't it to how we kind of communicate pain and how that develops over time and actually pain will be different for different people in the way that you describe it. **Kelly:** Yeah. Yeah.	Fab: Neil uses a 0–10 scale; physio introduced it; Fab: Kelly monitors his responses. IP: Empowering parent; pain educator Acceptance and integrating adaptive activities, avoid trampoline, swimming helps with pain etc))

	Simon T Dixon: So yeah, I think you can definitely observe somebody and as a mother don't you off is that something that you were advised to do or… **Kelly:** And I'll say to him, *'Would you like some Neurofen, would you like some Calpol*? So he's very aware of, Yes, I do. Yes, I don't." So *at the age of nine, he's unbelievable with regards to his understanding of what will make him feel better and what won't make him feel better.* And that scaling he's been using for a long time. *So he'll use that scaling* Yeah,… **Simon T Dixon:** Was that something you were advised to do, or did you kind of use that as a… **Kelly:** Yeah, somebody said for us to do that. *I think it was the physio,* the physio said to us and they've done it in the past with other young people with regards to visualize, you know, I've got so many balls or in a box or whatever. So, we've been using that probably for about maybe four years. **Simon T Dixon:** Yeah. **Kelly:** *And So he's very aware of that and he'll regular and if you ask him* he'll tell you at any point of what his scaling is which I think actually adults struggle with at times and…	
22.	**Simon T Dixon:** Yes. Yeah. **Kelly:** *and that understanding that he needs to rest and that will then make him feel better. Um, so after swimming he loves, so he is the swimming pool* if he could live in a swimming pool would be all good, because actually he just feel nothing. *So when he's swimming he is a completely different child.* **Simon T Dixon:** Yeah. **Kelly:** *He is completely painfree. He doesn't feel anything on his joints*. So we will regularly, we'll like weekly go swimming just to make sure that he has that sort of opportunity to be somewhere that he's completely free. **Kelly:** Yeah. I mean, it's just unbelievable to feel that he can go somewhere that can make him feel so much better. **Simon T Dixon:** Yeah. Yeah. What other kind of things do you do to cope and what other strategies do you have? I mean swimming sounds like that's something that he enjoys, but also he probably feels quite normal compared to everybody else in there and… **Kelly:** Yeah, he does. Yeah. Yeah. Which is quite nice,… isn't it? with him cycling So the trike side of things, *anything low impact* really and that's it really, bless him because *other things are more tricky like hand and eye coordination* is really tricky so… **Simon T Dixon:** Yeah. Yeah. **Kelly:** *we try tennis* God love him *but bless him it wasn't his thing. So we try things*, but then if *he wants to do the keyboard at school, So actually we're really going to go down that,* view and see if that's something that he feels comfortable with. **Simon T Dixon:** Yeah.	Fab: Weekly swimming; pain-free movement; Fab: Trike and keyboard explored. IP: Optimistic planner; activity facilitator
23.	**Kelly:** So loads of things are let's try it. If it doesn't work, then we know that's not going to be the case. he does cubs, So he's in the Scouts, so he does cubs. and there's another young person there who actually has it as well. So that kind	Fab: Neil attends Cubs;

	of makes it easier, but he's very reluctant to do the walking. So they walk from, *they might walk from* Middlebrook to Trove and then back again. I mean that's not for him. I mean he's a goner. (laughing, sarcastic tone) **Simon T Dixon:** Yeah, of course. **Kelly:** He's a goner… and Beavers used to be a Friday night. So he was ready really sporadic on when he went… **Simon T Dixon:** Yeah. **Kelly:** *because Friday.. he's done*. We're now Cubs is on a Monday. Great. *So beginning of the week we're much more better after a long weekend* and then he can easily kind of potentially do that but he only does the cubs and… 00:35:00 **Kelly:** then yeah there is nothing else everything else falls on the weekend to do anything. **Simon T Dixon:** Yeah. …	Fab: Avoids hikes; Fab: Weekend activities paced. IP: Strategic planner; inclusive parent
24.	**Simon T Dixon:** So, does that kind of mean that when you're planning things and you have to have that in mind quite a lot when's going to be the best thing to do to do things? **Kelly:** Yeah all the time. **Simon T Dixon:** On holiday and… things like that. Quite aware of what you're planning, when you're going to do stuff. **Kelly:** So *we're going to be going away…* which we went to Bland last year, but we hadn't done.. been on a holiday abroad. So we're going to Spain and I'm already thinking are we bringing a buggy or we're not bringing a buggy? I'm already in the two minds of do I hire one and… **Simon T Dixon:** Yes. Yeah. **Kelly:** get one of the big buggies or is it going to be all right or get the scooter *or so I'm already in my head thinking on our days out we'll have to do a bit of a day then we're going to have to have a rest.* We have to, so bless him. Everyone then has to It's hard,…isn't it? *Because it affects everybody. So it will affect my mom and dad are* coming with us. My sister's coming with us. So it's kind of everyone has to be like we have to Yeah. **Simon T Dixon:** Yeah. How do you cope with that? **Kelly:** Where if you had a child who didn't have it, there's no thinking, is there? There's just off we go and we're just going to do So it is Yeah. **Simon T Dixon:** How do you cope with that kind of emotionally? Because you kind of talk about it and it has an impact on everybody. Is that quite hard for you? And you can answer that as broadly or you don't need to because it's kind of merging into something which you might not want to go. So yeah. **Kelly:** No, that's absolutely fine. *Yeah. my mom and dad and my sister are really understanding.* So, to be honest, *it's quite easy. If they weren't, I think it'd be much more tricky as well.* **Simon T Dixon:** Okay. Yeah. Yeah. **Kelly:** *So they're happy to have a little break and have a cup of tea and have some food (chuckle)*, but I think it might be more tricky if we were going away with friends	Fab: Spain trip planned; Fab: Buggy vs scooter; Holi-Cont- The effect of illness on family & social life

	maybe who've got similar age children, because actually they probably would want to do more things,... **Simon T Dixon:** Yeah. Yeah. **Kelly:** ..and he probably couldn't do more things. So *when we've been to Butland's before, we'd have a morning out and then we'd come back, my dad would stay with him and then we'd go out.* So the only thing with that is then ...in a sense it's great because he has time with his granddad and they play games or whatever at home. But *it kind of, excludes everyone, doesn't it? In the sense we're doing something that he's then not doing, but actually he can't do it because he's finds it difficult and he's tired*. So, it's kind of that side of things. So, it depends who you're with, isn't it really? Otherwise, *it's kind of saying to people, he's going to really struggle and that it's not going to end.. It's not going to end very well if we continue the whole day. We're out the whole day because it's not going to be me or him really in that instant, isn't it? So, yeah, it's tricky for if people haven't got understanding, I think.*	Fab: Understanding family, rest breaks built in. IP: Inclusive planner; family-aware mother
25.	**Simon T Dixon:** Yeah. Is that something that you find that people do struggle to understand? **Kelly:** Yeah, definitely. Yeah, I don't think people understand at all, particularly now he's older. *when you're little, you kind of get away with a lot,...* **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** don't you? when they are little. they do get away with a lot. But I think as they've got older, yeah, *because it's invisible as well, I think people really struggle, similar rheumatoid arthritis,* isn't it? *people can't see it, which means that they don't know how much pain you're in.* So then there's just a lack of understanding, isn't there really? *And it's probably why I've never got a blue badge,* which I know is ridiculous, isn't it? *Because I potentially could get a blue badge,... but I feel like I'll be judged.* **Simon T Dixon:** Yeah. Yeah. **Kelly:** I've not got DLA for him, which I probably could do, *but I feel like I'll be judged in the same sort of scenario. and that's probably my own sort of inner sort of side of things because for mine,* I don't tell anyone, nobody. It took me a long time with the rheumatoid arthritis to ... **Simon T Dixon:** Yeah. Yeah. **Kelly:** to tell people.. *I felt like it was hidden because* I think I had to cope with it myself. I didn't tell anybody about it. And then now even I'm really picky on who I tell because actually people sympathise and actually you want empathy, not sympathy. I hate the whole poor old that must be really difficult more like God that must be really ... **Simon T Dixon:** Yeah. Yeah. **Kelly:** how did you deal with that, how was that for you, you want and that's what you want for him where people will go poor thing actually not poor thing, because he's really got great strength in some areas he just really finds this area really tricky for him that being is a constant thing. **Simon T Dixon:** Yeah. Yeah. **Kelly:** Yes, the sports you can't be in the football team and you don't particularly want to play. However, your maths is	Fab: No blue badge or DLA claimed. Fab: Fears judgment; compares with own RA. Holi-Cont- The invisibility and social suffering of illness IP: Self-protective advocate; privacy-aware parent

	great, isn't it? Your science is great. You're, really knowledgeable and it's continuing to have that because when you're little, sport is such a thing. But when you're in pain and you can't do it, that's really difficult and that's challenging, isn't it really for him? 00:40:00 **Simon T Dixon:** Yeah, when you talk about that kind of…how I suppose it's your experience that you're talking about and how you kind of I don't know conceptualize it and the way that in which you want other people to kind of understand you. How does that impact in the way are you thinking a lot about how that would impact your relationship and the way in which you might tell or not tell people about Neil. Do you know it's how I don't know if that's made sense really. **Kelly:** Yeah, in my own personal experience. **Simon T Dixon:** So you said you don't want people you'd be very picky and choosy about who you told because that judgment seems to be quite a big part of it now So does that stop you from telling people about a verb or does it okay **Kelly:** No, I tell everyone about Neil. So, it's completely different. It's very bizarre, isn't it? So, for me personally, not want to tell, but with others then I would be quite open to say actually he's struggling. **Simon T Dixon:** Okay. **Kelly:** And…that's the thing, isn't it? *I'm an advocate for him, but I'm shocking to myself. So, yeah.* **Simon T Dixon:** So, there's something about being judged yourself. You kind of know that it's important for people to be aware. **Kelly:** Yeah. Yeah. **Simon T Dixon:** Yeah. Yeah. **Kelly:** *Particularly around, so if he goes to Cubs and there's something he would find challenging, I'd make sure that, because his voice isn't, I can say who I can share to and I've got that self-confidence but as a child and before he could speak he couldn't sort of tell anybody.* **Simon T Dixon:** Yeah. **Kelly:** So you're that advocate for them aren't you? I'm really mindful that as time goes on he needs to be his own advocate… **Simon T Dixon:** Yeah. Yeah. **Kelly:** *because at school he won't yet say if he feels uncomfortable or he feels tired or because he don't want to upset anyone* but he needs to in time because I'm not always going to be his voice, he's have to say I found that difficult or… **Simon T Dixon:** Yeah. Yeah. **Kelly:** So as time goes on it's always this thinking that I'm gonna have to build that in him so he can share that with us as well. Yeah. **Simon T Dixon:** So, you're kind of hyper aware of that. when you think about that as being a parent that's I guess part of the role of being a parent but particularly important at the moment like you say it's a transition isn't it through how much can he communicate how much can he	Advocating for needs-fighting for voice to be heard.

	understand and you said something earlier about him being quite aware for his age being very aware and open.	
26.	**Simon T Dixon:** how do you find working with school in particular? Have they been understanding? Do you feel that they go away and they might research a little bit? Do they work with health care at all? **Kelly:** So, yeah. So, no, not really. Bless them. *So, when you've started, they said they didn't have anyone or never had anyone with hypermobility,* which I thought quite shocking because actually quite a lot of people have hypermobility. It's not uncommon really. So they weren't too sure I think what to do. So, he was under a physio already, so she came along basically and slotted to the school. So she comes three times a year and does the exercises who then teach the TA. So, I then said, '…ideally somebody needs to be doing the exercises with him.' With regards to, he won't do them at home because he's too tired after Saturday and Sunday was absolutely fine we'll do them. *But in school time, can he have a bit of time out that he can then do them.* So that took a lot of chats and conversations *around because obviously that's a budget, isn't it, of somebody having to do that with him*. So that happened and then I asked if an occupational therapist could come in and do an assessment on him with regards to his seating, … 00:45:00 **Simon T Dixon:** Yeah. Yeah. **Kelly:** his fine motor issues that he has. She then said, which I didn't say before, he's got dyspraxia or *diagnosing with dyspraxia at the same time.* **Simon T Dixon:** Okay. Yeah. **Kelly:** But dyspraxia and hypermobility are very common and very…. they run through similar lines really. I think it's quite difficult to know the difference between the two really. **Simon T Dixon:** Yeah. Yes. **Kelly:** So he had that, so then it's just been a constant when anything crops up that we're unsure about that just to let them know*. I don't think anybody's looked into it. I don't feel that they've researched anything themselves.* I said to them recently that he had the diagnosis of the Ehlers Danlos, *but I wouldn't be too sure that they would be aware.* Whenever he's moved to class, I've had to go into that class in the September to tell them what he can and he can't have because things didn't move with him. So, he had a slope that he needed to have. He had a special pen that he needed to have. **Simon T Dixon:** Yeah. Yeah. **Kelly:** And what I'd find is the year then he starts the next year and it just didn't come with him. and you just like very basic sort of stuff that needs to happen. and… **Simon T Dixon:** Yeah. Yeah. **Kelly:** ..just around they have a Tots group in the hall. So the main toilets were not being used when the parents were coming in for the Tots group which meant Neil then couldn't go to the toilet and nobody kind of thought he's not going to go, so he'd have to go to the toilet in year one which is a tiny toilet *which he can't go in*. *So I had to go to say to*	Fab: Physio involvement. Fab: OT assessment. Chaotic stage- still trying to understand symptoms Fab: Poor comms from school and lack of support.

	them, actually, he's going to need a toilet. *So can he go down to the adult toilet or the year six toilet instead. And then with the water drinking, they do restrictions or they had restrictions on because some children were messing around having water at their table to drink with their water, but Neil has to have the water. So she said, " no, that's absolutely fine." So when you go in they're absolutely fine but I have to constantly sort of say and tell them*. With the touch typing I was like, *he's got a touch type and no other child had ever started touching in year three before…* **Simon T Dixon:** Yes. Okay. **Kelly:** which I find quite fascinating we should be touch typing much younger *and then, then they haven't been able to put in a learning assistant in for him, somebody's gone off sick* or whatever *he's not had somebody for a period of time. Nobody tells me but Neil tells me.* So he will say, *" I've not had my physio and I've not had my.." And then I'll have to go in and go, " So I hear is somebody off sick?" Because Neil will tell me, " and…* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *they're like, " we're just trying to, move people around." So then he's not had the care.* But Neil will tell them now, "I was meant to have my physio on this day." **Simon T Dixon:** Yeah. Yeah. **Kelly:** So he's very much aware and when I said about, "*you've finished your touch typing now, Neil, I think you should use a laptop in all your lessons*." He went into the school and said to the TA, I want to use the laptop now in all of my lessons, she went to the Senco, she went to the teacher and went back to me and it's like, this is a triangle of all these people (chuckling). *So, umm, he's very much leading and he will tell them, he'll say,* "we've not had these on these days." So, he is confident in that side. *He's got a good relationship with the TA in the school…* **Simon T Dixon:** Okay. **Kelly:** who they've moved, we've had different ones. and then they didn't even tell us that somebody was leaving. So, we had one for a whole entire year. *We didn't even know she came back in September*, she'd gone. *And that's just a lack of communication.* Like, really, we should be, ideally we don't have any reviews, which is something else. So there's no review of his care. *So I am now looking in to doing an EHCP for the transition into secondary.* **Simon T Dixon:** Yep. **Kelly:** *But I've said that to the school in the past, they are not keen for me*. I don't know if they're not keen because I don't know if they think I'm asking them to do it or they know I'm going to do it myself. *So, I've got to email them this week to say I'm going to start the process*. and I don't know why they're reluctant. I probably should say, "What are you reluctant about? Do you think it's going to be more work for you? Because it is going to be more work for you?" I know the Senco, bless her is a full-time teacher and is a Senco, which is challenging itself, isn't it? Because actually there's many children who go there have got additional needs and actually how can a person who's got a full-time	Hol-Cont- Systemic and Professional Failure *Systemic Friction*

	job do a Senco position at the same time? I mean, that's quite unbelievable really. And that's perhaps why it's not, … 00:50:00 ..they struggle with that side of things really. Yeah. **Simon T Dixon:** Yeah. But on the other hand, with your advocacy hat on,… **Kelly:** Yeah. Yeah. No. **Simon T Dixon:** it doesn't really make a difference, does it? **Kelly:** No. **Simon T Dixon:** It's busy, your kind of the way I understand where you're coming from. And again, it goes back to those systems, doesn't it? Being stretched and how much time can people give you and you end up going privately and then you find that there is support out there and with school it's similar isn't it you're talking about somebody who in an ideal world would be able to give every child what they need but maybe because they haven't got the time yeah but it's challenging and… **Kelly:** No. **Simon T Dixon:** I think you're doing a brilliant job in trying to kind of average, in a really difficult world really, isn't it? **Kelly:** Yeah, yeah, no, it is, *(retacted) SEND is umm, struggling isn't it? It's struggling in general.* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *So it's got many, many issues.* **Simon T Dixon:** Yeah. Yes. **Kelly:** *So, I just, and it's kind of been and there are other children with much higher needs within the school*. So **Simon T Dixon:** Yeah. Yeah.	Fab: School EHCP resistance. Hol-Cont- Advocacy and leadership Fab: Kelly leads process. IP: Persistent advocate; education negotiator
27.	**Simon T Dixon:** you mentioned your professional work and I wondered, is that something that I don't know what you do, so you could talk about that a little bit but how that kind of overlaps, you mentioned it previously with kind of parenting and particularly in your context but also whether or not there was an influence is it something you've come into since having children or.. yeah. talk to me a bit about that. **Kelly:** So I'm a nursery nurse background. So I qualified as a nursery nurse. **Simon T Dixon:** Okay. Yeah. **Kelly:** So a man.. I led and managed a nursery. **Simon T Dixon:** Yeah. Yeah. **Kelly:** Then I did my degree in early childhood studies degree. So I worked then in the NHS as a school health nursery nurse weights,… **Simon T Dixon:** Cool. **Kelly:** …hearings, visions, emotional support, parenting advice, that sort of thing. **Simon T Dixon:** Yeah. Yeah. **Kelly:** Then I worked at children's centres. **Simon T Dixon:** Okay. **Kelly:** So within the children centre, I was a family support , supporting parents who were going through difficulties. *The advocacy side of things came through…* **Simon T Dixon:** Yeah. Yeah.	Fab: Employment history- Nursery nurse;

	Kelly: *…that's probably why* and then I led several children centers across (retacted) until I had George, but then I didn't go back after Neil. So I went part-time and worked in the church, in the safeguarding role. So within the church. **Simon T Dixon:** Okay. Yeah. **Kelly:** Trained the reps, um, so train, trained volunteers within churches to be safeguarding person that people could go to. **Simon T Dixon:** Okay. **Kelly:** *Did that for a period of time.* Then I worked at mind as a community service manager, so erm, *so did all of the* sort of *programming of what we're having on in but also supervised staff for, who were doing one-to-one support* with people as and *then I had a midpoint of my life. and I'm just waiting to have results.* I've just done my Stepup program to social care, social work I'm going to be a social worker. I'm starting my social work in May. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So I'm going into the fostering team within that. So the models theories and all of them sort of practices all sits within that doesn't it like the Kubler Ross I go to Kubler Ross the grief and… **Simon T Dixon:** Yeah. Yeah. **Kelly:** loss all the time… **Simon T Dixon:** Yeah. Yeah. **Kelly***: because I think I've been through the Kubler Ross because that's what happens doesn't it really we all go through for many things that we go through that and…* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *I talk to other parents or whoever I'm supporting how you're feeling at the moment is completely normal we all feel this and sometimes we are frustrated and angry and that actually other times we are sad but we will at time get acceptance and we will over that sort of side of things.* **Simon T Dixon:** Yeah. … **Kelly:** So loads of that's probably impacted, but also a long running alongside that I'm a chair of the, do you know the toy library in Banks Meadow? **Simon T Dixon:** Okay. Yeah. Yeah. Yeah. **Kelly:** Yeah So I'm the chair of the toy library, so probably since having my children the understanding of SEND being really expensive, we umm, so the influence there for me is that we give free memberships to all children with send. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So any child who's send they get a 20 pound free membership and they get a free membership and then they get 20 pound to spend in the actual toy library as well. 00:55:00 **Simon T Dixon:** Yeah. Yeah. **Kelly:** And we've gone in, so I deal with grant applications. *So we go in to get new resources, because I don't*, like, weighted blankets are really expensive for children, really. **Simon T Dixon:** Yeah, they are. **Kelly:** So if you want to have that snuggle sort of approach. **Simon T Dixon:** They Yeah.	Fab: Worked in childrens' centres, family support. Fab: Worked for church, training safeguarding volunteers; Fab: Worked at Mind; (Quest- Training to be a S/W) Fab: Just finishing social work training. Fab: Chair of a charity providing toys and equipment for families. (Quest- charity work)

	Kelly*:* So they're 100 quid, aren't they? Or 120 quid. Um, but we, our, our hire is from 40p a week. So we are completely low fee. **Simon T Dixon:** Yeah. Just making accessible is just Yeah. **Kelly:** actually accessible for everybody. Yeah. Because it doesn't always work and what we were finding is parents are buying all these items in the hope that it's going to solve sleeping issues. **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** And then it doesn't work and they've spent that money because everything is so expensive. *We've got the towers, all of the sensory lightings and we're always buying some more resources, really just and we with the physios work a lot with the OT's all of the send support services to say this is…* **Simon T Dixon:** Yeah. Yeah. **Kelly:** …what parents can have. and what do you if there are other items that are coming up that you would like us to buy, we'll buy them and then they can hire them out, we'll move with that. We're just building a new system that we can do a click and collect. So that's our move forward. So parents can have the access, then other times that they can pick and buy and collect. So, I think that's probably a great influence from me in the sense of *I probably always had the thought of additional needs, but probably until you become a parent and* have children with additional needs, you have then got that true empathy to say actually how this can be difficult. And not only that, we're on as you're probably aware on Banks Meadow, which is one of the most deprived areas in (retacted) here. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So *we give them a anyone who lives locally free membership because I'm aware children …* **Simon T Dixon:** Okay. Yeah. **Kelly:** who live in deprivation is really difficult as in parents are paying for food and, and clothing and actually toys are an extra and… **Simon T Dixon:** Yeah. Yeah. **Kelly:** ….that's really hard because then they're not going to be at the right attainment when they go to school and peers and all of them side of things. So we do give them and we've just gone in for a recent grant to hope that any child in Banks Meadow can all continually to have an access to us. I mean the ideal is we offer free for everyone but we are a charity, so our committee are like, *"Kelly you got to stop that"* sort of sense, so I've been doing that so it'll be 10 years this year I'll be on committee and… **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** that is very much that feel um, of send side of things. **Simon T Dixon:** And, you do you think, so when you were a Nursery nurse was that before having children. **Kelly:** Yeah. Yeah. Yeah. **Simon T Dixon:** And was the part, you know, since having children, you mentioned that then with additional needs that's become more of a, a, I suppose more present in your kind of but how you can relate the two is it helpful do you	IP: Professional carer; empathetic parent

	kind of feel that your experience can help others but also in your experience in work will help you in parenting and in your **Kelly:** Yeah. Yeah. So vice versa, isn't it? So I'm going into the fostering team within (retacted) for my social work, *but actually I was going to go into the children with disabilities team*, which were my two options and I did my placement with children with disabilities. And I think it's just having that true empathy for people actually, you know much, *obviously my boys do find things difficult but actually there are others who have much harder,* you know, *go through much more challenging things than I do.* Having that and understanding that, not that I would share, not share that professionally, I don't share my personal with them professionally, but I feel like I want to be the person that they have, that I would want, so in that sense of having that time spending that time with them, getting to know their strengths and how I can best support them because that doesn't always come true, does it? *And it's kind of saying, "This must be really challenging for you,* you're living with this 24/7." **Simon T Dixon:** Yeah. Yeah. **Kelly:** .. you know and very much around self-care. what are you doing, what are you doing for yourself, to help you through this on a day to day, *only because I probably have that understanding as a parent, but not as severe as somebody who's,…* **Simon T Dixon:** Yeah. Absolutely. Do you practice, what you preach though? **Kelly:** (*Laughing)no, no, I'm shocking.* No, actually being in social work and doing the training, it's so focused on self-care like it is very much. However, *it is my one area of development, because I am a shocker with that myself but I can see it in others and for my own self.* **Simon T Dixon:** Yeah. Have you moved at all? Is there anything that you do do that for yourself? 01:00:00 **Kelly:** For my own self care? Ermmm, so, ermmm, not really, my focus are the boys, really, you know, *my children really are my world and I love being busy, and so I think my self-care is being busy. I love that,* it's not an escapism because people love that, don't they, to escape,… **Simon T Dixon:** Yeah. **Kelly:** but *I'm fully aware where I am*. And I think yeah, erm, *yeah I just want them to be happy,* I think, in that sort of sense. But I am trying to do more walking, *I'm very aware to get out for a walk or to go swimming or to do, but spending time with them is my self-care in that sense that I just time with them and doing things with them.*	(Quest- Grant for families living in deprivation) (Quest- Reflecting on S/W training and why she worked in the Disabilities team) Fab: Went on placement in the children with disability team. (Quest- Advocates for Neil but neglects self)

		Fab: Tells other the importance of self care but neglects that herself. (Quest- Son's are 'core part of Kelly)
28.	**Simon T Dixon:** Because it sounds to me, a lot of everything that you do is, it's in the caring kind of sphere, isn't it? And yeah, I guess is there a break at any point for you? And again if that's something that energizes you and you feel that in itself is something that you, you know get positive feedback from and… **Kelly:** Yeah. That connection. **Simon T Dixon:** that's kind of your identity I guess isn't it your identity? **Kelly:** Yeah, it is, it all goes together, doesn't it really? In one point, and my arthritis is well managed now. So, that was more tricky at the time when the boys were younger and kind of not to be, you know, still to be getting flare ups yourself in that sense of the care for them, *because actually you have to put your own mask on before you help someone else.* And it's very much and I'm very mindful of that. So, you know, which I probably would have been less, you know, when they were younger, not forgetting medication, *but kind of like I would have put myself on a back burner, but actually I learned over time that, if you can't lift a child or you cant do you know what I mean*? *If you find things difficult, that's much harder.* but then in a sense *for my own care that was a battle as your probably, partner is aware of to get medication that you can feel good with.* So that in itself, to get on the biologic medication now, **Simon T Dixon:** Absolutely. Yeah. **Kelly:** *which works wonders, do you know what I mean?* **Simon T Dixon:** Yeah. Yeah. **Kelly:** But it took, God, years and a lot of, kind of, to get where we are today and not just stick on Methotrexate, you know, and that side of things. So um, yes, so I'm man, in a sense of, *I'm like a normal person* which is great because if that was not managed, *my own pain wasn't managed. I think I'd find it difficult to then* obviously *care for others,* you know, *well you can't.* **Simon T Dixon:** Have you ever had thoughts, or thought whether or not there's any kind of genetic link between your kind of arthritis and the hypermobility or the Ehlers Danlos. Do you think there's anything? **Kelly:** *Apparently not, there's not a link.* Obviously, my boys could get, God love them. as yours could get the arthritis and I just think my god, what a way to go which would be just terrific… **Simon T Dixon:** Yeah. Yeah. **Kelly:** but my mom had it, I've got it my sister has it and I've got two brothers and they haven't got it. So part of me	Fab: RA managed well now, harder when kids were younger

	kind of thinks it's not in a male, that's why I was given boys, maybe, my hope is that I'm not going to continue down the line of following that… **Simon T Dixon:** Yeah. Yeah. **Kelly:** but however my mom's dad had it, so actually it's kind of a bit like who knows there a trigger for it to happen and… **Simon T Dixon:** Yeah. **Kelly:** …it just happens doesn't it? So, erm*, however my rheumatologist would say that I am hypermobile but she doesn't know if the hypermobility came due to the arthritis.* **Simon T Dixon:** Okay. Yeah. Yeah. **Kelly:** So because I was never tested for and *when we were younger my mom wouldn't have thought God you're walking late. I don't think I was a late walker or it just wasn't checked was it?* My niece is hyper mobile So she has got hypermobility. **Simon T Dixon:** Okay. Yeah. **Kelly:** But it just depends on that severity isn't it? Because you can be but it doesn't affect everything else. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So with my other son, he, he's not affected in the way that Neil is, so they both got the same, but actually, he's had the further diagnosis, so it's not the same, it's that connection. *But, erm yeah, the genetic testing is more tricky, isn't it?* **Simon T Dixon:** Yeah. Absolutely. I think it's the unknown, isn't it? **Kelly:** Yeah. Yeah. **Simon T Dixon:** It's the kind of and…	Fab: RA in family. Fab: unsure about how hereditary; Fab: Rheumatologist uncertain. IP: Genetic ponderer; hopeful mother
29.	**Simon T Dixon:** I guess you kind of touched on it a few times is the invisibility… **Kelly:** Yeah. **Simon T Dixon:** ,….and people not quite understanding when you see professionals and you're leading the conversation because maybe, you know more than they do about things. that's challenging isn't it? And what's your experience, erm, how does that make you feel? I guess, how do you cope with that kind of… the unknown of things? Yeah. 01:05:00 **Kelly:** *Yeah, we shouldn't be there, should it really? Because I should be getting the care and support and they should be leading the conversation, shouldn't they? We are in a crisis of a health service, aren't we? In that sort of instance.* And I have made complaints before in the past with the health service, but it's never got anywhere. Like, *I 've not been,* you know, I've not been, you get *you ring PALS,* don't you, *and they're very empathetic, going, "I can see how that made you feel",* you know, *all my signs that I would use, but there's no action because they can't because they're restricted,* I was like I'm on a waiting list I've not seen somebody for 18 months now *and they're like, "Well,*	Fab: Kelly made complaints; Fab: Waited 18 months for care;

	we've got no one", and it's kind of like okay so what are you doing around that … **Simon T Dixon:** Yeah. Yeah **Kelly:** what is your I just find the, that sort of side of things frustrating … **Simon T Dixon:** Yeah. Yeah. **Kelly:** erm, which is, is erm, sort of tricky isn't it? In that instance but erm, **Simon T Dixon:** Yeah. Yeah. **Kelly:** ..*it would be nice,* you know, *that if we had a government-led system that we were able to get the care and support as and when we needed it*... So, his hydrotherapy he had, so we were on a waiting list for that and he had that for five weeks but now you're back on a waiting list again to kind of get some more hydrotherapy… ….because it's 80 quid each a session for half an hour, it's kind of like that, *that should be something as you would with a tablet for somebody who needs something. You should be able to have that, therapy side of things, just the same. But that is not the case."* **Simon T Dixon:** Yeah. arguably a natural kind of treatment I guess isn't it compared to a pharmaceutical you'd hope that they'd prefer on that side… **Simon T Dixon:** but yeah it's sounds frustrating as well … **Kelly:** Yeah. Yeah.	Fab: Hydrotherapy stopped and restarted; Hol-Cont- Systemic and Professional Failure Fab: Cost barriers persist. IP: System critic; exhausted advocate
30	**Simon T Dixon:** So kind of moving into the future something that I think you mentioned before, how do you see the future as a family and for the boys and something that you worry about. Is it something that you're positive about? **Kelly:** I sort of live, Simon, in the here and now, which I feel and I al, so to not worry because actually what you're worrying about is in the unknown, isn't it? Because you don't know what's going to happen in the future. **Simon T Dixon:** Absolutely. Yeah. **Kelly:** But if you weren't that sort of person, I think my god, you would have major worries, wouldn't you, of what's going to be the case. But we have talked about like, he is, Neil will be restricted on jobs, potentially. You know, erm, a physical job he would find more difficult and *actually how he'd even cope with the full day even now when he gets to 16*. When I was 16, I went McDonald's for 10 hours do you know what I mean *and you get a 45 minute break* and that's all you'd get, where erm, his future is I don't think he would manage that, but would people be as happy to employ somebody who can't manage them hours, and then he's got to have them conversations on an application form to say, as do I with my rheumatoid, you've got something people are, they shouldn't be because we've got the Equality Act in now 2010. **Simon T Dixon:** Yeah. Yeah. **Kelly:** But they are reluctant then to potentially start somebody who, potentially is going to find it more difficult,	Fab: Neil may struggle with full-time work;

	or need more regular breaks, it's them. *So he's got all of that to come up with his, future employers,* which is completely judging straight away, isn't it? Even off an application… **Simon T Dixon:** Yeah. Yeah. **Kelly:** if you've got several coming in, you'd hope that wouldn't be the case, but that's another advocacy, isn't it, that you have to sort of go through yourself, isn't it really? *And then if he goes to college or he goes to university,* you know, *he's going to be different and how's that going to be?* You know, even in secondary school with that transition it'll be a much bigger, so (redacted) is obviously very tiny site isn't it … **Simon T Dixon:** Yeah. Yeah.	Fab: Equality Act offers protection but stigma remains; Fab: Kelly compares with her own RA disclosure. IP: Protective mother; realist planner
31	**Kelly:** which he seems to manage but he goes to a secondary school we've got the whole lift situ, do you know what I mean, lift situation getting around to different sites, carrying of items, I mean, I carry his bag in, which is, you know, probably my own doing, but I carry his bag to school and back, you know what I mean, but he's then going to be going to school carrying a ruck sack of all of these books things that he's *then going to carry around that that's in itself they're tiny things, but actually they are things but I shouldn't even have to think about but I'm thinking about already,* how's he going to cope with carrying all of them items around? Yeah. **Simon T Dixon:** You're talking a lot of the practical things, aren't they? Which you wouldn't think about otherwise, would you? It would be the emotional impact or how will he, the friendships, all those things whereas you've on top. **Kelly:** Yeah. Yeah. 01:10:00 **Simon T Dixon:** Yeah, That's it. You've got that as well. **Kelly:** Which just adds to it, doesn't it? Really, to that understanding. **Simon T Dixon:** So in terms of I know you said you're going through a decision, a kind of a stage at the moment deciding where would be best and yeah, you said the impact on his brother, I think, yeah, what support are you getting around that, or is that just you as a family kind of talking about it? **Kelly:** Yeah. Nobody, nothing. not I don't think anyone's that concerned or, nobody's concerned or… **Simon T Dixon:** All right. **Kelly:** ..nobody's questioning anything. No, so, it's just us as a family to and it's hard because, I spoke to my sister the other day to say, what do you think? It's very difficult to know what to do and what's the right decision to make because we won't want to affect, my older son at all. We won't want to upset him either. and if they're together, you kind of think my older son's there, too. So, I've got an older brother. **Simon T Dixon:** Yes. Yeah.	Fab: Kelly helps with Harry's bags, she fear practical barriers when moving to next school. Holi-Cont- The effect of illness on family & social life

	Kelly: He can have a bit of not protection, not because, he's not going to do anything, because they're good boys but he's got an older sibling in the school, so we might make it much more easier. The other, also thing is that he, we, they go to rugby. So we're in (redacted) obviously and they go to (retacted) school. **Simon T Dixon:** Okay. Yeah. **Kelly:** So they don't go to (retacted) because we could get into (redacted) and did. So the only other thing is that he's not going to go with friendship groups either… **Simon T Dixon:** Okay. Yes. Yeah. **Kelly:** … because most of his friends are going to go to (redacted) and we are also going to split that, *which for me physically I feel a bit sick about also*. Because it takes a long time for him to build relationships and I think it's because he's different, in the sense of sport thing. I'm sorry, *but kids are obsessed with sport when they're little* and the football, and he's not football and *that just cuts you out from things rather than getting to know him.* So he started in reception but he would say, "I didn't have any friends till year one", you know, for quite a period of time he didn't have anyone that he knew… **Simon T Dixon:** Okay. Yeah. **Kelly:** ..which is heartbreaking, do you know what I mean, it is heartbreaking. *So we've got this second round now when he goes to secondary with the same thing and people getting to know him and the things that he likes. So that's going to be a, yeah.* **Simon T Dixon:** Yeah. Those transitions are so hard anyway, aren't they? **Kelly:** Yeah. Yeah. **Simon T Dixon:** Let alone with everything you've talked about on top, Okay. Yeah. **Kelly:** And the toilet pass and, do you know what I mean? All these things you just kind of, *if you had an accident and the staircases are huge*, so it's like now *but then it's the future of jobs and careers and everything,* isn't it really? It's kind of like yeah, we shouldn't have to, but it's that judging side, isn't it?	Fab: Neil won't attend same school as friends; Fab: Struggles with sport-based bonding; Fab: Fears isolation and practical barriers like stairs and heavy bags. IP: Empathetic planner; emotionally attuned parent
32	**Simon T Dixon:** I was just wondering about in terms of your partner. Do you live with your partner? **Kelly:** Yeah. Yeah. Yeah. **Simon T Dixon:** And do they think similarly along the same what kind of parts do you play in the relationship of one of you more kind of do you play the advocate more and how does it, what's the dynamic? **Kelly:** Yeah, I probably do to be honest. I'm a bit louder (chuckling). So, he's much more chilled out than I am. So, in that instance of he's much quieter, so, he's more like Neil. But I'll check in things with him because I'm very mindful of my professionalism. So I will say do you think I've got this wrong? You know, I will do that sort of check in. **Simon T Dixon:** Yeah. Just is that something that you think about a lot then? Parent versus professional, where am I and am I overstepping the mark and Yeah. Okay.	Fab: Partner is quieter and more present-focused;

	Kelly: Yeah, really regularly. Which is bizarre isn't it to think that way but I will think about that often, even in like, my friendships with parents in the playground *because like, do I say, "I'm aware of that" or, "actually you could get support with that or have you looked at that" and it's kind of like is that my place to say it or am I stepping the mark in that at.. it's very difficult that dynamics isn't it?* because you want to help, you don't be too forceful and you don't want somebody to go, "that's not any of your business," either. That sort of side of things is quite tricky, isn't it? as well. So, I will check in with him. I would say until recently I've done all of the appointments. **Simon T Dixon:** Yeah. Yes. **Kelly:** But, like I've had to be at every one which is a control thing, isn't it? *But I feel like I've had to say my things.* However, more recently he has taken, you know, him to an appointment, Erm, but otherwise I will have done all of them and he is a very much a here and now, he's not a worrier… 01:15:00 **Simon T Dixon:** Okay. **Kelly:** ..which probably quite helpful because I don't think worrying gets you anywhere in that sort of..	Fab: Kelly checks in with him to balance her assertiveness and professionalism. (Chaos/Quest- Overlap between professional and personal life) Fab: Kelly attends most appointments; IP: Assertive advocate; reflective professional; relational negotiator
	Simon T Dixon: Erm, how, do you have different perspectives on.. on, you know, health or do you kind of see things differently? Do you often say, the way that you might, erm, see Neil's, maybe his future or how he's strugg or are you quite aligned with what you think? **Kelly:** Yeah, no, we probably do see things differently. *He's very much, "he'll be all right",* do you know what I mean? *"He's going to be okay."* **Simon T Dixon:** Yeah. Yes. **Kelly:** *He probably is going to be okay, erm, and he's resilient and he'll be all good. But you know….* **Simon T Dixon:** Do you need that yourself,… **Kelly:** I think yeah,… **Simon T Dixon:** do you think? Have that balance? Yes. **Kelly:** ..maybe. *But then sometimes it's kind of like is that lack of understanding I think as well*, isn't it? It's very difficult isn't it? Like, *my mom and dad would do the same. They go, " it's going to be fine." And you kind of like, "Yeah, you can't say that because you don't actually know." That would be the more sort of counseling side of me would be that sort of way, you can't say he's going to be okay if you don't actually know.* **Kelly:** *The hope is he's going to be okay and he's going to have a future happy life,* isn't it? *But when you live in the here and now, this is where we are,* isn't it? This is where the stEP'sthat we need to take. So, Yeah. Yeah. **Simon T Dixon:** Yeah. That sounds like a bit of protection, doesn't it? The practical elements of what do we do right now how can we help in the moment and what can we do in	Fab: Partner and parents say "he'll be fine"; Fab: Kelly questions this optimism; Fab: Balances hope with practical

	blocks that you put in place and that sounds like the professional and then yeah and… **Kelly:** Yeah. Yeah. **Simon T Dixon:** but I think it's really important, but then you've got the other part haven't you which is probably the deeper part of the subconscious and all that stuff but, I think it sounds like you play as everybody as families do,…	stEP'sand professional insight. IP: Hopeful realist; emotionally attuned parent; professional thinker
34	**Simon T Dixon:** how's the relationship between the boys? do they get on really well? And how do, how do they interact? And how's that affected by the kind of chronic pain as well? **Kelly:** Yeah, no, they do get on really well and they've got really good relationship and see, I've been really mind, so I'm one of four and we've got a really good relationship and I really feel you need your siblings no matter what, your siblings are going to be the people that are going to be there for you, aren't they? No, my friends are great, *but actually family is there forever, so I think probably was very mindful when they were little around about spending as much time together, you know the four of us together or…* **Simon T Dixon:** Yes. Yeah. **Kelly:** ..*and having that time with them together and to love each other's quirks, we've all got quirks,* haven't we? in that sort of sense, I would say. So, George is dyslexic and I, I've had a recent diagnosis of dyslexia and I think because George was, I think I always knew I was, but *I was just in denial. So, I think he's had that. Neil, I will also say with the Ehlers Danlos, the hypermobility comes some neurodivergence.* I think there is something there. And I don't know if that will come out in an Ed Psych erm, when he does an EHCP. I don't know, I need to find out. Will any of that come out in that sort of, you might know more, Simon. You might be able to tell me that. Erm, will that side come out if he has an assessment done? *Erm, because we can, he erm, he needs to put a filter on quite regularly and (laughing), we talk about it in that instance of, "we've got this" but however, his dad probably needs, he's learned his filter in that. So we're very neuro divergent and we talk about the strengths that brings and actually,* who, who's and *George's very aware that he's very kind and caring and he sees that side*. Neil really struggles, so they are completely opposite, *even in what they eat, the food patterns of what food they each like. However, one is me and one is Ian, so there is a very, very different, the mix kind of goes.. but actually goes well together really.* So George is very protective over Neil, but Neil idolises George, like, he thinks he's the bee's knees with everything, you know in that sort of instance. **Simon T Dixon:** Yeah. Yeah. **Kelly:** So they do, and they like the same things, which I think is always a key isn't it? Part. They play Robox together. **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah.	Fab: Kelly has three sisters. Fab: Neurodiverse family Fab: George helps Neil physically and emotionally;

	Kelly: They love similar games, they love Lego. The things that they can do, they will do together, you know, sometimes we're in the car and you wouldn't even think I was there, do you know what I mean? *I'm driving, but they are chatting about whatever they're chatting about (chuckling).* **Simon T Dixon:** Yeah. Yeah. **Kelly:** I'm the third part. *I'm trying to get into the conversation, but they're just so involved with the conversation they're having*. yeah, it's a lovely and I really hope it stays because I think they'll need each other for the future, the time and boys are easy, aren't they, in that sort of, more than girls,… 01:20:00 ..in that sort of instance of relationships and dynamics and you know, all of them, boys go, "Yeah, fair enough." And they forgotten if they've had a tiff about something, they're over it and we've moved. Then it's kind of like, yeah, erm, so, *I'm very much in a boy household, which even the cats are boys*, Simon. I've got two cats. They're boys in a boy dominant dominant world. which I'm the lucky chosen one. So, yeah. **Simon T Dixon:** Do you feel that they have an understanding of each other and like you say, they kind of, you encourage them to kind of celebrate difference **Kelly:** *Celebrate difference, but you know, you know, one.* **Simon T Dixon:** …they have an understand of each other in terms of what their limitations are and when they might and they're quite empathetic with each other. **Kelly:** they're really empathetic. *So, George will struggle with spellings*, you know, he's the older one, but Neil will then know a spelling and he'll tell George, *and there'll be no joke or laugh about it. Do you know, we know that that's what he has and he finds that difficult. where George would help him if he needed to climb or to be mindful on if we go out to a park* or anything, *there's somebody always around Neil to make sure that he's okay and he would never have anyone say anything to Neil or if we go to*, so we do the send nights at the hub, and he would be around him all the time and he would help him if he sort of physically needed any help. he would have done when he was little. as well,… **Simon T Dixon:** Yeah. Thank you. **Kelly:** but that's just involving him in his, isn't it? And it is constantly around, your and George will say, "I've taught Neil", because they're both good at math. *"I've taught him everything, haven't I, Mum?" And I'm like, "yeah, of course have." You probably to be honest, and "I've taught him this and I've taught him that". So he's very mindful that he's, what he's taught him as well,* which is a nice,… **Simon T Dixon:** That's nice. It's empowering, isn't it? **Kelly:** *Yeah. It makes me feel good, doesn't it?* Yeah. Yeah. And they're very loving. They're huggy. They're quite tactile. they will love each other and that's really important, isn't it, to have that, when they want that physical touch. And Yeah, so, erm **Simon T Dixon:** Absolutely. I think Yeah.	Fab: They bond over games and protect each other socially; Fab: Kelly fosters closeness. IP: Nurturing parent; relational guide

35	**Simon T Dixon:** So when you reflect back on kind of I suppose your experience of being a parent within that context of chronic pain what would you say what are your reflections of that question is it **Kelly:** it's hard. *Frustration is probably my key point of not getting the care and support that's needed from the early point. I think not being listened to professionally is really frustrating. Erm, and I say I don't worry,* but, you know, *the whole journey's been a worry from him not, hitting milestones to MRIs to blood tests to,* all of that sort of side of things *has been a worry, probably less now he's got older, but probably more so when he was younger really. I'm so thankful that he's academic, because if he wasn't, I think he and I probably really struggle with regards to what are we good at?* Do you know what I mean? That strength based thought, I know you can pull loads of things out, can't you? But that would also be really tricky and I think it would have affected him with that even more so than anything else *and really having support family, I think having that connection with others and helping others. So with the toy library side of things, the thought that I've helped other people who have gone through a similar scenario and we can offer them something that you,* erm *feel of is needed,* erm really. *Education of professionals just needs to be improved, like from the interactions with.* When you become an ed psych, Simon you have a lot to live up to, but you seem very kind and caring, so I get that from you already, so that's nice, in that sense but having that a good approach.. **Simon T Dixon:** Mhm. Yeah **Kelly:** ...I think with young people, getting to know them spending time to get to know them, I think is that importance isn't it and knowing what they're finding difficult and challenging, but talking to them being that child focused having them at the centre point of all decisions I think that you make and how you can have an impact on them potentially. *Because , you know, Neil will say they were really nice or* he came out of that paediatrician that we had that wasn't great and he said, "That was useless weren't it?" *and that's a nine-year-old. I didn't even say anything that he's very mindful.* **Simon T Dixon:** Yes. Yeah. Very observant, aren't they? **Kelly:** they're probably the worst judge to be honest. **Simon T Dixon:** Yeah. Yeah. It's true. 01:25:00 **Kelly:** And I will tell a professional I think they've done a really good job. **Simon T Dixon:** Yeah. Yeah. **Kelly:** *I'll be the first advocate to say, "You did that really well. that was really great. you're really caring, you're really thoughtful, you listen really well." I'll be the straight away to say, I'll give chocolates, flowers, or whoever if I feel like they've done gone above and beyond, but it shouldn't be above and beyond.* It should be just how all interaction be with young people. Yeah. But I don't think we're quite there yet, are we? **Simon T Dixon:** No. Will we get there?	Fab: Early worry over milestones, MRIs, and blood tests; Fab: Gratitude for Neil's academic strengths; Fab: Desire to improve professional empathy. Fab: First to be grateful and reward good professional practice.

	Kelly: Yeah, We will, we will. Got to keep holding,… **Simon T Dixon:** What you need? Yeah. **Kelly:** haven't we? Yeah. Yeah.	IP: Experienced parent; empathetic professional; advocate for change
36	**Simon T Dixon:** If you could give some advice to parents that are going through the same journey as you, maybe at the start of the journey, what would be your main things that you might say to them? **Kelly :** Erm,(6 second pause) It's a tricky one, isn't it? I've kind of got to put myself back to where, *God the anxiety at that age, the anxiety to the worry that things are not going to happen is just really hard, isn't it? Erm, and that you feel quite alone and that's the only other thing.* And actually that's the lack of support locally, that there's not a support group, you know, for either, you know, for different medical needs, is there? *That you're not alone, to talk to somebody else. Nobody really links you up with anybody else, but actually, I think if you can go and find somebody who's had a similar experience and just sort of listen to.. perhaps what they're have gone through, not that, the only thing I find with that, I had that with rheumatology but in initial stages that sometimes it can be a bit of a competition, which I find really awkward and that's probably why I don't share with others..* ***Simon T Dixon:*** *Yeah.* **Kelly : ..**because I went and had an experience and somebody had asked me, "what medication you're on" and this and they're like, "I've got this and I've got that". An*d that's not help.. that is a not a helpful sort of, to feel that my child's worse than your child or.. you know, that isn't comfortable. But having somebody who you connect with, that could help you sort of practically and emotionally, to have somebody that you can talk to ,it's great isn't it I've got a friend that I would talk to, you know, and she would say to me, "Kelly you've got to chase that up",* she's an honest friend*, like, "Sort that out, do you know what I mean",* in that sort of way. But when you become you know, disheartened by things, "Go back", and having that person to say that is quite true, isn't it really? and probably your own self-care (laughing), probably to make sure that you're healthy yourself, isn't it really? And you … **Simon T Dixon:** Yeah. **Kelly :** you do things for yourself or your own being is probably in a good place, isn't it? Get some help, I think, if you're feeling that it's overwhelming. I think in that sort of instance, isn't it? That's why I think **Simon T Dixon:** Is that something you've considered before in terms of any support groups for you or…not in terms of your arthritis, but in terms of is there any other external support that you've kind of thought about or accessed before? **Kelly :** Yeah, I looked at the Ehlers Danlos. They do a support group but there's no local, so I think there is one in	Fab: Lonely and lack of peer support; Fab: Discomfort with comparison and competition in peer groups; Fab: Value of honest friendships; Fab: Importance of self-care. IP: Wise parent; community connector

	Leicester, but it's adults, so it's not children and the same with the hypermobility. So there's not that, our physio connected me with a parent but it was around what's trike to get, it wasn't around anything else *and the SEND side of things I always feel a little bit, they do the SEND nights…* ***Simon* T Dixon:** Okay. Yeah. **Kelly :** but because it's not a visible thing, it, it's very that in itself you feel a little bit like, should I go to these things or not go to these things? And then I have to think professionally of other people I know might be going to these things… **Simon T Dixon:** Yeah. **Kelly :** which I know I really shouldn't have to think about but I'm bringing my children p prof profession personally into a professional space which is very difficult to kind of, so I would perhaps go out of county if I felt, so that I'm not linking up with families that I know potentially, which is another viewpoint, *but it's too much to think about*, isn't it but yeah. *If you want to start a group, you have to start something yourself*, don't you? It's that side of things. It's tricky. **Simon T Dixon:** Yeah. I think it feels I'll talk to you a little bit afterwards about a couple of things… if you've got time. **Kelly :** Yeah. No,…	Holi-Cont- The invisibility and social suffering of illness
37	**Simon T Dixon:** Is there anything else you'd like to share that I haven't asked you about or something that you think within your kind of story or in your experience that you think you might be something you'd like to share that you haven't Yeah. **Kelly:** I don't. I was going to say just I've got some notes here, didn't I? *All appointments are always in the daytime. So whenever we do appointments for this pain sort of side or any health things, they're all in the daytime. And I find that's really frustrating…* 01:30:00 ..*because actually you're taking,* however Neil loves it out of school. **Simon T Dixon:** Yeah. Yeah. **Kelly:** You know what I mean? So all the physio had to be in school time, the pediatrician is school time, the podiatry is school time. they will not do an extended or out of hour session. **Simon T Dixon:** Yeah. **Kelly:** So for parents, I'm quite lucky because I've got flexibility, but if it was somebody else and they had to work 9 to5, half five, *they would really struggle to take their child to appointments*. So there does need to be, how that affects family. *That's a massive family life potential issue,* isn't it? yeah. So, I did think I was going to put that. **Simon T Dixon:** And also I think the allowances of school as well and here's an impact on schooling isn't there and… **Kelly:** *Massive impact. Yeah. Yeah. Because you're taken out and you miss chunks of work,* don't you?	Fab: All appointments in school hours;

	Simon T Dixon: that's different for different children I guess you say with Neil maybe that's less of a impact but **Kelly:** Yeah. Yeah. Yeah. Yeah. **Simon T Dixon:** for it might be for others? **Kelly:** For those it would be really significant. Yeah. if they were struggling in a particular area. *And the only other thing is generally* when they do Neil's physio, he'll be taken out of things that they feel he doesn't need to attend, which actually I feel he does. So he might be taken out of PSHE, where personally I think that's the most important subject above anything else, because that's how we feel. So they get taken out of things that they think isn't as important. But I, as a parent feel he shouldn't be taken out of that because actually we really should be talking about his wellbeing. **Simon T Dixon:** Yeah. do you feel that's a limitation that the school again it comes down to communication a little bit, really you should be making the decision together shouldn't you on those types of things and what's helpful and **Simon T Dixon:** Yeah. **Kelly:** Yeah, and actually, they don't see PSHE is a priority, I think in that sort of instance. Yeah, and I and that when *I'm looking for some support for his EHCP and I hadn't realised,* but when I asked them for a statement, the school said that they think it affects his wellbeing within school with him, how he feels about his peers. *no one's ever told me that, but it was just written down.* and actually as a parent, that's really hurtful. Do you know what I mean to say? *You noticed that, but you've never said shared that with me.* So, yeah, that's a tricky one, isn't it? I was going to see if there's anything else. I just write some things. I think that's it. I think that was everything. **Kelly:** No, that's everything, Simon. Yeah. **Simon T Dixon:** Okay. **Simon T Dixon:** Thank you So much for sharing everything if at any point do you feel after today… **Kelly:** Yeah. Yeah. **Simon T Dixon:** if you want to kind of chat to me again about anything in terms of kind of I'm worried about anything that you've said or it will then just pick up the phone or just email me and… **Kelly:** Yeah. Yeah. Yeah. **Simon T Dixon:** we can talk. and if you want any data withdrawing then you can do that as well. Just let I'm gonna stop recording if Okay.	Fab: Neil pulled from key subjects; Fab: EHCP resistance; Fab: School notes emotional impact without informing Kelly. *Systemic Friction* school's lack of transparency: IP: System-aware parent; persistent advocate

Appendix F-

Kelly- Extract of table of transcript segmented into moves, summary of 'move',

identified Fabula and Sjuzet* and Identity Positioning in each 'move'

Move #	Move Name	Summary of Move	Fabula	Sjuzet	Identity Positions	Supporting Quotes
1	Interview Opening & Family Intro	Kelly introduces George and Neil, noting early motor delays.	George walked at 21 months; Neil also bum-shuffled.	Normalising sibling similarity; calm tone.	Observant mother;	"These are similar this is how it works."
2	First Hypermobile Diagnosis	George's thumb locks; GP refers to rheumatology; diagnosis of hypermobility.	Thumb lock; GP referral; rheumatology confirms hypermobility.	Factual, accepting tone.	Trusting parent; early system-user	"He's hyper mobile… he'll just be over flexible."
3	Neil's Motor Delay & Buggy Reliance	Neil walks at 2½; Kelly carries him until age 5; buggy limitations.	Neil late to walk; buggy reliance; social judgment.	Humorous and resigned.	Protective mother; resourceful planner	"I probably carried him till he was about five."
4	Paediatric Referral: Motor & Bowel	Paediatrician notes motor delay, bowel issues, and wetting.	Referral at 18 months; constipation from 6 months; wetting issues.	Building a case for "something more."	Concerned parent; emerging advocate	"I feel like there is something probably more here."
5	CP Suspicion & Testing	CP suspected; MRI and blood tests performed; Neil	MRI and bloods; traumatic experience; results normal.	Vivid, emotive; describes distress.	Vulnerable parent; empathetic observer	"He saw a hospital as a place where pain

		associates hospital with pain.				happens. ”
6	Unsympathetic Paediatric Care	Paediatrician dismisses Kelly; she must chase appointments.	Doctor calls her “neurotic”; constant chasing; doctor retires.	Sarcastic tone; invokes Carl Rogers.	Frustrated advocate; professional insider	“None of the Carl Rogers... none of that malarkey. ”
7	New Paediatrician & Private Decision	COVID delays; new paediatrician fails to engage Neil; Kelly goes private.	COVID delays; failed referral; private care decision.	Animated frustration.	Decisive advocate; child-centred parent	“There is no child focus around this.”
8	Private Diagnosis & Whole-Child View	Private clinic diagnoses Ehlers-Danlos; sees Neil holistically.	Private consult; diagnosis; multi-system symptoms.	Warm, relieved tone.	Hopeful mother; knowledgeable consumer	“Nobody saw him as a whole issue.”

Appendix G-

Kelly- Extract of Stage 4- Categorical Content, including table of themes

Move	Transcript	Codes
1.	**Simon T Dixon: Yeah. So, okay, So, let me just ask you. (cough) So, if you could share your story that when you, kind of first realised that your child was experienced chronic pain and what that was like for you and your family, just kind of tell me your story, I guess.**	
	Kelly: Okay. yeah, that's fine. So, I've got an older son, So um, George is 12 nearly 13 and Neil is um 9 nearly 10, um So George came, bless him, came first obviously. He didn't walk till he was um, much older. So he was 21 months when he walked, normally it's sort of, well age and stage, I know it varies but it's generally one, isn't it? *So he was a lot older when he walked,* um, So he bum shuffled everywhere, um, So when Neil came along um, I just, quite, he um, alSo bum shuffled everywhere, *So I kind of just thought actually these are similar, er this is how it works*. However, no one else in my family at the time um, had the same experience, because sometimes it goes through doesn't it? families as such. *at the time, and it didn't seem to affect him in any other way, um.*	Delayed Gross Motor Milestones & Bum Shuffling Parental Perception of Normalcy and Lack of Family History
2	**Kelly:** Um, George when Neil was a baby um, George had um, he, his thumb. we were out shopping in Matalan and his thumb locked, just did a complete lock um and I really struggled to kind of move it to get it out of a lock, um, So I thought that's a bit strange, So we went to the, and then over time it just continued to happen, So we went to the GP, got referred to rheumatology, and *she said, "oh, he's hyper mobile*, So he's over flexible," um and checked all of his joints and things and that was it really, it was kind of just that one off, um, he's got Hypermobility, um, and he'll just be over flexible. *So, I just thought that's okay.*	George's thumb locked unexpectedly Hypermobility diagnosis and condition played down Kelly and Neil reassured
3.	And then when Neil um, just really struggled to walk, So he was really late, So he didn't walk till he was two and a half, very much old er um, and which is.. all sort *of impacts*, you probably, in the sense of he bum shuffled, So whenever we went anywhere we could hardly get him out of the buggy, because obviously there's not many places that you can go to that you can let a child just bum shuffle.	Delayed independent mobility

	Simon T Dixon: Okay. **Kelly:** So, *he was in the buggy*, obviously, um *for periods of time or I carried him everywhere*. So I, bless him, *I probably carried him till he was about five (chuckled),* I mean, *and everyone would say to me, "really Kelly, should you still be carrying him now..", you know, " at this age" and I'm like, "what can I do". And then the whole buggy thing was an issue, with regards to the buggy only goes up to the three,* doesn't it*? It's kind of like what do I do next? Do I, kind of, get the next buggy up or, um. And it's kind of that sort of conversation of , if we're going on short journeys shall I just pick him up and carry him, and um.*	Carried Neil until age five Dilemma about equipment for older child Practical adaptation for short journeys"
4.	So we went under a pediatrician at about 18 months I think, So we did go under a pediatrician and sort of said, you know, I feel like there is something probably more here, **Simon T Dixon:** Okay. **Kelly:** *he's over flexible, So he didn't sit very much late, So fine motor, gross motor, really late.* **Simon T Dixon:** Okay. **Kelly:** But then not only that, he had bowel issues from a baby, So, as soon as he hit six months, he had bowel issues from a baby, was on medication, and none of our family had any sort of constipation or anything in that sense. So, we kind of thought, *this seems to be something else that seems to added into the cycle of that, um and as he got older, we had wetting issues, So he would wet, So obviously then, that, the two were sort of connected* um, together. So we went under, um *the hospital to see how, what could we do, and I was sort of saying to the pediatrician I think there is something more here*	Referral to paediatrician at 18 months Kelly suspects something more is wrong Over-flexibility noted in Neil Delayed fine and gross motor skills
5.	**Simon T Dixon:** Okay. **Kelly:** they did do a um they sort of thought cerebral palsy, **Simon T Dixon:** Okay. **Kelly:** to start off with. So we had a MRI scan and he had blood tests, *but when you've got a little one that's only 18 months and you're having to do blood tests (chuckles),...* **Simon T Dixon:** Yes. Yeah. **Kelly:** it's quite horrific, it is, *even though I got the numbing cream*, er. *However, when they're little, it's a bit easier to when they get older (chuckling)...* **Simon T Dixon:** Yeah. Yeah. **Kelly:** *because they kind of don't know what's going to happen.* However, *I would say it probably affected him in his trust with professionals,* because he sort of, *saw a hospital as a place where pain happens*, **Simon T Dixon:** associates the two. Yeah. **Kelly:** yeah, not anything good happens. So we did have to have the blood test done, er, and that is just hard, isn't it? because you're, you're holding somebody's, obviously *two other members of staff there* and you're going through that	Early misdiagnosis and invasive tests in diagnostic journey Medical trauma and loss of trust in professionals

	and it's just horrific, isn't it? *To be so little and to have that sort of feeling really, um. But thankfully it came back and that wasn't the case,* **Simon T Dixon:** Okay. **Kelly:** *but, we were still like what is it, you know we're still on this road* **Simon T Dixon:** Okay.	
6.	**Kelly:** um. The paediatrician, I have to say was not very empathetic, **Simon T Dixon:** Really? Okay. **Kelly:** at all, um, thank goodness *he's now retired,* which I think that's the most positive, um that's happened (chuckling), um , we did not, um, he he, just, *he just said on numerous occasion, I've got worse children than him basically, you know, yeah, um, that you're neurotic,* you know, you are, you know in a sense, you know, um, and the, I'm just *with regards to appointments, you know, So that constant chasing of an appointment to see a paediatrician,* um, *if I didn't constantly chase it just wouldn't happen and I really fear for other children who are going through a similar pain issue* **Simon T Dixon:** Yeah. **Kelly:** *that if their parents haven't got the knowledge of a system or the self-esteem and confidence how that, you know, how that affects that child, that must be really difficult,* um. So it was, *the frustration was huge*, really. My husband did come, um to the appointment, um, but the last one I saw him at, um I just couldn't even engage with him, I just, he was just, you know, *none of the Carl Rogers, none of the old empathy and the genuine* (chuckling, animated), none of that malarkey going on at all,	Dismissive and unempathetic professionals Burden of parental advocacy for care and appointments
7.	So um, and then we recently saw another paediatrician, So he retired and then we obviously, we had COVID and… **Simon T Dixon:** Yeah. Yeah. **Kelly:** then nothing was happening, you, know, and then they had no paediatricians um, or they had some but had no waiting list, So we saw one last year, we saw one and Neil um came along and he's like eight at the time. So we walk into the appointment *and she's like, you know what you here for today, sort of thing, talks to me and I'm like, "Talk to him he's the one we're here for he's the one who's struggling". (Animated. High pitched)* **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** *Just the frustration of that interaction even with the young person*, you know, *as he's got older he's fully aware of what he's going through,* **Simon T Dixon:** Yeah. … **Kelly:** he's very… *he knows* his um, *his strengths, he knows what he struggles with*, um *but it's just that constant look at you to say what's sort of going on* really, um So that was last February and then um, we went private in the end	Frustrated in navigating healthcare system Frustration with Dr approach and not talking to Niel.

	because um, we didn't get anywhere really, to be honest. There was just a back and forward, I'd asked to be referred to rheumatology in (retacted), that's where you would be referred to*. however, she was very much like, "oh I've tried to refer somebody today, but they wouldn't take that, So I don't think they'll take yours." And I'm like, I don't mind the other person, it was about me, it's not child focused, you know, it's not child focused.* **Simon T Dixon:** Yeah. **Kelly:** *There is no child focus around this,* um, *So it was very much she just didn't understand*. She was walking um, and I said to her, *"you know he really walks in, he turns his foot over and she's just like,* you know, *just like,* "what's the matter?" *just looking at him like, "what's the matter" and you're like, I, "surely you can see" you know (laughing) um. So I was leading, and I have, So all this time, I've led his care really, So I've been that person to coordinate* **Simon T Dixon:** Yeah **Kelly***: care constantly* um*, without being the expert*, which is quite a worry*, So Google is an expert really (chuckling) So you're googling things which isn't appropriate at all um, and can be quite worrying as well,* um but I'm leading *and I'm saying he, we need to do this test and we need to do this test and we need to do this test. That shouldn't be the case, you know, there should be somebody, well the pediatrician should coordinate that care um, but I'm asking the questions to them, you know, um, which is a worry and it it shouldn't be something that is um, that is done all the time.*	Not child focussed/needed to ask to see Rheumatologist Kelly advocating and leading conversation with professionals Reliance on self-education and online information
8.	So we went privately last year to Leicester and he's had a diagnosis of Ehlos Danos syndrome. **Simon T Dixon:** Yeah. **Kelly:** So a form of hypermobility, um, So he, um, So yeah, So basically, God love him, he has all of the flexible side of things, So his whole body is, So he's a little scarecrow, God love him, in that sense, um. But then also he has his bowel, So his bowel, um, is over.. So overflex, but then he's about a, um no, no sorry, his bladder is over flexible, his bowel is under flexible. So it's not stretchy enough, basically. But, then he also has um, really thin skin, So he got bruising, **Simon T Dixon:** Okay. Yeah. **Kelly:** *So he gets bruised quite easily. Um, sprains and that sort of things he gets um quite easily um as well, So there's quite a, but nobody saw him as a whole per.., no one saw him as a whole issue really in that sort of sense. Everybody kind of, um, was just picking their points,* you know, part, *part of him, but not seeing as the whole, So and the interaction we had with the pediatrician when you pay privately, it's very different (chuckling)* **Simon T Dixon:** Yeah.	Positive difference in private healthcare – holistic, child-focused car Neil's symptoms and differences. NHS Dr's not seeing Neil holistically. Privately much better.

Theme	Subtheme	Associated Codes

Diagnosis & Health System Navigation	Symptoms and Differences	• Delayed Gross Motor Milestones & Bum Shuffling • Parental Perception of Normalcy vs. Lack of Family History • Neil walked at two and a half, much later than George • Delayed independent mobility • Over-flexibility noted in Neil • Delayed fine and gross motor skills • Neil's symptoms and differences. • Neil is academically strong • Limits to participation in typical childhood activities • Neil's differences, struggles to sit still. • Ongoing pain • Limit to accessing activities. • Joint pop in and out. • Fine motor/coordination challenges shape participation • Additional Dyspraxia diagnosis and overlap between dyspraxia and hypermobility. • Differences in how hypermobility or diagnosis presents between siblings • Family openness about neurodivergence and difference
	Onset and Diagnosis Journey	• George's thumb locked unexpectedly • Hypermobility diagnosis and condition played down • Kelly and Neil reassured • Referral to paediatrician at 18 months • Kelly suspects something more is wrong • Early misdiagnosis and invasive tests in diagnostic journey • Relief and validation at finally receiving a diagnosis • Long journey to stable symptom management • Complexity of comorbid neurodevelopmental and physical conditions. • Uncertain of genetic links to the family illnesses • Uncertainty and complexity around genetics
	Navigating Healthcare Systems	• Frustrated in navigating healthcare system • Positive difference in private healthcare – holistic, child-focused car • NHS Dr's not seeing Neil holistically. Privately much better.

		• Navigating healthcare systems/trying different medications • Health system barriers and lack of timely support • Long waiting lists and lack of ongoing access to vital therapy • Frustration at inflexible health appointment scheduling • Systemic barriers create inequity for less flexible families
	Experiences with professionals and Neil developing advocacy	• Dismissive and unempathetic professionals • Neil currently struggles to express discomfort or needs at school/encouraging self-advocacy. • Child becomes informant about missing supports. • Increasing child agency/self-advocacy in communicating needs. • Child begins to self-advocate for adjustments. • Growing self-confidence in expressing needs. • Frustration at lack of professional listening and timely support • Children's awareness and judgement of professionals • Aspiration for higher standards in professional interactions
Family Adaptation, Roles & Wellbeing	Family Adaptation & Routines	• Carried Neil until age five • Dilemma about equipment for older child • Practical adaptation for short journeys" • Family routines adapted to accommodate different needs • Family adaptation and humour in the face of challenges • Adaptation of family routines to support rest and recovery • Parental vigilance and interpreting child's pain signals • Importance of routine activities that foster wellbeing • Trial and error in finding accessible, enjoyable activities • Family adaptation to timing and energy needs • Planning and Logistics: • Impact on Family and Others • Social Exclusion/Feeling Left Out • Need for Understanding and Support

		• Volunteering/leadership in local SEND support resource. • Collaboration with professionals and services to support families • Focus on children and family as central to her sense of self-care • Ongoing parental adaptation and support for transitions • Contrasting parental personalities and their impact on advocacy • Parenting roles and negotiation of advocacy/control • Shifting responsibilities and attempts at shared caregiving • Differences in parental perspectives on coping and the future • Grandparent are hopeful/lack understanding • Emphasis on celebrating individual strengths and personalities • Everyday routines and shared interests strengthen sibling bonds • Affection and physical closeness as emotional support • Disruption to schooling and family routines • Parental perspective on the value of wellbeing education
	Sibling Impact	• Ongoing school choice and sibling impact dilemmas • Possible sibling support, but also may impact older brother if Neil goes to Grammar school • Awareness and understanding among siblings • Potential impact on older brother • Sibling presence as a protective factor during transitions • Sibling relationship as a source of support and protection • Siblings as ongoing companions and emotional supports • Mutual empathy and practical support between siblings • Sibling pride in teaching, helping, and supporting each other
	Kelly's Professional Identity and Parenting.	• Relating her professional values to her personal experience • Financial/system pressures influencing medication choices

		• High cost of specialist equipment for SEND children • Parental frustration at systemic financial burdens • Professional identity influences parenting/decision-making • Relating professional life to her personal life • Professional background in children's services and advocacy. • Transition to social work reflecting ongoing commitment to supporting others. • Application of professional grief/loss models (e.g. Kubler-Ross) to personal journey
	Emotional and Mental Health Impact	• Medical trauma and loss of trust in professionals • Feeling listened to and validated by professionals • Emotional toll of self-doubt and not being believed • Lonely parent • Parental anxiety about making the right decisions for wellbeing • Impact on child's self-esteem and in turn Kelly's • Emotional impact of repeated advocacy burden • Intrusive medical monitoring and loss of privacy • Adverse reactions and distress with new medications • Neil's discomfort and embarrassment in public settings • Parental acceptance and mixed feelings about child's perspective • Lack of self-advocacy for her own needs. • Empathy for others based on lived experience. • Empathy for families trialling expensive interventions. • Empathy for others based on lived experience. • Empathy for other families facing even greater challenges. • The challenge of practising self-care as a parent/carer. • Emotional Self-awareness and honesty about limits in self-care. • Struggle to prioritise personal self-care outside of parenting

		• Improved management of her own chronic condition over time • Realisation of importance of self-care to support caregiving • Self-aware and thoughtful about parenting when in pain • Frustration around healthcare • Coping by focusing on the present, not worrying about the distant future • Kelly anxious about transition and friendship making. • Kelly reflecting on Neil struggle to make friends and how hard that was for her. • Parental anxiety and sense of isolation at the start of the journey • Reminder for self-care amidst challenges • Parental hurt at not being informed or included
	Advocacy	• Burden of parental advocacy for care and appointments • Frustration with Dr approach and not talking to Niel. • Not child focussed/needed to ask to see Rheumatologist • Kelly advocating and leading conversation with professionals • Reliance on self-education and online information • Parental negotiation for child's inclusion • Parental advocacy for reasonable adjustments in school activities • Child's reluctance to self-advocate; parental role as spokesperson • Self-judgment and telling others: • Advocacy for Neil as he can find it challenging to speak for himself • Encouraging independence: • Parental negotiation for reasonable adjustments and OT input. • Ongoing need for parent to communicate and update school about child's needs. • Parent must ensure accommodations are maintained with each transition. • Parental intervention needed for basic access (toilets). • Parent-initiated advocacy leads to specific, practical adjustments. • Innovative accommodations (touch typing) require repeated parental push. • Parent must follow up and advocate for reinstatement of supports.

		• Parent-led initiation of EHCP for secondary transition. • Parental understanding of systemic constraints but continued advocacy • Frustration at having to lead conversations with professionals • Experience of complaints processes that lack practical outcomes • Recognition and praise for good professional practice
Social Inclusion, Stigma & Peer Relationships	Peer Relationships & Exclusion	• Social exclusion and participation dilemmas at peer events • Social and physical exclusion in school settings • Inclusion in supportive peer activities with adjustments • Exclusion from sports is a challenge to Neil's identity and social participation • Impact of transitions and differences on peer relationships and inclusion • Anticipation of future social judgement/discrimination • Inclusion and protection in peer and SEND community settings • Challenges of invisible conditions for inclusion in support settings
	Social Stigma & Public Perceptions	• Awareness of social perceptions and stigma with mobility aids • Ongoing discomfort and visible difference in group settings • Invisible illness and lack of understanding • Fear of judgment • Preference for empathy over sympathy • Concern about future employment limitations and workplace barriers • Recognition of legal protections but fear of ongoing discrimination
Educational Experiences & School Systems	Experiences of Educational Systems	• Lack of proactive school adaptation for SEND needs • School 'obsessed' with handwriting. • Lack of school experience with hypermobility. • Need for external professionals to guide school. • Lack of school initiative in researching or understanding ED • Lack of continuity in reasonable adjustments (equipment, supports). • Loss of vital accommodations/supports during school transitions.

		• School rules inadvertently exclude or disadvantage child with additional needs. • School's failure to notify parent about lost provision/staff suppo • School's practical challenges in maintaining support. • Importance of positive relationships with key staff. • Lack of communication and continuity from school about key staff and care. • School reluctance or resource issues regarding EHCP process. • SEND challenges • Awareness of wider context and needs among school population. • Anticipating practical and accessibility barriers in educational transitions • Worry about practical challenges (access, accidents) in school • Impact of missed schoolwork and inappropriate removal from important subjects • School's lack of communication about wellbeing concerns
Coping, Strengths & Community	Hope, Coping & Resilience	• Use of pain/fatigue scaling as a coping strategy • Child's adaptation to chronic pain as "normal" • Resilience and adaptability in the face of pain • Child's self-awareness and communication of needs • Swimming as a key coping and pain relief strategy • Emphasis on resilience and hope for the child • Live in the moment, but pragmatic in routine and approach • Sense of relief and gratitude for child's academic strengths • Importance of child-centred practice and listening to young people
	Support Networks & Seeking Help.	• Efforts to boost inclusion and attainment for SEND children • Value of family and support networks • Lack of local support groups and importance of peer connection • Unhelpful comparisons and competition among parents • Value of honest, supportive friendships for practical and emotional help

		• Lack of appropriate local and child-focused support groups
	Financial/Resource Barriers.	• Awareness of high costs for SEND families and aim to reduce barriers. • Innovative solutions to improve access for SEND families. • Recognition of financial strain for families in deprivation. • Aspiration to give families the support she values as a parent.

Appendix H-

Kelly- Stage 5- Categorical-Form analysis

6.	**Kelly:** um. The paediatrician, I have to say was not very empathetic, **Simon T Dixon:** Really? Okay. **Kelly:** at all, um, thank goodness *he's now retired,* which I think that's the most positive, um that's happened (chuckling), um , we did not, um, he he, just, *he just said on numerous occasion, I've got worse children than him basically, you know, yeah, um, that you're neurotic*, you know, you are, you know in a sense, you know, um, and the, I'm just *with regards to appointments, you know, So that constant chasing of an appointment to see a paediatrician,* um, *if I didn't constantly chase it just wouldn't happen and I really fear for other children who are going through a similar pain issue* **Simon T Dixon:** Yeah. **Kelly:** *that if their parents haven't got the knowledge of a system or the self-esteem and confidence how that, you know, how that affects that child, that must be really difficult,* um. So it was, *the frustration was huge*, really. My husband did come, um to the appointment, um, but the last one I saw him at, um I just couldn't even engage with him, I just, he was just, you know, *none of the Carl Rogers, none of the old empathy and the genuine* (chuckling, animated), none of that malarkey going on at all,	**Intensifiers-** "The pediatrician… *was not very empathetic, at all."* **Direct Speech (negative)-** "The just said on numerous occasion, *'I've got worse children than him* basically,'… that *'you're neurotic'"* **Repetition-** *"constantly* chasing of an appointment," **Paralinguistic Markers (Chuckling, animated)/De-intensifier-** " you know, none of the Carl Rogers, none of the old empathy and the genuine *(chuckling, animated),* **Intensifiers**- The frustration was "huge, really"; "none of the old empathy… at all"

7.	So um, and then we recently saw another paediatrician, So he retired and then we obviously, we had COVID and... **Simon T Dixon:** Yeah. Yeah. **Kelly:** then nothing was happening, you, know, and then they had no paediatricians um, or they had some but had no waiting list, So we saw one last year, we saw one and Neil um came along and he's like eight at the time. So we walk into the appointment *and she's like, you know what you here for today, sort of thing, talks to me and I'm like, "Talk to him he's the one we're here for he's the one who's struggling". (Animated. High pitched)* **Simon T Dixon:** Yeah. Yeah. Yeah. **Kelly:** *Just the frustration of that interaction even with the young person*, you know, *as he's got older he's fully aware of what he's going through,* **Simon T Dixon:** Yeah. ... **Kelly:** he's very... *he knows* his um, *his strengths, he knows what he struggles with*, um *but it's just that constant look at you to say what's sort of going on* really, um So that was last February and then um, we went private in the end because um, we didn't get anywhere really, to be honest. There was just a back and forward, I'd asked to be referred to rheumatology in (retacted), that's where you would be referred to. *however, she was very much like, "oh I've tried to refer somebody today, but they wouldn't take that, So I don't think they'll take yours." And I'm like, I don't mind the other person, it was about me, it's not child focused, you know, it's not child focused.* **Simon T Dixon:** Yeah. **Kelly:** *There is no child focus around this,* um, *So it was very much she just didn't understand*. She was walking um, and I said to her, *"you know he really walks in, he turns his foot over and she's just like,*	**Paralinguistic Markers (Animated/High Pitched)-** *"Talk to him he's the one we're here for..." (Animated. High pitched)* **Repetition-** *"it's not child focused*, you know, *it's not child focused*. There is *no child focus* around this".

	you know, *just like,* "what's the matter?" *just looking at him like, "what's the matter" and you're like, I, "surely you can see" you know (laughing) um. So I was leading, and I have, So all this time, I've led his care really, So I've been that person to coordinate* **Simon T Dixon:** Yeah **Kelly:** *care constantly* um*, without being the expert*, which is quite a worry, *So Google is an expert really (chuckling) So you're googling things which isn't appropriate at all um, and can be quite worrying as well,* um but I'm leading *and I'm saying he, we need to do this test and we need to do this test and we need to do this test. That shouldn't be the case, you know, there should be somebody, well the pediatrician should coordinate that care um, but I'm asking the questions to them, you know, um, which is a worry and it it shouldn't be something that is um, that is done all the time*.	**Active Voice-** *"I've led his care really," "I'm leading and I'm saying* he, *we need to do this test."* **Repetition-** *"coordinate care constantly"*
8.	So we went privately last year to Leicester and he's had a diagnosis of Ehlos Danos syndrome. **Simon T Dixon:** Yeah. **Kelly:** So a form of hypermobility, um, So he, um, So yeah, So basically, God love him, he has all of the flexible side of things, So his whole body is, So he's a little scarecrow, God love him, in that sense, um. But then also he has his bowel, So his bowel, um, is over.. So overflex, but then he's about a, um no, no sorry, his bladder is over flexible, his bowel is under flexible. So it's not stretchy enough, basically. But, then he also has um, really thin skin, So he got bruising, **Simon T Dixon:** Okay. Yeah. **Kelly:** *So he gets bruised quite easily. Um, sprains and that sort of things he gets um quite easily um as well, So there's quite a, but nobody saw him as a whole per.., no one saw him as a whole issue really in that sort of sense. Everybody kind of, um, was just*	**De-intensifier (Affective)-** "So he's a little scarecrow, *God love him..."*

	picking their points, you know, part, *part of him, but not seeing as the whole, So and the interaction we had with the pediatrician when you pay privately, it's very different (chuckling)* **Simon T Dixon:** Yeah.	**Paralinguistic Markers (Chuckling)-** "thank goodness he's now retired (chuckling)," "Google is an expert really *(chuckling)"*
9.	**Kelly:**. So as you can imagine (high pitch, chuckle) um, they were lovely to Neil, they were chatting with him getting to know him, really interested in what I was saying, *took the whole* sort of um whole *eight year, nine years that we've had through and um So it was a very different um, So it was a very different experience really.* **Simon T Dixon:** And was that almost instantly in the first appointment that you had? **Kelly:** *Yeah. Yeah. Yeah. Which is shocking, isn't it?* **Simon T Dixon:** Yeah. Yeah. **Kelly:** Yeah. So, particularly around, he's been in a under a *Paediatrician since he was 18 months and then we've got nowhere until he's like, nine. So,*	**Paralinguistic Markers (high pitched/chuckle)-** "So as you can imagine *(high pitch, chuckle)* um, they were lovely to Neil, they were chatting with him getting to know him.." **Intensifier-** 'Shocking"

	yeah. And he was like, "No, completely agree with you", you know, did a few sort of tests and things and he said, you know that's um and that's what it is. And then in the sense of, you know, you just feel, thank god, thank god we've got a diagnosis, which is terrible isn't it? But i always knew there was something **Simon T Dixon:** Yeah. Yeah. **Kelly:** But um you felt actually just listened to, *I think in the sense that actually somebody did listen and I'm not crazy*. I think it, you start to think am I crazy? You know, you start to think yourself, I think I might be cra..(chuckling) I think I might be thinking something that's not here **Simon T Dixon:** Yeah **Kelly:** and *having to really check yourself out with* that as well, and do you think that that was that, as well.	**Person Shift (I - You)-** "I think it, *you start to think am I crazy?"* **Mental Verbs-** *"you start to think am I crazy?* You know, *you start to think* yourself, *I think* I might be thinking something that's not here"

Appendix I-

Maddy- Working Transcript- StEP's1,2, 3 and 6

Move	Transcript	Key:
	Working Transcript – organized into segments with sjuzet underlined. Fabula and sjuzet overlap in *Italics.*	- Fabula within move identified as Fab:..... - Holistic Content- Annotated in green - Holistic Form- Annotated in yellow - Identity Positions- Annotated in blue
1	**Simon T Dixon:** Can you share your story with me? maybe starting with when you've kind of first realised that your child was experiencing pain. **Maddy:** yeah so probably help to know that, *um uh* doesn't really have any um or *wasn't having a great* uh relationship with her biological dad *before all this happened*. **Simon T Dixon:** Okay. **Maddy:** um her stepdad is actually a team leader for the ambulance service. okay so some of it we kind of differ um a little bit in how we react to her or interact with her because of his profession um and probably there is a little bit of how I react to her because of um my profession with working with children with sen um. **Simon T Dixon:** Okay. **Maddy:** Faith had some signs *before all of the medical side started* that she was *probably* on the autism spectrum um that's become more pronounced throughout so her coping strategies of lowered so going back to the medical side um she started two years ago with a lot of pain around her time of the month. it we'd been to the doctors numerous times and they'd kind of just *downplayed* it and said it's that time we've been sensitive.	Fab: Pain started 2 years prior; doctors dismissed it; poor relationship with bio-dad; parents' professions (ambulance/SEN) influence care. Hol-Con- layers of complexities- illness compounded by relational and neurodevelopmental complexity Hol form- (Advocacy / institutional battle.) IP: The Analytical Professional.

2	**Maddy:** and we ended up visiting A&E *three times* um because at that point Faith was then fainting through the pain *um multiple times* one of which her I'll call him dad, he's stepdad. So*, if Faith ever talks about him, dad is stepdad, sperm donor is her biological father, that's where she is at this point.* um her dad ended up having to send paramedics into A&E with a bed for her because they didn't have one and she couldn't stay conscious um we kind of just kept getting passed back to the pediatrician who for a while they were querying endometriosis... **Simon T Dixon:** Yeah. **Maddy:** but they didn't want to test for it because of her age so we were kind of in limbo for quite a while and yeah it wasn't nice that bit because we just wanted answers to see her going through all the pain but to not kind of know what was going on was really hard um and scary to be honest because there were a lot of different things floating around that it could be... um she kept *getting rushed in* thinking it was appendicitis but obviously it wasn't it was just where the pain was presented and finally on the last um her pediatrician was actually in A&E at that point and so Faith at that *point didn't want to tell* us that she was actually having bleeding when she was going toilet, obviously for a 14 year old girl it was embarrassing, um but she finally admitted it in the room with him and that's when kind of everything got put together and it was right, we know *where this is likely to now be going.*	Fab: 3 A&E visits; Faith fainting; diagnosis delayed; Faith (14) admitted to bleeding, leading to clarity. Hol form- (Advocacy / institutional battle.) Hol con- (Professional Knowledge as Resource and Burden) Hol-Con-Uncertainty- 'Living in limbo'. (Systemic Navigation and Ongoing Uncertainty) IP: The Practical Problem-Solver.
3	**Maddy:** um so three months after that she had um colonoscopy and endoscopy and it was confirmed, her diagnosis is actually only that 15 centimeters of her bowel is affected but it's *right at the very end of it* and so actually it's the hardest to treat and quite often is the most significant as far as symptoms so we are now after huge amounts of steroids and everything else she's kind of um she's not in remission the chances are she never will be because of where it is um but she's kind of stable, um but there's a lot of treatment to keep her like that. **Simon T Dixon:** Yeah. **Maddy:** so she's had the diagnosis now for 16 months, we it was literally January the 2nd last year we got it. um We had *about a year before that* of things *gradually getting worse.* **Simon T Dixon:** Okay. Yeah. Okay. **Maddy:** so it kind of then once we got the diagnosis actually got a whole lot worse for about six months. okay so *the test they do for it is the calprotectin test* um or one of them um it's a stool sample basically a normal person's range should be under 50. when they first did Faith's, when she presented with the blood in the November of the year before her um diagnosis,	Fab: Distal colitis confirmed (15cm); Calprotectin level spiked (300 to 4,700); stable but not in remission; high-dose steroids at home. Holi Con- (Systemic Navigation and Ongoing Uncertainty) Hol con- Monitoring symptoms- (Parental Responsibility and Vigilance)

	hers was about 300. by the March after her diagnosis it was at 4,700. **Simon T Dixon:** Yeah. Mhm. Okay. **Maddy:** so *and at that point* um Sheffield Children's wanted to admit her to being impatient. The only thing that stopped that was because where it is, it's not like Crohn's, *so she's still taking the nutrients from everything*. um So although it was ridiculously high and we had to go on very high steroid use and her other blood work was okay. so they allowed us to go home at that point and start the steroids at home, and but yeah, otherwise she'd have been an impatient for a good couple of weeks *while they got that under control before letting her back home from everything I've then read and spoken to her IBD nurse with* um *Sheffield Children's Hospital have been amazing.*	IP: The Trauma-Aware Parent. Hol form- (Advocacy / institutional battle.)
4	**Maddy:** And during all this time, as her levels have been getting better and so she's on um Infliximab infusions which I don't know sort of what your knowledge is but basically Infliximab was originally made as chemo drug and wasn't good enough but it turns out it treats um immune diseases quite... Yeah. **Simon T Dixon:** Sorry. Yeah. Yeah. **Maddy:** so it's used for rheumatoid arthritis, it's used for Crohn's and Colitis. She's also on another immunosuppressant as a tablet form and she has to have daily enemas. *Yeah, all of that is quite a lot for a 15 year old girl um so she's been all over the place with it* but she also then is dealing with daily fatigue and joint pain so we've had referrals through to um rheumatology. She's under OT and physio. **Maddy:** We are waiting for a psychiatry appointment and we are waiting for a sleep clinic appointment because her sleep has just been *absolutely battered* by this so it's then trying to work out what pain and fatigue is due to side effects from the drugs, what it what's the colitis what's the sleep it's it's all been a bit of a minefield really um she is under a private counsellor at the minute to *try and deal with it all* uh but I'm the punch bag exactly. **Simon T Dixon:** Okay.	Hol-Con- (Systemic Navigation and Ongoing Uncertainty) Fab: Treatment includes Infliximab, oral immunosuppressant, daily enemas; has fatigue/joint pain; referred to multiple clinics/therapies; sees a private counsellor. Hol-Con- (Relational Strain and Emotional Containment) Hol con- Parental Responsibility and Vigilance Hol form- (Emotional Absorption) IP: The Emotional Buffer.

5	**Maddy:** (Becomes upset/tearful) um God sorry. **Simon T Dixon:** No, it's okay. It's okay. Take a break if you need. It's okay. Okay. **Maddy:** no, you're fine it's just it is what it is so during all of this um *she cannot mask for love no money now so everything is a big deal* um she's *gone down the route* of severe anxiety and OCD with things and her brothers get *a bit of a bashing* at times, they're older um and she'll go very silent on her step-dad at times. During all of this her biological dad has had absolutely no contact and hasn't even asked her how she is *so that has obviously played a part in things and that is impacting now her relationship with her stepdad...* **Simon T Dixon:** Mhm. **Maddy:** because she's waiting for him to disappear on her as well um so yeah she's a bit of a minefield and then I just try and keep it all together but it's it's been a lot um there's a lot of worries about her future. She had got her career lined out. She decided what GCSEs, what A levels, what uni she needed to do to get there.	Fab: Severe anxiety/OCD; biological father has zero contact; Faith fears stepdad abandonment; worries about her future career plans. Holi con- Neurodivergence shapes experience of illness and coping. Hol Form- Expert Sense-Making IP: The Dismissed Seeker. Hol Form- Expert Sense-Making Hol con- Illness embedded in pre-existing relational insecurity.
6	**Simon T Dixon:** Okay. **Maddy:** *That might not be a possibility now depending on how she is* um she was *pretty* academic before and she is now in school two, six, nine, twelve lessons a week and the anxiety that everything is kind of created means that actually for a couple of those best things she can't actually get into lessons, *she's kind of sitting in their sensory room just trying to actually be in school rather than in the lesson* and so there isn't a great look *a lot of hope for really to be honest ever going back full-time before GCSEs. We have had a lot of fights with her school over their support* and we have a very good OT that has ended up coming into all the meetings with me just so that there is now an official professional on her caseload to back up what we're saying and to get things passed through. Obviously, I know *that there's sort of hoops* that school have to j ump through and everything else but it hasn't been particularly easy um so that's added an extra layer of stress there. They have now reduced two of a GCSE well *we've quit* two of the GCSEs so *at least she hasn't got as much to go back to and try and keep up to date with. But her panic is*	Fab: Low attendance (max 12 lessons/week); uses sensory room; Maddy fought school, brought in OT; 2 GCSEs dropped; Faith anxious about exam accommodations. Hol Con- (Systemic Navigation and Ongoing Uncertainty) Hol form- (Advocacy / institutional battle.) Hol con- (Professional Knowledge as Resource and Burden)

	already setting in about um her what her actual taking the exams is going to look like, whether she's going to get the private room, whether she's going to get the extra time, which is over a year away but she stresses then about that. So, we're kind of *at the point of let's as long as you get five GCSEs let's just concentrate on that.* **Simon T Dixon:** Mhm. gosh.	IP: The Institutional Combatant.
7	**Maddy:** So, yeah, between trying to hold down a full-time job which isn't the easiest and home life and Faith's school and Faith's health and hospital visits, and we bought a border collie puppy three months before she got diagnosed. Oh gosh, yeah, that wasn't the greatest of thoughts um *but he had been to try and get her socialising a bit more and out doing classes with him.* But obviously then her health has meant that a border collie puppy is *not ideal so he's actually ended up being my headspace instead* um *he doesn't do busy environments very well.* **Simon T Dixon:** Okay. **Maddy:** So, me and him go and hide in the woods for a couple of hours every evening and just breathe and it works. So, yeah, it's been a lot. **Simon T Dixon:** Yeah. Yeah. It sounds like it's been a lot. What in terms of I mean you touched there about that's kind of one of your coping strategies is that going and getting space. Is there anything else that's helped you through? **Maddy:** um yeah**,** *my husband um to be honest he's the straight talker and sensible.* **Simon T Dixon:** What's this? **Maddy:** *I would say I have probably got a* um *high chance of being on the spectrum as well.* **Simon T Dixon:** Okay. **Maddy**: I would, I would say if I went for a diagnosis I would probably *be ADHD and autistic in there and so my head doesn't switch off um and I will go through 101 outcomes anyway without then the stress and anxiety of everything that's been going on so he kind of tends to ground me* um *and get me to think straight*. Work have also been really good um. I work in quite a small setting. So we all work the same room together we are all quite close friends um in fact two of my friends at work their children are in Faith's year **Simon T Dixon:** Okay. Yeah. **Maddy:** so yeah we kind *of they get it and there has never ever been any, you're not completing your job, you're not doing this.* um *they've got my back and I've never kind of had to worry at any point that I'm gonna have a comment of, well she's going out again to pick a daughter up again.* um *so it's been quite refreshing. Yeah***.**	Fab: Maddy juggles work/care; dog is Maddy's coping mechanism; husband helps ground her; Maddy suspects she has ADHD/Autism; work provides support. IP: The Solitary Processor. Hol Con- *(Coping, Support, and Sustaining Hope)* Hol form- Expert sense maker Hol con- (Professional Knowledge as Resource and Burden)

8	**Maddy:** *but sometimes it is wondering then with where her head is whether it's just a physical symptom of what's going on in her head at that moment or whether it is actually pain.* **Simon T Dixon:** Yeah. Yeah. **Maddy:** so yeah, *she don't make life easy.* **Simon T Dixon:** And how do you manage that then? Mhm. **Maddy:** um It's a balancing act all the time. I want to be able to just go stay at home, *don't worry about school, but that doesn't help her anxiety. that doesn't help the long term.* She's gonna have to live with this. She's got to find her own coping strategies and her own way of working through things because otherwise what is her adult life going to look like? um she isolated herself a huge amount, she was already having a few um troubles with friendships *before all of this.* she masks she was masking very well when she got to comp. *Obviously socially things change as a teenager*. and she went from a one class per year junior school up to a 2,000 child comp and that was a big change for her so she was already having some problems. *All of this has meant she's hidden herself away.* **Simon T Dixon:** Okay. Yeah. **Maddy:** um she's got about three friends and they are all older than her. Yeah. *So nobody in her year, so I don't think that helps with the not wanting to go to school* and things like that. But it's it's like said it's that balancing act between pushing her to try and do things without going too far because we're all very aware that if she does too much we have wipe out for two days, three days after it. and at the beginning that was a constant cycle. *She's learning to understand her limits now a bit better.* **Simon T Dixon:** Mhm. Okay.	Fab: Maddy questions if pain is mental/physical; balances pushing for independence; Faith is isolated (3 older friends); learning to manage limits (avoiding "wipe out"). Hol form- (Expert Sense maker) Hol con- (Professional Knowledge as Resource and Burden) Hol form- Emotional Absorption Hol con- (Parental Responsibility and Vigilance) IP: The System Realist.
9	**Maddy:** but *it's just then been celebrating massively her* um *putting herself out there and her strides then in itself*. So, before it, she we all used to boulder a lot um that kind of stopped. Her um middle brother obviously carried on, he's 19, so he was doing his own thing anyway, *and but she's just started going back to do that with him now.*. okay And *so that's been a massive strive both socially and her anxiety getting out there and doing something, but also it's her being able to exercise and things again without too much pressure.* **Simon T Dixon:** Okay. **Maddy:** she can quite she can do a couple climbs, *she can rest and watch the others do it and do it that way. and that's we have to be very careful then with that*.	Fab: Faith resumed bouldering with brother; Maddy is not allowed to watch; Maddy appreciates the break from Faith's attachment. Hol-con- Continuity / hope counterpoints (Coping & hope).

	So, *we celebrate it, but I'm not allowed to watch her at the minute*. okay go figure. **Simon T Dixon:** You used to go together. Yeah. **Maddy:** Yeah. Yeah. we used to we used to climb together. So her brother was in a squad climbing so he used to go to squad and her and I used to climb together. **Simon T Dixon:** Okay. Yeah. **Maddy:** *and now it's something she doesn't really want me to do with her. She wants to do it with her brother.* **Simon T Dixon:** Okay. Yeah. **Maddy:** which to be honest has been quite nice because um *with everything that has gone on, she's kind of been attached to my side and not willing to leave me.* **Simon T Dixon:** Yeah. **Maddy***: and that gets a bit overwhelming at times and tiring in myself so the fact that she's that's where she's now actually she's just gone climbing with him and so I at least get a couple of hours where I know she's doing something she's going to be happy about and I can just switch off.* **Simon T Dixon:** Yeah. Yeah. I think Yeah, like you say that space seems like it's important to you. is there any Yeah. **Maddy:** um *you kind of think you're getting over it as they get to teenagers, you think they're not going to need you so much and it's kind of gone back to her being a toddler again and being by my side. So, yeah,* it's been a bit of an adjustment.	IP: The Protective Shield. Hol con- (Relational Strain and Emotional Containment) Hol con- Emotional Absorption Hol con- Coping, Support, and Sustaining Hope
10	**Simon T Dixon:** Yeah. Is there any other ways in which you feel it's kind of impacted not just you but the wider family and relationships and **Maddy:** yeah but so this yeah, my mum doesn't believe in labels, um so when we try and explain that Faith might not be seeing things quite the same way and that might be why there's certain reactions from her, that doesn't help. um Both my parents were teachers, were secondary school teachers as well so they although they try not to they are forever talking about her schoolwork and she needs to be in lesson when she's in school and Faith is feeling that as pressure and then I get my mum and dad complaining	Fab: Grandparents pressure Faith; Maddy mediates family conflict; middle brother is a calm support; reduced couple time; daily "good/bad thing" ritual is difficult Hol con- (Parental Responsibility and Vigilance)

	to me and then I get Faith complaining to me and I'm in the middle yet again trying to calm them both down really. um Yeah. there's been a lot of that. um Her eldest brother and her go head to head sometimes. They're very similar and both quite fiery um and she doesn't have as much patience for his jokes when she's not feeling great. So, they're kind of very hit and miss whether they get on recently. um The middle brother, the middle one, *he and her have become a lot closer. He's always been quite calm and we call him Victor Meldrew. He's that old man in a 19 year old's body so he does kind of just and and she seems to like listen to him.* So, like the climbing, she's willing to take direction from him where she won't anyone else, um, and me and her stepdad to be honest we don't get as much time as we used to together. um It gets quite draining**.** um And it's sad because we used to have this silly thing where every night it was like, right tell us one good thing, one bad thing about your day and she struggles to tell us good things.	Hol con- Emotional Absorption IP: The Family Mediator.
11	**Maddy:** um And I wouldn't say it's ever led to arguments between us. um We have different ideas of how to deal with it. um He's kind of *quite no-nonsense,* look she just needs to get on. Yeah. um I'm probably a little bit too much the other way in that I see that it's not just about her physical health. There is so much going on in her head and I think we have talked about looking at diagnosis for um the neurodivergent side but *we talk a lot about that anyway.* She knows my job, she knows my specialism. um And I think it probably would help her, but with everything else going on it's like, let's just try and get you stable first. But I think because that plays such a massive role in how she reacts and deals and sees things and probably how I react and deal and see things as well*. I can see little things that my stepdad probably doesn't see. And so he always says I'm kind of a bit soft and I'm like, well you're a bit matter of fact.* um And then the fact that she kind of needs someone around her **Simon T Dixon:** Yeah. **Maddy:** if not for her health but just for her to feel safe in herself. it's kind of led to then us not necessarily being able to spend quite as much time together. Yeah. um And there has been although I have been quite lucky not had to reduce my hours or really take much time off, and just the added bills from hospital parking and moving to get a private counsellor in because we all know the waitlist for CAMHS, she'll have aged out of the system before she gets there. and that's not a negative that's kind of the reality. We're both aware of that so we went down	Fab: Parents have differing approaches; neurodivergent diagnosis postponed; financial strain from hospital/private counselor; Faith fears passing illness to future children. Hol con- (Parental Responsibility and Vigilance) Hol Form- Emotional Absorption Narrative: "The Safe Person" The Grief-Stricken Observer. Hol con- (Relational Strain and Emotional Containment)

	that route, but obviously there is then a financial impact on all of that as well, um, yeah, it's just there's always something. And then you even kind of go further and like you were saying about um thinking about having children, she's never particularly been a child that was like, I want to be a mummy when I grow up. I think she always thought she would be. And now we have days where all she does is cry because she can't bear the thought that if she ever has children she'll pass this on to them.	
12	**Maddy:** and so we have some days where she's not sure, some days where she's adamant she'll never have children *because she can't bear this to be somebody else's future.* **Simon T Dixon:** Mhm. Yeah. **Maddy:** um Which then makes me sad because I was never the child that particularly wanted to be a mum, but I wouldn't be without any of the three of them. They've changed my life kind of thing. And I'd hate that she was missing out on that because she's scared of a health condition. I mean, if that's their choice not to have children, then I'll always support that. But if it's purely because of what this has done to her, then that's sad. So, yeah, I feel like I've got all heavy there. **Simon T Dixon:** It's okay.	Fab: Faith may choose not to have children due to health fears; Maddy expresses sadness. Hol con- Emotional Absorption Narrative: IP: The Knowledgeable Advocate.
13	**Simon T Dixon:** Like I say, you know, it will go where it goes. I think it's um yeah I you know you're kind of going through the story really and talking about how you cope and you're flitting back and forth from different, different things which is interesting. One thing you said quite near the start was about how it's changed your relationship um and how you kind of you said you're a punching bag but then kind of on the other side of it she's become more attached to you. I just wondered if you kind of talk me through that a little bit, tell me tell me a bit more about the story. Okay. Mhm. **Maddy:** I'm her safe person. Okay, um, her biological dad and I split up when she was four. um *The boys have different relationships with their dad.* um She had one until a couple of years ago. *A lot of things kind of happened.* He's got another family and there were issues going on between Faith and them. um *But I think she feels a lot of abandonment from him..* um *And the fact that then he's not really checked in on her or anything else* um *it doesn't help that my oldest son was working with him up until a month ago and so knowing that there was daily contact and he wasn't checking in on her kind of didn't help.* um So she yeah,	Fab: Faith feels abandoned by bio-dad; stepdad (Ollie) is supportive, but Faith fears he will also leave; Maddy is the constant "side person" who won't disappear. IP: The Rights Defender. Hol con- (Relational Strain and Emotional Containment) Hol Form- Emotional Absorption Narrative: "The Safe Person"

	she struggles with that. um Ollie, my husband now um he has been in their lives for the last six years. **Simon T Dixon:** Yeah. Yeah. **Maddy:** and they do have a really strong relationship and she calls him dad, she, depending on what day *she wants to change her name.* um They are very good together*. But she's scared he's gonna leave too. Yeah. I'm the only one that doesn't go anywhere other than granny and granddad*. So, **Simon T Dixon:** Mhm. Yeah. **Maddy:** um, *my mum's not the easiest, so all three of them in varying degrees keep things away from granny anyway because it's just easier than not getting a lecture.* um So kind of yeah, I'm I'm the go-to but I'm also the one that's not going to disappear if she kicks and scream. Actually, she doesn't physically kick us she well she does quit scream.	Hol con- Coping, Support, and Sustaining Hope Hol Form- Emotional Absorption Narrative: "The Safe Person"
14	**Simon T Dixon:** Yeah. Mhm. Yeah. **Maddy:** *but I'm never going anywhere and she knows that.* So, I get the outbursts, I get the stroppy behavior and the silences. um *She has a* really annoying habit *at the minute of walking out of a room mid conversation if it's not something she wants to hear.* um We are a family that very much don't shout. I don't believe the children need it. Don't get me wrong, they get it sometimes when tension's high and things, but I'm very aware that um especially my eldest, he was definitely the teaching method. um *You start shouting out here mini switches off.* **Simon T Dixon:** Yeah. Yeah. Okay. **Maddy:** I would much rather sit and explain my feelings and and my thoughts and then we try and talk things through. um *Faith doesn't always like that option at the moment*. um And her counselor has recommended that if she's struggling and she feels overwhelmed to walk away from a conversation. That however doesn't always go down too well here because walking out mid conversation is rude, um, *on the whole, she's a really good kid, do you know what I mean?* If she thinks she has done wrong, *that is far more punishment than anything that ever needs to be doled out*. She has a very strong sense of justice. **Simon T Dixon:** Yeah. Mhm. Okay.	Fab: Faith directs anger at Maddy; uses outbursts/silence; Maddy struggles when Faith ignores her (24-hour silence); Maddy relies on husband/dog walk for coping; Faith is attached but reactive; Maddy feels she is walking on eggshells. IP: The Relational Partner. Hol con- Relational Strain and Emotional Containment

	Maddy: um So there's normally a reason behind it and we will then tend to talk it through. Yeah. um But yeah, like the other week she came in calling her teachers not very nice names because they'd annoyed her at school, and I told her it wasn't respectful to saying to call teachers names. I got that they'd upset her but she didn't need to call names. And that was when the door was slammed and she just walked out. So, she got called back and told that that was disrespectful as well. **Maddy:** um Which she didn't like and then I wasn't spoken to for 24 hours.. Which is a normal teenage thing, but with everything going on, that kind of hurts me and cuts me more than anything else. um **Simon T Dixon:** Yeah. Yeah. Yeah. **Maddy:** And I do struggle with that. And like I said before, my husband tends to calm me down. um And then I go take the dog for a walk in the woods for a couple of hours in silence and yeah, *for woods and forests seem to kind of be my calming place. So, I do try and make sure that if I am feeling overwhelmed, that's where I take myself.* um... *I think I've got to the point now at 42 where I'm quite aware of where my sort of limits are and what I can take and we will try and walk away from each other.* um. **Simon T Dixon:** Yeah. Yeah. **Maddy:** But you kind of feel like you're walking on eggshells quite often around here. You don't know what mood she's gonna be in and what you're going to get. and she seems to be able to moderate that level of frustration and anger with everyone else. Yeah. Apart from me, yeah, tends to hold it all in and give it me. So, yeah. **Simon T Dixon:** Yeah. It's Yeah. **Maddy:** but then at the same time, like you said, she also needs me and so she will end up spewing everything that's gone on during the day at me within seconds of me walking through the door and I get blow-by-blow account and all of her feelings around it all. And then I'll make one comment about, "*Well, did you try this?*" and I get one straight at me and she then slams the door and walks off and you're like, "Okay, maybe my opinion wasn't needed then." But yeah. **Simon T Dixon:** Okay. Yeah. Yeah.	Hol Form- Advocacy & Institutional Challenge Hol form- Grounded Resilience Narrative: Hol con- Coping sustained through relationships, solitude, and small successes. (Coping, Support, and Sustaining Hope) Hol con- Relational Strain and Emotional Containment Hol form- Emotional Absorption Narrative: "The Safe Person"

15	**Simon T Dixon:** Also something you said um a couple of times is that you kind of I think you mentioned it previously about um I think you fight you use the word fight with school and then you kind of mention it there is that yeah I suppose can you tell me a bit more about, about that and the difficulties maybe around that or your experiences around that? Yeah. **Maddy:** So, um school started uh when she was first off before the diagnosis and *everything else.* She ended up with quite a bit of time off and the attendance officer turned up on our doorstep *even though I was ringing every day and explaining the situation and I'd had a long conversation with them about we don't know what's going on,* we're at A&E constantly. I'd picked her up from school and taken her straight across to A&E. um *She had had a panic attack at school during it all where then a teacher, she'd been allowed in the corridor to try and calm down*. um... a teacher who *no longer works there* um then harassed her in the corridor into going back into a classroom. um And that was her first major panic attack and it left her with T-Rex arms for *a whole weekend.* um That didn't go well. um *School didn't like mine and her step-dad's response up to that.* um Especially her stepdads in the fact that they'd not called for an ambulance or anything else and that was the very first time anything like that had ever happened. and she'd actually hyperventilated *to a point where her whole arm muscles had seized.* um So we'd had a few run-ins with them with that and then a week later the attendance officer turned up on our doorstep while I was at work with no prior warning or anything else and I um completely understand they need to check that children are actually ill and whatever else um are safe and safeguarded. um *However, they'd also had a lot of contact with me around it all and so it kind of pressed my buttons a bit*. And Faith actually answered the door to him and he kind of was trying to question Faith on the doorstep about what was going on which then *obviously surrounding her time of the month and everything else, Faith was absolutely mortified.*	Fab: Conflict started early: attendance officer visited despite communication; Faith was harassed during a panic attack,(resulting in T-Rex arms/seized muscles); Maddy angry that school didn't call ambulance; attendance officer questioned Faith (mortifying her). Hol form- (Advocacy / institutional battle.) IP: The Witness to Trauma Hol con- (Systemic Navigation and Ongoing Uncertainty) Hol form- (Advocacy / institutional battle.)
16	**Maddy:** So, *we had words about that.* um And we called a meeting and *I decided to throw my weight around a little bit* and explained what my job was and what I um did. And so they kind of then went, "*All right, okay. Well, we better get the SENCO into this meeting as well then.*" Yeah. *They had no intention of any of that beforehand even though we'd asked for support and we'd explained. um There was a lot of just trying to harass us really. um* The SENCO at the time was really good. She put breaks in place for Faith. She was still on a full-time timetable at that point. um But she'd put timeout cards in place, um, he, we	Fab: Maddy fought school, revealed her job (SEN), forcing SENCO involvement; initial SENCO left; Maddy brought in IBD information (CICRA) for diagnosis meeting; the rude attendance officer was confronted, then became the family's biggest advocate (due

	did a lot around then trying to calm Faith when she was at school. um And she was somebody that Faith felt she could go to when she was having a hard time. **Simon T Dixon:** Okay. **Maddy:** She left three months later. How it goes, isn't it? **Simon T Dixon:** Yeah. Yeah. **Maddy:** um We then got her diagnosis and um we went into a meeting. **Simon T Dixon:** Okay. Yeah. Yeah. **Maddy:** and my husband came with me and he'd actually printed out pictures of what IBD was and everything else because *she was getting a few comments thrown around of, "Get over it, it's tummy ache."*. So, we'd pulled off all the information *on his side* from health, um, there is a really fantastic organization called um CICRA, it's called um C-I-C-R-A. Basically, it is um Crohn's and Colitis UK but for children. um *So they'd sent packs upon packs of information for schools for teachers about what it was Faith was going through.* She has her own radar key. um All of those kind of things. And the attendance officer uh walked in while we were in reception waiting for this meeting and just went "One minute" and walked back out. *My husband doesn't do well at being spoken to quite rudely like that.* **Simon T Dixon:** Can you just say that again... because you broke up and you had just had to say it and I was like **Maddy:** Well, we were we were sat in reception and the attendance officer just walked in and went "One minute" and walked back out. **Simon T Dixon:** Okay. Yeah. **Maddy:** So, yeah, didn't do well. um My husband had been on a full night shift and not gone to bed yet at this point*, so really wasn't doing yeah, sure, yeah*. And he was like, "I'm not being spoken to you like that." *I will just say at this point the attendance officer is now our biggest advocate at school.* **Simon T Dixon:** Okay. **Maddy:** He's incredible. *Just that conversation of you didn't need to speak to us like that and then him*	to having a daughter with MS) and a safe person for Faith. Hol form- (Advocacy / institutional battle.) Hol con- (Professional Knowledge as Resource and Burden) Hol con- (Systemic Navigation and Ongoing Uncertainty) Hol Form- Grounded Resilience Narrative: IP: The Conversion Strategist. Hol con- Coping, Support, and Sustaining Hope Hol form- (Advocacy / institutional battle.)

	sitting and going through everything. Turns out *his daughter has MS and he's* actually *only a few years older than Faith, so he then got it. He now will do anything for me that he possibly can.* um We have a running joke at work that he always calls me and himself by the first the first names on the phone. So, he rings work and it's, *"Hi, it's Jared. Is Maddy there?" And they all now, it's, "Oh, it's Jared for you."* So, he's actually turned into our biggest sort of cheerleader there. **Simon T Dixon:** Yeah. **Maddy:** And Faith will go to him over everything. I owe him gold when we leave that school.	
17	**Simon T Dixon:** So, how would you say that that's that's made a massive difference now having that because you talked about the importance of safe people. Okay. **Maddy:** Yeah. So, having him there that she knows she can go to makes a difference. um We've kind of gone back and forth a lot with school. I've had to make it very clear unfortunately **Simon T Dixon:** Yeah. **Maddy:** because it shouldn't be like this and it concerns me to some extent that I know the the um code of practice. I know what reasonable adjustments are, I know everything that's out there *and I've still had to fight and and throw my weight around a bit and everything else to get what Faith needed.* um What about the children that's parents don't know that? What about those parents that feel like there's something wrong with their child, something's not working, whatever, but don't have the medical background that we've got as a family, the education background that we have as a family, *and we've still had to fight. We've had to get her OT in on meetings to agree things.* **Simon T Dixon:** Yeah. Mhm. **Maddy:** um The meetings we have at the moment are with the assistant SENCO and she's lovely. Um, but she's still doing her qualification, so everything we agree has to go back to the head SENCO who agrees it, now that I've got an OT on board. Um. But also Faith has then had one teacher quite a few times recently challenging her about why she's having rest periods, even though it's written into her support plan because of needing them for the fatigue and everything else. The teacher that has challenged her	Fab: Maddy regrets having to fight to get reasonable adjustments; Faith's rest periods are challenged by the lead SENCO who avoids meetings; Maddy highlights the need for advocacy, especially since Faith is one of only three children with significant medical needs; Faith is already panicked about exam flares (a year away) Hol form- (Advocacy / institutional battle.) Hol con- (Systemic Navigation and Ongoing Uncertainty). Hol Form- Expert Sense-Making Narrative Hol con- (Professional Knowledge as Resource and Burden) IP: The Strategic Fighter.

	every single time is the *lead SENCO that signs off on all these and will not actually come to a meeting with me.* **Simon T Dixon:** Yeah. Yeah. Mhm. **Maddy:** And it's like if you're doing that role, you should be their biggest cheerleader, their champion, you should be the one making sure everybody is following their plans. *And I get that there's a lot of children in that school. um I can imagine their SEND registry is fairly high* knowing the area. um I know mine is and I'm the preschool alone, do you know what I mean? We've 50 on register, we've got a 35% SEND register and a few on our watch list, so I can imagine what theirs is like. um *But I also know from the attendance officer that there are only three children with significant medical needs in that school.* One is Faith, another is a child with epilepsy and the third is a child with rheumatoid arthritis that from what I can understand has very similar support planned to Faith. She's in the same year as Faith, um If there's only three children in all of that and they're all children that actually are very academic, they're not trouble, you should know those children and having to fight for everything we've had to fight for. um **Simon T Dixon:** Okay. Yeah. Yeah. **Maddy:** They're telling us that her exam conditions are already set in stone and in place for next year. I don't believe them. um So I *know there's still going to be another fight for her* GCSEs and the amount of children in Faith's situation that end up from the stress of it all flaring right before their GCSEs and ending up in hospital, ending up not able to take their GCSEs and special consideration having to be put in for them. *It worries me* because where her head is now and where her thought processes go, she's already panicking about that and we're a year away. Yeah. um So yeah, great times.	Hol form- (Advocacy / institutional battle.) Hol con- Coping, Support, and Sustaining Hope Hol form- (Advocacy / institutional battle.)
18	**Simon T Dixon:** So looking into the future, I know you kind of said yeah, you said that, yeah, obviously that's where a couple of times you kind of got there and said that it's it's hard to see hope. It's the times where you can or because I think so, yeah, yeah, because there's he did say about you know this this you know she's gone bouldering today and she started to do that again. There's little things that feel, but I just wondered whether or not this you know if it feels like Yeah. Yeah. Tell me about that. Yep. **Maddy:** Yeah, *I think she needs to find her tribe.* I think that makes a big difference. um I never had a huge	Fab: Maddy believes Faith needs to find her "tribe" of supportive friends; Faith struggles with future plans, especially her career goal of being a police detective (potential stoma would prevent front-line work); family is considering moving to a house with an annexe for long-term

	friendship group at school. I always kind of felt a bit of the odd one out. I now realise that probably was because I'm neurodivergent and that plays a part. um I think that is playing a big part with Faith rather than the illness and the um joint pain and everything else. But then that's another layer on top of it that *then the tentative friendships she's got, if she's then having a bad day, they're seeing her as being negative* or, "Oh, she's not coming out again," or whatever else. *And so that then straight away impacts on that friendship.* um The three friendships she's got are very strong. **Simon T Dixon:** Yeah. Okay. Mhm. **Maddy:** And *they're all a little bit weird like her, so that helps.* um She she just needs to settle. And I think she's getting there with the counselling. I wouldn't say it's remedied everything. And I think some things it then doesn't necessarily help because she goes over and over, *but I think once she can come to terms with things...* she's gonna have to change some plans for the future. She wanted to be a police officer. um That was all she ever wanted to be, a detective. She wants to go and solve crimes, um, *if she if her illness doesn't stay under control and she ends up with um a stoma, she can't be um on the front line.*. That is one of the biggest things that she struggles with. um And she's struggling with looking forward now. We have some good days where she then talks about studying law instead and going down that route, but then it cycles back to panic over she might not even pass the GCSEs, so how is she going to do that? So, we talk a lot around um doing it slow. She doesn't have to do it the same way as everyone else which is GCSEs, A levels, uni. She can take her time and **Simon T Dixon:** Yeah. Mhm. **Maddy:** do it over three years instead. *There's no time limit, deadline set for her.* *um* We do however keep talking about moving house and we do keep looking at houses with annexes because there is the thought that at some point she may end up needing to be with us longer term depending what her health does. One of my cousins has um uveitis and, and rheumatoid arthritis, *um, her, her choice she never married she never had children she's a few years older than me but at the moment she cannot get her flares under control* and she's ended up moving back in with her parents just so she's got support and they've done it well and she's fantastic she's still doing some work and	support/independence; Faith is sensible with meds/diet but has lost her "silly side" glimpses of adolescence during sleepovers are cherished. Hol con-(Coping, Support, and Sustaining Hope). IP: The Independence Builder. Hol con- Parental Responsibility and Vigilance Hol-con- Coping, Support, and Sustaining Hope

	everything else she's just got that background support. **Simon T Dixon:** Yeah. Yeah. **Maddy:** and I think our long-term plans are, *if we can have somewhere that's got something where Faith can still, if she needs to have us more by, but keep her own independence, then that's never going to be a bad thing to have*. Hope it doesn't end up like that, I hope she can get it kind of under control a bit more. And she is making sensible decisions and *I'm very lucky that she's not kind of gone*, *"I don't want to take this medication anymore,"* and then we're having those battles. **Simon T Dixon:** Yeah. Yeah. **Maddy:** She's very sensible around like she's absolutely terrified of needles. So to start with the infusions were *horrific.* Now she's kind of, *"Right, I know I've got to do it because it makes me better for so many weeks."* So at least there's a bit of sense in those. She wants to make herself better. **Simon T Dixon:** Yeah. Yeah. **Maddy:** *She is quite good at I know which foods don't necessarily help*. So, *I will stay away from them on the whole*. *but you don't ever want your 15-year-old to think like that,* **Simon T Dixon:** Absolutely not. **Maddy:** do you? I mean, **Simon T Dixon:** No. Yeah. **Maddy:** *she should be up to trouble and running a muck* and she's had to grow up quite a bit. **Simon T Dixon:** Yeah. Do she still have times, **Maddy:** Yeah. It's just yeah. **Simon T Dixon:** where she can do that or do I guess less, but yeah, are the times where she can be an adolescent, be **Maddy:** um, yeah, she does. It's nice like when her friends, *it doesn't happen often,* but when her friends do come for sleepovers, like one's sleeping tonight and I know at midnight they'll still be giggling and	Hol form- Expert Sense-Making Narrative: Hol con- Coping, Support, and Sustaining Hope Hol form- Grounded Resilience Narrative

	Simon T Dixon: Yeah. Yeah. Yeah. Yeah. **Maddy:** and that is we sit and just grin *because that's music to our ears because* you don't hear that very often anymore from her. She kind of lost her silly side a bit and she was a bit of a goofball before and **Simon T Dixon:** Mhm. Yeah. **Maddy:** *now she just hasn't really got patience for a lot of things.* **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. **Maddy:** um, *which is sad, but can slowly start seeing with this with like the climbing that there's little glimmers there of who she was* **Simon T Dixon:** Yeah. Yeah. **Maddy:** and hopefully she'll get there. But yeah, it's just her building up and her learning to listen to her body. Yeah.	Hol con- Coping, Support, and Sustaining Hope Hol form- Grounded Resilience Narrative
19	**Simon T Dixon:** Yeah. Like you say, she had to grow up quickly, hasn't she? and kind of be aware of things that yeah, I mean I just thinking when you were talking then your experiences of having you know other children who are older and how different their experiences might have been. Yeah. But I don't know they may have had similar, you know, it might be they've had problems with health or other areas, but I just wondered if you reflect on that a little bit. **Maddy:** um I think there's always, I hate to say I'm one of those moms that treats their sons and daughters differently, **Simon T Dixon:** Okay. Yeah. **Maddy:** but I think there always is a little bit of that. um My boys are two very different personalities. You know how they always say *the second born is the troublemaker*, the one who's going to end up in trouble. Yeah, it's complete opposite with my two. My, uh, my second, Jack, sent me a reel the other day on Facebook, some silly things saying, *"If you ever needed somebody to help you hide a body, which child would you choose, and why is it your second born?" And he just sent me one saying, "But that's not me, that's your firstborn." That's my firstborn. He is a wind-up merchant,* **Simon T Dixon:** Okay. Yeah.	Fab: Maddy describes her three children's diverse personalities and parenting approach (open policy/truth-telling); eldest son is a practical "wind-up merchant"; middle son (Victor Meldrew) is book smart but lacks common sense; Faith, the youngest, has been the organizer but Maddy tends to defend her more in arguments. Hol con- Normal mother/family dynamics- celebrating their differences.

	Maddy: *but it's his way of showing everyone he loves them.* Yeah. So, we kind of joke he's got two modes: he's either annoying or annoyed, and he's a very typical red head and he can fly off the handle fairly quickly, but then he comes around fairly quickly as well. um I always trusted that if he got into trouble, there was a good reason for it. And normally it was that he'd got somebody else's back and he was just trying to support them. Um, he is, he is not particularly a sit in a classroom child. He learns whilst doing **Simon T Dixon:** Mhm. Yeah. **Maddy:** and he has got a very huge amount of common sense. um I couldn't he was 16 and we had a crash outside our house. So he put his high vis vest on that he'd got from spending a weekend working with his dad, his real dad um um went and started diverting traffic **Simon T Dixon:** Okay. **Maddy:** in the middle of the road while waiting for police. *um So, very sensible kid in some respects.* **Simon T Dixon:** Okay. Yeah. Okay. **Maddy:** um, so, I kind of always trusted that if he got the bus to Sheffield doing thing that he could handle it and he knew I was at the end of the phone and we have quite an open policy in our house so *we tell the truth*. You might get into trouble for it, *but you're going to get into a whole lot less trouble if you tell the truth.* **Simon T Dixon:** Mhm. Yeah. **Maddy:** um *I'd rather my children know they can come to me with anything that is a worry for them then how I was brought up with my mom,* "Let's just not tell her because I'm gonna get told off, whatever." **Simon T Dixon:** Yeah. Yeah. **Maddy:** Yeah. Yeah. um *My middle, my Victor Meldrew* **Simon T Dixon:** Yeah. Yeah. **Maddy:** Has zero common sense. But he can tell you the chemical makeup of anything. um He's very book smart, **Simon T Dixon:** Mhm. Okay.	IP: The Diplomatic Peacemaker Hol con- family values/encouraging honesty.

	Maddy: but he's the one at 16 I still would have wanted to hold my hand to cross the road. And Faith's always kind of been in the middle of them. um **Simon T Dixon:** Yeah. Yeah. **Maddy:** Although she's the youngest, she's always been the one that's organised them. So, *I'm not sure I've ever particularly parented different.* I tend to end up standing up for her a little bit more when there's disagreements between them. *So, if her and her eldest brother are arguing, I tend to be like, cut her a bit of slack, which then I don't always know if that's actually a good thing*	
20	**Simon T Dixon:** Has that changed? **Maddy:** because I think sometimes she plays on that and *she's like, "I've got an illness."* So, yeah, it's uh it's such a **Simon T Dixon:** Has it changed since the illness though? you always kind of has that? Has the way that you your parent changed since, over the last year? **Maddy:** Yeah. **Simon T Dixon:** Two years? Yeah. Okay. **Maddy:** She never got cut slack before. um So, one of my *biggest* disagreements with their dad was when she was little, she used a *cop a strop* and he used to tell the boys to give her whatever she wanted to stop her crying. *And I was like, "No, not a chance. Just step over her. She'll stop crying eventually. Just because she's the baby doesn't mean she gets her own way. Just because she's the girl doesn't mean she gets her own way."* Not up for that. um And she used to hate that. She now has a little brother on her um biological dad's side who he does exactly the same thing with and she still sees how spoiled he's then kind of turned into. So, she gets it and she will now go, "Thank you for not making me that." **Simon T Dixon:** Okay. Yeah. **Maddy:** So, but no, I wouldn't say I particularly parented them the three of them differently. *um I may be parented differently for each child, but only as far as how we dealt with disputes.* **Simon T Dixon:** Mhm. Yeah. Yeah.	Fab: Maddy's parenting has changed due to illness; she now picks battles more carefully and avoids pushing Faith, sometimes creating tension with her husband; Maddy prioritizes teaching Faith to find ways to cope with responsibilities for her future independence. IP: The Resource Manager. Hol con- Differneces in parenting approach- Coping, Support, and Sustaining Hope

	Maddy: So, my eldest used to be back and forth, whole long conversation over why something was right, why something was wrong. um He would argue until he was blue in the face if he thought he was right. um My middle child um just the thought that he disappointed you was enough. *And so really it was always a quick, "Please don't do that,"* and that was the end of that. um, um, *Faith was kind of in between, depended on her mood as to whether she'd just take it like that or whether she wanted to have the full long, "Why is this right? Why is that wrong?" um I think since the illness though I don't like to fight with her.* **Simon T Dixon:** Yeah. **Maddy:** um I pick my battles a bit more. *I don't tend to push things too much* um just because in the scheme of things, sometimes it's just not worth it. And depending on her energy levels, her pain levels, *she's half of the time she just won't even tolerate a conversation because she can't deal. It's all-encompassing when it comes to her head.* **Simon T Dixon:** Mhm. **Maddy:** um And so just asking her to put her pots in the dishwasher, *I'm just like, "You know what? I'll just do it myself because it's just not worth it."* Which then can annoy my husband because he's like, *"She still needs to be doing what she needs to be doing. um You still do it when you're poorly." And I'm like, "Well, I know, but"* **Simon T Dixon:** Yeah. Mhm. **Maddy:** and we have started. I do try and have those conversations then with her of, "*Do you know what? I get that you're having a bad time and I'm not saying you've got to do it this second, but today those pots need to go in the dishwasher, whatever.*" um At some point she's gonna be an adult. um *She's not gonna have someone there to do it all for her. She is going to have to learn to find ways around it.* **Maddy:** And yeah, in the scheme of things, pots can stay till the day after when you feel a bit better. *Do you know what I mean? But if she's going to be able to hold a job down,* um *relationships down, she's got to find a way through. And although we can support her and we'll always be there, with how independent Faith has always been in the past, there's kind of a level of she's got to work this out for herself. We can't spoon feed her. She's got to be willing to put it in.*	Hol form- Expert Sense-Making Narrative Hol con- (Relational Strain and Emotional Containment)

	Simon T Dixon: Yeah, it's just an added dimension. **Maddy:** So, yeah. Yeah. Yeah.	
21	**Simon T Dixon:** It sounds like, you know, it's you play all, you know, you play all of those different roles as parents, don't you? You know, in a normal kind of, you know, in a typical kind of fashion, I suppose, and then with the illness on top, it just throws into question all of that, doesn't it? That's what it feels like what you're talking about. It's, "What's right," **Maddy:** I feel **Simon T Dixon:** What's right? **Maddy:** you feel like you're constantly trying to balance pushing her without pushing her too hard, caring for her without turning her into some sort of baby or her losing her independence, and her making sure she understands all the way through that we've got her back, that we love her and support her and we believe her because with it being that kind of hidden illness um and with how she's had school react to it um and some family members. *Paramedics don't make sympathetic family members.* **Simon T Dixon:** Yeah. Yeah. **Maddy:** um And so her dad is sympathetic, but he's very practical. Yeah. *Okay. "You're having a bad day, so what can we do about it to make it better?"* um My brother is also a paramedic. **Simon T Dixon:** Okay. Yeah. **Maddy:** So, Uncle Kieran has always been really fun and and the kind of clown actually doesn't have a lot of sympathy for her either. He's quite practical in it. um And my husband's brother is a paramedic as well. **Simon T Dixon:** Wow. Teachers and paramedics. Yeah. **Maddy:** So, the poor kid hasn't got a hope of any sort of sympathy. *And I don't know if that's why then I lay it on a little bit thicker as well for her.* **Simon T Dixon:** Yeah. Yeah. Yeah. Yeah. Protector almost, aren't you? **Maddy:** Yeah. Yeah. It's not easy. *And she does get it, but sometimes she'll say to me, she's like,*	Fab: Maddy balances being a protector and fostering independence; family members (many paramedics) are practical, not sympathetic; Faith wishes for someone to just say "I understand"; Faith has found a valuable WhatsApp support group (E-pals) through CICRA of peers with similar conditions. Hol con- (Professional Knowledge as Resource and Burden) Hol con- Coping, Support, and Sustaining Hope IP: The Sympathetic Caregiver. Hol con- Relational Strain and Emotional Containment

	"Sometimes I just want someone to go, 'We understand.'" **Simon T Dixon:** Yeah. Yeah. **Maddy:** *"I don't want someone to go, 'Well, will this make it better?' I don't want someone to go, 'Oh, poor you.' I just want someone to go, 'I understand,'"* and she struggles with that. And she has however got a really good group of online friends through CICRA. um They do an E-pals um group. **Simon T Dixon:** Okay. Yeah. Okay. **Maddy:** um, so, they're meant to do it through email. Teenagers being teenagers have all shared their phone numbers and have got a WhatsApp group. **Simon T Dixon:** Yeah. Yeah. **Maddy:** However, that means she's now in a WhatsApp group with 20 odd kids similar ages to her all over the country that have similar diagnosis, similar drug regimens, *and get it.* **Maddy:** So, when they asked about adding this other, this new drug to it, *her first port of call* was to go on WhatsApp to all of her friends going, *"Who's on this? What's it like?"* um **Simon T Dixon:** Yeah. Yeah. **Maddy:** And I think that's helped in that she's not the only one. Yeah.	Hol form- Emotional Absorption Narrative: Hol con- Coping, Support, and Sustaining Hope
22	**Simon T Dixon:** Yeah. Is there a parent version of that? Have CICRA got a kind of parent voice group or anything? Yeah. **Maddy:** Crohn's and Colitis have. um I just don't do it. **Simon T Dixon:** Okay, okay. **Maddy:**. I know I could *and my professional head would 100% direct people to that.* um I'm not good at it. I'm *um an introverted extrovert, an extroverted introvert, whichever way around it is.*	Fab: Maddy doesn't use parent support groups due to being an "introverted extrovert"; she relies heavily on her husband (Ollie) for support and calming down; Maddy boxes off relationships, saving the full emotional load for Ollie; Maddy struggles with the "selfishness"

	Simon T Dixon: Okay. Yeah. Okay. Yeah. **Maddy:** um, I'm very good at putting on a front. I don't do well in social situations myself. um I probably *have got worse over the last couple of years*. um I have a couple of friends other than the girls I work with that kind of know what's going on to a depth. *One of them has it works for the NHS so it has some medical background.* And and actually her husband's a paramedic as well, so she gets the whole sympathy side of things. Yeah. um, so, *I kind of feel like I've got enough sounding off to them.* **Simon T Dixon:** Yeah. Mhm. **Maddy:** Although my poor husband is the main person that hears it all. And he's also though the only person that can calm me down when I am starting to sort of stress out and things. So, you're probably better doing this interview with him to be honest with what it's like **Simon T Dixon:** But it would be interesting. It's another strand, isn't it? Because you know, I actually have only interviewed mums to be honest. So, it would be interesting to have a male voice or a dad's voice in it. um Maybe for like, you know, next research be interesting. **Maddy:** Yeah. Yeah. **Simon T Dixon:** But yeah, so you're relying, so there's a reliance on your relationship, isn't there? That's that's something that's really important to you for support because. Yeah. Yeah. Yeah. That's come across quite quite thick, I suppose. I don't mean that I mean it's obviously important to you. **Maddy:** Yeah. *I think um I think I to some extent um managed to box my different relationships off with different parts of my life*. And he's the one that gets it all. um So he has to get it from the daughter and the wife. Um, but yeah, I don't tend to necessarily go into huge amounts of detail with everybody because um I would like to think I'm quite cool and collected. um And this isn't necessarily *a subject that I can always be cool and collected with, and once I start that, it's it's hard to kind of rein it all in.* As you can tell, I go off on tangents then once I am quite emotive. So, yeah, I try and just stick with the if anyone asks how she's doing or anything else, *it's like, "Yeah, she's we've got it under control," or, "Yeah, we've had this medication added. She's doing okay." You don't often get asked*	of her own pain while her child is ill. Hol con- (Relational Strain and Emotional Containment) Hol con- (Professional Knowledge as Resource and Burden) Hol form- Grounded Resilience Narrative: IP: The Controlled Self Hol form- Grounded Resilience Narrative: Hol con- (Relational Strain and Emotional Containment)

	as the parent of a child that's ill, how you're doing. **Simon T Dixon:** No. No. **Maddy:** um, and I think sometimes it feels a bit selfish to think, "Well, what about me?" instead of, "She's the one actually going through it." um But then I'd try and be a bit kinder to myself and remember that actually we're still going through it all as well and we're probably a little bit more helpless *because let's be honest, any parent would take it on for themselves in a heartbeat instead of having your child go through it.* **Simon T Dixon:** Yeah. Yeah. **Maddy:** Yeah. You can't do that, can you? So,	Hol form- Emotional Absorption Narrative:
23	**Simon T Dixon:** Yeah. No. No. If you had a if you could say something to another parent who's in the similar or in a similar position or maybe would be in a similar position in the future, what would it be? It's one of those questions. **Maddy:** Oh, *it would be completely what I wouldn't do and it would be find that support network because there are other parents out there that get it and* and you shouldn't have to go through it all on your own. **Simon T Dixon:** Mhm. Yeah. **Maddy:** um, I completely haven't done that, but at the same time, I think our family has a slightly different perspective of of we've got the kind of medical side of it. So, like whenever she has new medication or **Simon T Dixon:** Yeah. Yeah. **Maddy:** a test result come back, my husband then sits and explains everything to me or or we've had those conversations before *they've even come up with a doctor because he knows where it's likely to go.* **Simon T Dixon:** Yeah. Yeah. **Maddy:** um, So, the medical side doesn't particularly scare me. *It's not nice and I wish she didn't have to have any of that and* I am aware of what treatments may come in the future. um *But none of that particularly scares me.* It's what's done what's her future looks like with her head and what she can	Fab: Advice to other parents: Find a support network; Maddy's family medical knowledge (husband) helps them; Maddy is more scared of Faith's mental health/future pain/fatigue than the medical diagnosis itself; Maddy stresses the difficulty for parents without knowledge to fight to be heard (took over a year). IP: The Targeted Martyr Hol con-Parental Responsibility and Vigilance

	manage on a day-to-day basis with pain and with fatigue. It's those things that are the bigger deal. And the medical's kind of cut it or don't cut it thing for a long time. **Simon T Dixon:** Mhm. Yeah. **Maddy:** But *I see other parents on Facebook groups and things like that that genuinely have absolutely no idea*, didn't know where it was possibly even going when this child started to get ill. *We've got an inkling that that could be one of the things that they started to investigate.* Um, but there are parents out there that have no idea and no support and then to be battling hospitals **Simon T Dixon:** Mhm. Yeah. **Maddy:** because in all honesty, it took us over a year and multiple visits to both GP and A&E to be listened to. And in all that time, you then felt even more lost because you just wanted to be heard and a medical professional to take what you're saying about your child is, "There's something wrong." **Simon T Dixon:** Mhm. Yeah. **Maddy:** So, I think when you're constantly fighting, you're then exhausted and you just need that bit of support. I'm lucky I've kind of got it. Yeah. But there are others that don't. **Simon T Dixon:** Yeah. Mhm. **Maddy:** And I'm lucky that we've got the knowledge as a family that we have on both sides of it that that fight's maybe not necessarily been easier, but we've made our points easier. Yeah. um There's an awful lot of children missed, not just through pain and medical reasons, but there's an awful lot of children that are missed because they're not bad enough or or whatever else in their parents then don't know to be able to push. um And I think the world just needs to be a bit kinder and support a bit more because like we talked about before this interview, it all comes down to money and the way that councils work and everything else, and that then plays a part on the parents and their support networks as well. So, yeah. There's my own agenda.	Hol form- (Advocacy / institutional battle.) Hol form- (Advocacy / institutional battle.)
24	**Simon T Dixon:** So, because you've said you've said obviously your position, I suppose your profession um has impacted and given you knowledge that's been really helpful. I know what you do, but just for the interview, if you want to kind of just say what you do	Fab: Maddy's profession (Early Years SENCO, neurodiversity specialist) influences her to focus on Faith's

	and how you think that's been helpful or how that might have impacted the way that you parent. **Maddy:** um I am an *Early Years SENCO. um I specialize in neurodiversity, um particularly autism*. um *I mainly work with pre-verbal children.* **Simon T Dixon:** Okay. Yeah. **Maddy:** And that does, I think, tend to play a part in my parenting because I work a lot on body language rather than those verbal conversations. um I think that's probably played a part for a long time without me even really realizing it. **Simon T Dixon:** Mhm. Yeah. Yeah. **Maddy:** um It also means that like we've talked about during all of this, I tend to end up thinking about Faith's head and where she goes with her thought processes and things like that probably more than our actual physical health. Yeah. um And unfortunately it also means I know, um the waiting lists. I know what is actually out there. um For a little while we were kind of in a um awkward position which is why we went for the private counselling. So, like we've talked about before this, we actually live on the edge of four different areas. So, all the um counselling groups and things like that that her hospital which is Sheffield Children's were recommending Faith didn't qualify because we live in Rotherham. **Simon T Dixon:** Okay. **Maddy:** And Rotherham won't touch Faith because she is under a Sheffield hospital. **Simon T Dixon:** Mhm. Yeah. Mhm. **Maddy:** So, *we kind of go around in circles with all of these things* um which is why we ended up going down the private route. um Unfortunately, that will probably be the option if she decides to go down an autism or an ADHD assessment because again we know uh being NHS and being education, we know what the waiting lists and things like that are like. um Although I don't think the actual piece of paper would make a difference. We talk about the characteristics and coping strategies and things. So, yeah, I think that probably plays quite a big part in it. I work on coping strategies and and ways to make things better rather than necessarily a pat on the back, and that is the way I revert to with my parenting when I don't know what	mental processes; her knowledge means she knows the long waiting lists and local authority boundary issues (Rotherham vs. Sheffield) that forced them to use private care; Maddy's impulse to problem solve is not always what Faith needs (sometimes just wants a hug). Hol con- (Professional Knowledge as Resource and Burden) IP: The System Victim. Hol con- Systemic Navigation and Ongoing Uncertainty Hol form- Expert Sense-Making Narrative

	to do or try and fix the problem. I try to come up with the solution. uh So, yeah. **Simon T Dixon:** And that's sounds like it's challenging because sometimes there isn't that solution. **Maddy:** And *sometimes your child just wants a hug and to be told it's going to be okay.* um And yeah, I try and problem solve. Not always ideal.	
25	**Simon T Dixon:** But I suppose that's, you know, going back to that when we you kind of searching for hope, aren't you? And that seems like that's something that's um kind of highlighted a bit and through solutions and problem solving you're looking at something that may be an answer and or hope at the end of the day maybe. um Yeah. Yeah. It's tricky, isn't it? It's uh But I I do think there's something what you've, you've been talking about that we all bring our experiences, don't we? We all bring our kind of the way in which we've um what we're doing I suppose in our professional life, but also our experiences and our parents as you've mentioned and, you know, how we were brought up and how that all kind of ends up where you know with us at where we are today and how we deal with stuff and how we maybe view things and see the future. Well, yeah, I mean I I I'm sorry I just kind of s um it up I guess, but um is there anything else you thought was important for me to know or is anything else you wanted to talk about something we haven't spoke about or? **Maddy:** I think I've just talked to your ears off a little more than you know. **Simon T Dixon:** Not at all. It's been really interesting and this is exactly how it's supposed to be really. You it's your story really and we're trying to just, you know, the whole point of what this is I guess in the way that I want to look at it is learning through stories. So, I analyze it how you've talked about things um and kind of we've been making meaning from it. It's not necessarily, you know, there's a like I say right or wrong and it's your experience of what's happening and that's what's important rather than, you know, I'm not comparing it to anybody else. I'm not saying it's the same as this or the same as that. This is common. **Simon T Dixon:** It's it's just about how you kind of everybody's context different, isn't it? **Maddy:** Completely. *And I think when you've got a child that's ill, it affects not just the household or the education or anything, it affects wider. So, yeah, like*	Fab: Maddy emphasizes that illness affects the entire wider family (parents, uncles, etc.) and brings in their tra uma/experience; Faith is the first person in the family with this condition; Maddy concludes with hope, seeing glimmers of light moving forward. IP: The Pragmatic Realist.

	we've talked about my parents definitely playing a part in in how things have been dealt with and wider family like her uncles, and, and I think that does quite a bit with every family, but obviously that's then a whole load more people's input and experiences and...and trauma or, whatever else has gone on before that impacts on it. I mean, in some respects, we're quite lucky in that Faith is the only one, um, in our family that has had to deal with any of this, um, that also then she's the first person and kind of the test case subject for how do you deal with this... um, so yeah, there's always going to be different perspectives and different ways of doing it and I don't think we've done it necessarily the all the way through by any means, but we're hopefully seeing glimmers of light out the other side and that's all you can hope for. So, yeah..... **Simon T Dixon:** Okay. And if there's nothing else that you want to add, I'm going to stop recording. one sec. I got to see how to do this now again. There we go. Manage Stop recording.	IP: The Hopeful Advocate. Hol form- Grounded Resilience Narrative Hol con- Systemic Navigation and Ongoing Uncertainty Hol con- Coping, Support, and Sustaining Hope

Appendix J-

Maddy- Extract of table of transcript segmented into moves, summary of 'move', identified Fabula and Sjuzet* and Identity Positioning in each 'move'

Move #	Move Name	Fabula	Sjuzet	Identity Positioning	Supporting Quotes
1	**Initial Symptoms and Professional Framing**	Faith's pain begins; family has medical/SEN backgrounds; relationship with biological dad is strained.	Maddy uses clinical framing and professional dialect to establish the family context. She links medical symptoms to a psychological background immediately.	**The Analytical Professional** *Maddy positions herself as an expert observer who processes her daughter's illness through a vocational lens.*	"Probably there is a little bit of how I react to her because of um my profession with working with children with SEN."
2	**Medical Uncertainty and Systemic Dismissal**	Pain starts around menstruation; doctors claim it is just "period pain" and downplay it.	She uses adversarial framing to describe the medical system. She highlights the frustration of being told they were being "sensitive."	**The Dismissed Seeker** *She positions herself as a parent whose intuition is being invalidated by medical authority.*	"...they'd kind of just downplayed it and said it's that time we've been sensitive."
3	**Historical Context and Emotional Underpinnings**	Discussion of Faith's lack of relationship with her	Maddy uses reflective analysis to consider how past family	**The Trauma-Aware Parent**	"before all this happened... it's been quite a

		biological father.	trauma impacts Faith's current ability to cope with pain.	*She positions herself as a protector who is attuned to the psychological layers behind physical symptoms.*	difficult relationship."
4	**The Family Safe-Space and Targeted Outbursts**	Faith directs her anger, silence, and frustration primarily toward Maddy.	She uses the "punch-bag" metaphor to describe her role. The Sjuzet emphasizes the intimacy and "trust" required for such outbursts.	**The Emotional Buffer** *She positions herself as the essential emotional containment unit for her daughter's distress.*	"I'm the one that she trusts the most not to leave... I'm also the punch bag for it."
5	**Escalation and Constant Medical Intervention**	Continuous trips to A&E; long conversations with staff; multiple tests and monitoring.	Through repetition ("constantly"), the Sjuzet conveys a sense of exhaustion and a life revolving around hospital corridors.	**The Practical Navigator** *She positions herself as the logistical lead managing a high-frequency medical crisis.*	"I'd had a long conversation with them... we're at A&E constantly."
6	**Initial Battles with School for Recognition**	The school refuses to provide support; Maddy begins	Maddy uses combative language ("fights", "run-ins"). The Sjuzet	**The Institutional Combatant**	"We have had a lot of fights with her school

		to "fight" for adjustments.	focuses on the lack of institutional empathy.	*She positions herself as a warrior defined by her resistance against institutional neglect.*	over their support."
7	**Personal Coping and Solitary Decompression**	Maddy walks the dog in the woods to handle the stress of the household.	The Sjuzet shifts to a calm, sensory tone, contrasting the "spewing" at home with the quiet of the woods.	**The Solitary Processor** *She positions herself as an individual who requires isolation to maintain her psychological boundaries.*	"I need that time in the woods with the dog... to just be me for a bit."

Appendix K-

Maddy- Extract of Stage 4- Categorical Content, including table of themes

Move	Transcript	Themes
1	**Simon T Dixon:** Can you share your story with me? maybe starting with when you've kind of first realised that your child was experiencing pain. **Maddy:** yeah so probably help to know that, *um uh* doesn't really have any um or *wasn't having a great* uh relationship with her biological dad *before all this happened*. **Simon T Dixon:** Okay. **Maddy:** um her stepdad is actually a team leader for the ambulance service. okay so some of it we kind of differ um a little bit in how we react to her or interact with her because of his profession um and probably there is a little bit of how I react to her because of um my profession with working with children with sen um. **Simon T Dixon:** Okay. **Maddy:** Faith had some signs *before all of the medical side started* that she was *probably* on the autism spectrum um that's become more pronounced throughout so her coping strategies of lowered so going back to the medical side um she started two years ago with a lot of pain around her time of the month. it we'd been to the doctors numerous times and they'd kind of just *downplayed* it and said it's that time we've been sensitive.	• Biological father absent; • **Husband as a pragmatic paramedic** **Professional bias in reaction** **Identifying autism traits**

		• **Doctors downplaying pain;** • **"Time of the month" dismissal;**
2	**Maddy:** and we ended up visiting A&E *three times* um because at that point Faith was then fainting through the pain *um multiple times* one of which her I'll call him dad, he's stepdad. So*, if Faith ever talks about him, dad is stepdad, sperm donor is her biological father, that's where she is at this point.* um her dad ended up having to send paramedics into A&E with a bed for her because they didn't have one and she couldn't stay conscious um we kind of just kept getting passed back to the pediatrician who for a while they were querying endometriosis... **Simon T Dixon:** Yeah. **Maddy:** but they didn't want to test for it because of her age so we were kind of in limbo for quite a while and yeah it wasn't nice that bit because we just wanted answers to see her going through all the pain but to not kind of know what was going on was really hard um and scary to be honest because there were a lot of different things floating around that it could be... um she kept *getting rushed in* thinking it was appendicitis but obviously it wasn't it was just where the pain was presented and finally on the last um her pediatrician was actually in A&E at that point and so Faith at that *point didn't want to tell* us that she was actually having bleeding when she was going toilet, obviously for a 14 year old girl it was embarrassing, um but she finally admitted it in the room with him and that's when	• **Repeat A&E visits;** • **Fainting from pain;** • Sperm donor status; • **Lack of hospital beds;**

	kind of everything got put together and it was right, we know *where this is likely to now be going.*	• **Refusal to test due to age;** • **Living in diagnostic limbo;** • **Misdiagnosis (Appendicitis query);** • **Embarrassment regarding symptoms.**

3	**Maddy:** um so three months after that she had um colonoscopy and endoscopy and it was confirmed, her diagnosis is actually only that 15 centimeters of her bowel is affected but it's *right at the very end of it* and so actually it's the hardest to treat and quite often is the most significant as far as symptoms so we are now after huge amounts of steroids and everything else she's kind of um she's not in remission the chances are she never will be because of where it is um but she's kind of stable, um but there's a lot of treatment to keep her like that. **Simon T Dixon:** Yeah. **Maddy:** so she's had the diagnosis now for 16 months, we it was literally January the 2nd last year we got it. um We had *about a year before that* of things *gradually getting worse.* **Simon T Dixon:** Okay. Yeah. Okay. **Maddy:** so it kind of then once we got the diagnosis actually got a whole lot worse for about six months. okay so *the test they do for it is the calprotectin test* um or one of them um it's a stool sample basically a normal person's range should be under 50. when they first did Faith's, when she presented with the blood in the November of the year before her um diagnosis, hers was about 300. by the March after her diagnosis it was at 4,700. **Simon T Dixon:** Yeah. Mhm. Okay. **Maddy:** so *and at that point* um Sheffield Children's wanted to admit her to being impatient. The only thing that stopped that was because where it is, it's not like Crohn's, *so she's still taking the nutrients from everything.* um So although it was ridiculously high and we had to go on very high steroid use and her other blood work was okay. so they allowed us to go home at that point and start the steroids at home, and but yeah, otherwise she'd have been an impatient for a good couple of weeks *while they got that under control before letting her back home from everything I've then read and spoken to her IBD nurse with* um *Sheffield Children's Hospital have been amazing.*	• Colitis diagnosis; • Hardest area to treat; • "Not in remission"; • Diagnostic limbo • Invasive treatments (Infusions, Enemas); • Side effects vs. Symptoms; • High steroid use;

4	**Maddy:** And during all this time, as her levels have been getting better and so she's on um Infliximab infusions which I don't know sort of what your knowledge is but basically Infliximab was originally made as chemo drug and wasn't good enough but it turns out it treats um immune diseases quite... Yeah. **Simon T Dixon:** Sorry. Yeah. Yeah. **Maddy:** so it's used for rheumatoid arthritis, it's used for Crohn's and Colitis. She's also on another immunosuppressant as a tablet form and she has to have daily enemas. *Yeah, all of that is quite a lot for a 15 year old girl um so she's been all over the place with it* but she also then is dealing with daily fatigue and joint pain so we've had referrals through to um rheumatology. She's under OT and physio. **Maddy:** We are waiting for a psychiatry appointment and we are waiting for a sleep clinic appointment because her sleep has just been *absolutely battered* by this so it's then trying to work out what pain and fatigue is due to side effects from the drugs, what it what's the colitis what's the sleep it's it's all been a bit of a minefield really um she is under a private counsellor at the minute to *try and deal with it all* uh but I'm the punch bag exactly. **Simon T Dixon:** Okay.	• Invasive treatments (Infusions, Enemas); • Managing multiple medications. • Sleep deprivation; • Colitis or medication side effects? **Analyzing coping strategies** • **Mother as punch bag;**

5	**Maddy:** (Becomes upset/tearful) um God sorry. **Simon T Dixon:** No, it's okay. It's okay. Take a break if you need. It's okay. Okay. **Maddy:** no, you're fine it's just it is what it is so during all of this um *she cannot mask for love no money now so everything is a big deal* um she's *gone down the route* of severe anxiety and OCD with things and her brothers get *a bit of a bashing* at times, they're older um and she'll go very silent on her step-dad at times. During all of this her biological dad has had absolutely no contact and hasn't even asked her how she is *so that has obviously played a part in things and that is impacting now her relationship with her stepdad...* **Simon T Dixon:** Mhm. **Maddy:** because she's waiting for him to disappear on her as well um so yeah she's a bit of a minefield and then I just try and keep it all together but it's it's been a lot um there's a lot of worries about her future. She had got her career lined out. She decided what GCSEs, what A levels, what uni she needed to do to get there.	• **Inability to mask;** • **Severe Anxiety, panic attacks & OCD;** • Abandonment anxiety • Career plans uncertain
6	**Simon T Dixon:** Okay. **Maddy:** *That might not be a possibility now depending on how she is* um she was *pretty* academic before and she is now in school two, six, nine, twelve lessons a week and the anxiety that everything is kind of created means that actually for a couple of those best things she can't actually get into lessons, *she's kind of sitting in their sensory room just trying to actually be in school rather than in the lesson* and so there isn't a great look *a lot of hope for really to be honest ever going back full-time before GCSEs. We have had a lot of fights with her school over their support* and we have a very good OT that has ended up coming into all the meetings with me just so that there is now an official professional on her caseload to back up what we're saying and to get things passed through. Obviously, I know *that there's sort of hoops* that	• **Sensory overload;** • Education/exam uncertainty

	school have to jump through and everything else but it hasn't been particularly easy um so that's added an extra layer of stress there. They have now reduced two of a GCSE well *we've quit* two of the GCSEs so *at least she hasn't got as much to go back to and try and keep up to date with. But her panic is already setting in about um her what her actual taking the exams is going to look like, whether she's going to get the private room, whether she's going to get the extra time, which is over a year away but she stresses then about that.* So, we're kind of *at the point of let's as long as you get five GCSEs let's just concentrate on that.* **Simon T Dixon:** Mhm. gosh.	• 'fight' with school to get needs realised • She knows there are 'hoops to jump through for the school. • Dropping GCSE's to take pressure off, encouraging some resilience
7	**Maddy:** So, yeah, between trying to hold down a full-time job which isn't the easiest and home life and Faith's school and Faith's health and hospital visits, and we bought a border collie puppy three months before she got diagnosed. Oh gosh, yeah, that wasn't the greatest of thoughts um *but he had been to try and get her socialising a bit more and out doing classes with him.* But obviously then her health has meant that a border collie puppy is *not ideal so he's actually ended up being my headspace instead* um *he doesn't do busy environments very well.* **Simon T Dixon:** Okay. **Maddy:** So, me and him go and hide in the woods for a couple of hours every evening and just breathe and it works. So, yeah, it's been a lot. **Simon T Dixon:** Yeah. Yeah. It sounds like it's been a lot. What in terms of I mean you touched there about that's kind of one of your coping strategies is	

	that going and getting space. Is there anything else that's helped you through? **Maddy:** um yeah, *my husband um to be honest he's the straight talker and sensible.* **Simon T Dixon:** What's this? **Maddy:** *I would say I have probably got a* um *high chance of being on the spectrum as well.* **Simon T Dixon:** Okay. **Maddy**: I would, I would say if I went for a diagnosis I would probably *be ADHD and autistic in there and so my head doesn't switch off um and I will go through 101 outcomes anyway without then the stress and anxiety of everything that's been going on so he kind of tends to ground me* um *and get me to think straight*. Work have also been really good um. I work in quite a small setting. So we all work the same room together we are all quite close friends um in fact two of my friends at work their children are in Faith's year **Simon T Dixon:** Okay. Yeah. **Maddy:** so yeah we kind *of they get it and there has never ever been any, you're not completing your job, you're not doing this.* um *they've got my back and I've never kind of had to worry at any point that I'm gonna have a comment of, well she's going out again to pick a daughter up again.* um *so it's been quite refreshing. Yeah*.	• Solitude in the woods and with dog • Mental overactivity (Neurodivergence)
8	**Maddy:** *but sometimes it is wondering then with where her head is whether it's just a physical symptom of what's going on in her head at that moment or whether it is actually pain*. **Simon T Dixon:** Yeah. Yeah. **Maddy:** so yeah, *she don't make life easy.* **Simon T Dixon:** And how do you manage that then? Mhm. **Maddy:** um It's a balancing act all the time. I want to be able to just go stay at home, *don't worry about school, but that doesn't help her anxiety. that doesn't help the long term.* She's gonna have to live with this. She's got to find her own coping strategies and her own way of working through things because otherwise what is her adult life	**Focus on "head" vs. "body"**

	going to look like? um she isolated herself a huge amount, she was already having a few um troubles with friendships *before all of this*. she masks she was masking very well when she got to comp. *Obviously socially things change as a teenager*. and she went from a one class per year junior school up to a 2,000 child comp and that was a big change for her so she was already having some problems. *All of this has meant she's hidden herself away.* **Simon T Dixon:** Okay. Yeah. **Maddy:** um she's got about three friends and they are all older than her. Yeah. *So nobody in her year, so I don't think that helps with the not wanting to go to school* and things like that. But it's it's like said it's that balancing act between pushing her to try and do things without going too far because we're all very aware that if she does too much we have wipe out for two days, three days after it. and at the beginning that was a constant cycle. *She's learning to understand her limits now a bit better.* **Simon T Dixon:** Mhm. Okay.	• **Isolation/Hidden away;** • Consant fatigue
9	**Maddy:** but *it's just then been celebrating massively her* um *putting herself out there and her strides then in itself*. So, before it, she we all used to boulder a lot um that kind of stopped. Her um middle brother obviously carried on, he's 19, so he was doing his own thing anyway, *and but she's just started going back to do that with him now.*. okay And *so that's been a massive strive both socially and her anxiety getting out there and doing something, but also it's her being able to exercise and things again without too much pressure.* **Simon T Dixon:** Okay. **Maddy:** she can quite she can do a couple climbs, *she can rest and watch the others do it and do it that way. and that's we have to be very careful then with that*. So, *we celebrate it, but I'm not allowed to watch her at the minute*. okay go figure.	• **Bouldering and spending time with his brother.**

Table 3: Coding Notation

Typical boy.. . – Sjuzet is underlined
When both fabula and Sjuzet- *Italics*

Subtheme key:

Medical Dismissal & Diagnostic Limbo
The "Minefield" of Treatment:
Educational Conflict
Advocacy as a Necessity
[redacted]
Knowledge as a burden
Managing the 'self'
Abandonment trauma
Faiths psychological decline
'The safe person'/ 'punch bag' dynamic
The husband/ stepdad anchor
Sibling and peer relations
Wider family and financial strain
Derailed futures
Adaptation and Hope

Theme	Subtheme	Associated Codes
1. Systemic Invalidation & The Battle for Care	**1.1** Medical Dismissal & Diagnostic Limbo	☐ Doctors downplaying pain ☐ "Time of the month" dismissal ☐ Repeat A&E visits ☐ Fainting from pain ☐ Lack of hospital beds ☐ Refusal to test due to age ☐ Living in diagnostic limbo ☐ Misdiagnosis (Appendicitis query)

Theme	Subtheme	Associated Codes
		□ Embarrassment regarding symptoms □ Trauma of undiagnosed pain
	1.2 The "Minefield" of Treatment:	□ Colitis diagnosis □ Hardest area to treat (Distal) □ "Not in remission" □ Invasive treatments (Infusions, Enemas) □ Side effects vs. Symptoms □ High steroid use □ Managing multiple medications □ Sleep deprivation □ Colitis or medication side effects? (The ambiguity of symptoms) □ Constant fatigue
	1.3 Educational Conflict	□ Attendance officer intrusion □ Teacher harassment during panic attack □ Physical trauma (T-Rex arms) □ Lack of safeguarding □ Invasion of privacy at doorstep □ Staff rudeness □ Inflexible policies (Lead SENCO) □ Disbelief in promises (School's lack of reliability)

Theme	Subtheme	Associated Codes
	1.4 Advocacy as a Necessity	▯ "Throwing weight around" ▯ Leveraging professional status ▯ Fighting for support / Fight for an OT ▯ Educating the school (CICRA packs) ▯ Husband as defender ▯ Converting the "enemy" to advocate (Jared) ▯ Advocating for the voiceless ▯ Constant battling to have voice heard
2. The Professional Mother (Dual Identity)	**2.1** [redacted]	▯ Professional bias in reaction ▯ Identifying autism traits ▯ Analysing coping strategies ▯ Focus on "head" vs. "body" ▯ Making sense through experience as a SENCO ▯ Professional experience / Perspective (ND focus and solutions) ▯ Reading body language
	2.2 Knowledge as a burden	▯ Awareness of system failures ▯ Knowing the waiting lists ▯ Knowledge of Code of Practice ▯ Postcode lottery frustrations (Rotherham vs. Sheffield)

Theme	Subtheme	Associated Codes
		□ Professional awareness of systems and approach to solutions □ Guilt over privilege/knowledge □ Problem-solving vs. Comforting
	2.3 Managing the 'self'	□ Solitude in the woods and with dog □ Mental overactivity (Neurodivergence) □ Avoiding support groups □ "Introverted extrovert" □ Putting on a front □ Boxing off relationships.
3. The Shadow of Trauma & Mental Health	**3.1** Abandonment trauma	□ Biological father absent □ Sperm donor status □ Bio Dad does not ask about Faith □ Abandonment anxiety □ Fear of Stepdad leaving □ Similarities and difference in parenting approach between Faith's Mum and Bio Dad
	3.2 Faiths psychological decline	□ Inability to mask □ Severe Anxiety, panic attacks & OCD □ Sensory overload □ Isolation/Hidden away

Theme	Subtheme	Associated Codes
		□ Loss of "silly side" □ Knowledge of psychological impact □ Fear of passing illness to children □ Grief over future motherhood
	3.3'The safe person'/ 'punch bag' dynamic	□ Mother as punch bag □ "Safe person" role □ Targeted outbursts □ The punishment of silence □ Walking on eggshells □ "Spewing" emotions
4. Family Dynamics & Support Systems	**4.1** The husband/ stepdad anchor	• Husband as a pragmatic paramedic • Ollie, the straight talker • Ollie grounding Maddy • Husband bears the brunt • Practical vs. Emotional support
	4.2 Sibling and peer relations	□ Eldest brother clash (fiery) □ Middle brother support (Victor Meldrew) □ Bouldering as connection / Bouldering and spending time with brother □ Differences in Faith and her brothers / Maddy's sons' personalities □ Siblings (General) □ Online peers (E-pals)

Theme	Subtheme	Associated Codes
		□ Finding "the tribe" (WhatsApp group)
	4.3 Wider family and financial strain	□ Parents not understanding ND and Faith's behaviour / Maddy playing peacemaker □ Limited sympathy (Paramedic family) □ Financial impact (Parking/Travel)
5. Future Uncertainty vs. Resilience	**5.1** Derailed futures	□ Career plans uncertain (Wanted to be a police officer) □ Education/exam uncertainty / Worries about passing GCSEs □ Dropping GCSEs to take pressure off □ Stoma fears □ Changing timescale, adapting □ Housing plans for the future.
	5.2 Adaptation and Hope	□ Building resilience and independence / Sensible decision making □ Encouraging independence with a look into the future □ Picks battles with Faith now □ Seeing glimmers of hope / Some hope about future on a 'good day' □ She knows there are 'hoops to jump through' for the school (Navigational resilience)

Appendix L-

Maddy- Stage 4- Categorical-Form analysis

Move 15-	
Simon T Dixon: Also something you said um a couple of times is that you kind of I think you mentioned it previously about um I think you fight you use the word fight with school and then you kind of mention it there is that yeah I suppose can you tell me a bit more about, about that and the difficulties maybe around that or your experiences around that? Yeah.	
Maddy: So, um school started uh when she was first off before the diagnosis and everything else. She ended up with quite a bit of time off and the attendance officer turned up on our doorstep even though I was ringing every day and explaining the situation and I'd had a long conversation with them about we don't know what's going on, we're at A&E constantly. I'd picked her up from school and taken her straight across to A&E. um She had had a panic attack at school during it all where then a teacher, she'd been allowed in the corridor to try and calm down. um… a teacher who no longer works there um then harassed her in the corridor into going back into a classroom. um And that was her first major panic attack and it left her with T-Rex arms for a whole weekend. um That didn't go well. um School didn't like mine and her step-dad's response up to that. um Especially her stepdads in the fact that they'd not called for an ambulance or anything else and that was the very first time anything like that had ever happened. and she'd actually hyperventilated to a point where her whole arm muscles had seized. um So we'd had a few run-ins with them with that and then a week later the attendance officer turned up on our doorstep while I was at work with no prior warning	**Enactment:** Maddy recreates the "doorstep" scene to frame the school as an intruder into the family's private home. **Intensifier:** Using the word "harassed" labels the school as the aggressor. **Use of Humour:** She uses a funny-sounding nickname for a scary physical seizure to make a heavy topic easier to tell. **Change in Tone:** She drops the humour and switches to a serious, medical tone to show the physical reality. **De-intensifier:** She uses professional language to "soften" her anger so she still sounds like a reasonable expert.

or anything else and I um completely understand they need to check that children are actually ill and whatever else um are safe and safeguarded. um However, they'd also had a lot of contact with me around it all and so it kind of pressed my buttons a bit. And Faith actually answered the door to him and he kind of was trying to question Faith on the doorstep about what was going on which then obviously surrounding her time of the month and everything else, Faith was absolutely mortified**.**	**Intensifier:** She uses the word "absolutely" and "mortified" to emphasize the emotional damage the school caused. **De-intensifier:** She uses "a little bit" to downplay her own aggression while admitting she used her power.
Start of Move 16 **Maddy:** So, we had words about that. um And we called a meeting and I decided to throw my weight around a little bit and explained what my job was and what I um did. And so they kind of then went, "All right, okay. Well, we better get the SENCO into this meeting as well then." Yeah. They had no intention of any of that beforehand even though we'd asked for support and we'd explained. um There was a lot of just trying to harass us really. um The SENCO at the time was really good. She put breaks in place for Faith. She was still on a full-time timetable at that point. um But she'd put timeout cards in place, um, he, we did a lot around then trying to calm Faith when she was at school. um And she was somebody that Faith felt she could go to when she was having a hard time.	**Mimicry/speaking in the 3rd person-** She speaks in the 3rd person voice of the school staff to show they only respect titles/status.
Simon T Dixon: Okay.	
Maddy: She left three months later. How it goes, isn't it?	**Change in Tone:** She uses a dry, cynical tone to show her frustration with the "broken" school system.
Simon T Dixon: Yeah. Yeah.	
Maddy: um We then got her diagnosis and um we went into a meeting.	**Mimicry:** She mimics the dismissive "3rd person" voice of people at school to show their ignorance.
Simon T Dixon: Okay. Yeah. Yeah.	
Maddy: and my husband came with me and he'd actually printed out pictures of what IBD was and everything else because she was getting a few comments thrown around of, "Get over it, it's tummy ache.". So, we'd pulled off all the information on his side	**Mimicry/ speaking in the 3rd person:** She quotes her husband's 3rd person reaction to show the "raw" anger she felt but didn't say herself.

from health, um, there is a really fantastic organization called um CICRA, it's called um C-I-C-R-A. Basically, it is um Crohn's and Colitis UK but for children. um So they'd sent packs upon packs of information for schools for teachers about what it was Faith was going through. She has her own radar key. um All of those kind of things. And the attendance officer uh walked in while we were in reception waiting for this meeting and just went "One minute" and walked back out. My husband doesn't do well at being spoken to quite rudely like that.	**Enactment:** She uses "He said/She felt" to enact the power imbalance. Note the shift from parent to observer of her daughter's trauma.
Simon T Dixon: Can you just say that again… because you broke up and you had just had to say it and I was like	**Change in Tone:** The story shifts from an angry "fight" to a positive "success" story.
Maddy: Well, we were we were sat in reception and the attendance officer just walked in and went "One minute" and walked back out.	
Simon T Dixon: Okay. Yeah.	
Maddy: So, yeah, didn't do well. um My husband had been on a full night shift and not gone to bed yet at this point, so really wasn't doing yeah, sure, yeah. And he was like, "I'm not being spoken to you like that." I will just say at this point the attendance officer is now our biggest advocate at school.	**Humour/Mimicry:** She mimics the now-friendly phone calls to show the conflict is resolved and they are now on the same team.
Simon T Dixon: Okay.	
Maddy: He's incredible. Just that conversation of you didn't need to speak to us like that and then him sitting and going through everything. Turns out his daughter has MS and he's actually only a few years older than Faith, so he then got it. He now will do anything for me that he possibly can. um We have a running joke at work that he always calls me and himself by the first the first names on the phone. So, he rings work and it's, "Hi, it's Jared. Is Maddy there?" And they all now, it's, "Oh, it's Jared for you." So, he's actually turned into our biggest sort of cheerleader there.	

Simon T Dixon: Yeah. **Maddy:** And Faith will go to him over everything. I owe him gold when we leave that school.	

Appendix M-

Ethics application

The University Of Sheffield.

Application 059789

Amendment - Complete (Submitted on 17/01/2025) | Delete

Description of changes

Due to difficulties in recruiting participants and exhausting all possible sources I have changed the focus of my research. - Rather than exploring the narratives of former Young Carers' experiences of living with someone with Fibromyalgia I have changed focus. The revised focus and rationale is explained below. - The research will now be exploring the narratives of parents who have a child suffering from chronic pain (CP), with a focus on understanding their experiences and the impact of their child's condition on family life, particularly in relation to the child's educational journey. Chronic pain, a significant health issue among school-aged children and young people (CYP), is linked to various challenges. There is a number of quantitative studies that identify these challenges which include- poor school attendance, academic struggles, and broader social and emotional impairments. However, the impact of Chronic Pain on school functioning extends beyond simple metrics such as attendance, affecting cognitive, emotional, and social domains in complex ways. Despite the profound effect Chronic Pain can have on children, there is limited research that centres on parents' perspectives, especially concerning how they navigate their child's Chronic Pain within the context of education. There also appears to be little qualitative research in this area and none using a Narrative Orientated Inquiry (NOI) methodology. - I plan to keep the same methodology, data collection and data analysis methods. - To recruit participants I will primarily be reaching out to schools within the Local Authority I am currently on placement with. I will ask colleagues in the Educational Psychology Service to share a research poster with the Special Educational Needs Coordinators (SENCo's) in their link schools, who will be asked to share with prospective participants who fit the criteria. As well as this, I will share the poster on Facebook support groups to recruit participants through this medium (I will follow the ethical guidelines around this, as detailed in the original application. If this is unsuccessful I will reach out to fellow student on my course and in other year groups of the DEdCPsy training course to share with schools in their Local Authorities. I will also share on EPNet (Online mailing list for Educational Psychologists) if other recruitment streams are unsuccessful. - The inclusion criteria is- Participants are require to be parents/carers of a CYP who is aged between 5-17, is currently on roll at a school or college and experiences Chronic Pain. Chronic Pain is defined as the following- Pain that persists for more than three months and continues beyond the normal period of tissue healing and may include the following conditions; juvenile idiopathic arthritis (JIA) or inflammatory bowel disease (IBS), complex regional pain syndrome (CRPS), widespread musculoskeletal pain (juvenile fibromyalgia), recurrent abdominal pain (RAP), and chronic headache.

Additional ethical considerations

Do the proposed changes pose any additional ethical considerations?
Yes

Description of how these ethical considerations are addressed

As I are now exploring parents experiences of their children there is a risk that the CYP may be impacted, both now (if they are aware that they are the subject of the research and are being discussed) and in the future (If they read the thesis or any publication arising from the thesis and are impacted by the sensitive nature of the narratives). To minimise the risks of harm to participants' CYP the following strategies will be implemented and considered to address the concerns effectively: 1. Anonymisation and Confidentiality Identifiable Information will be removed: I will ensure all data is anonymised, removing or altering any specific details (e.g., names, locations, or unique circumstances) that could lead to identification. Use of pseudonyms- I will replace real names with pseudonyms, protecting individual identities. 2. Parental Consent and Awareness Potential implications will be discussed with participants: During the informed consent process and within the Participant Information Sheet, I will explain the nature of the research and the potential for participants or their families to recognise themselves in the thesis. I will also emphasise that participation is voluntary, making it clear that participants can choose not to answer specific questions or withdraw from the study at any time. I will suggest that participants may consider gaining consent from their child and discuss all implications and benefits with them prior to participating. 3. Member checking and validation of narratives- I will give participants the opportunity to review their anonymised narratives before finalising the thesis to ensure they feel their story is represented accurately and respectfully. I will invite participants to think about whether the narratives might cause undue distress if read by their children. 4. Referral to Support Services I will provide participants with information about support services (e.g., Mind and Samaritans) which they can access if discussing their experiences during the study or reading the final thesis raises distressing feelings. 5. Researcher Reflexivity Throughout the research process I will reflect on my role as a researcher and maintain ongoing sensitivity to potential unintended consequences of your work, adapting my approach as needed during the study.

Additional risks

Do any of the proposed amendments to the research potentially change the risk for any of the researchers?

No

Supporting documentation revisions

documents which you have previously provided, you should give a description of the document which clearly indicates that this is a new version, e.g. by providing an appropriate version number. It is also helpful to the reviewers if you clearly mark the changes you have made in the document itself (e.g. by highlighting new text or using tracked changes in Word).
Yes

Uploaded documentation
- Participant_information_sheet__Amendment_.docx

Other relevant information

Decision

Should be approved

Original application

Section A: Applicant details

Date application started:
Wed 10 April 2024 at 17:53

First name:
Simon

Last name:
Dixon

Email:
stdixon1@sheffield.ac.uk

Programme name:
DEdCPsy

Module name:
Research thesis
Last updated:
21/01/2025

Department:
School of Education

Applying as:
Postgraduate research

Research project title:
Former Young Carers retrospective narratives of living with someone with a diagnosis of Fibromyalgia

Please provide details of how your project has been academically reviewed
- Supervisor feedback

Similar applications:
- not entered -

Section B: Basic information

Supervisor

Name	Email
Penny Fogg	p.fogg@sheffield.ac.uk

Proposed project duration

Start date (of data collection):
Fri 31 May 2024

Anticipated end date (of project)
Tue 15 July 2025

3: Project code (where applicable)

Project externally funded?
No

Project code
- not entered -

Suitability

Takes place outside UK?
No

Involves NHS?
No

Health and/or social care human-interventional study?
No

ESRC funded?
No

Likely to lead to publication in a peer-reviewed journal?
No

Led by another UK institution?
No

Involves human tissue?
No

Clinical trial or a medical device study?
No

Involves social care services provided by a local authority?
No

Is social care research requiring review via the University Research Ethics Procedure
No

Involves adults who lack the capacity to consent?
No

Involves research on groups that are on the Home Office list of 'Proscribed terrorist groups or organisations?
No

Indicators of risk

Involves potentially vulnerable participants?
Yes

Involves potentially highly sensitive topics?
Yes

Section C: Summary of research

1. Aims & Objectives

This research aims are to explore the narratives of former young carers who provided care for someone with Fibromyalgia. By centring their stories, the project aims to give voice to a currently underrepresented group: former young carers. There is a particular lack of research with former young carers who specifically lived and supported someone with Fibromyalgia. Additionally, existing research on young carers tends to focus on the negative aspects of their role and often relies on quantitative methods and is with young carers who are providing a caring role at the time.

This project will explore how participants feel their experience as a young carer has shaped their lives as adults, examining both the challenges they faced and any positive outcomes. It is important to acknowledge the evolving nature of the term "former young carer." For the purposes of this research, we will classify someone as a former young carer if their primary caregiving responsibilities have ended because they no longer live with the someone with Fibromyalgia, and they have become an adult.

By prioritising the narratives of former young carers and the impact of caring for someone with Fibromyalgia, this research hopes to generate valuable insights. The project can empower participants by providing them with a platform to reflect on their experiences and share their stories. Furthermore, the findings can inform the development of improved support systems for both former young carers and individuals with Fibromyalgia.

2. Methodology

The research advert poster will be posted on Young Carer and Fibromyalgia support groups on Facebook via the admin of the group. I will also approach the local Young Carer and Fibromyalgia support groups contacts by telephone and/or email if they are available and I will send the poster to them electronically. I will also use the EPNet group (Online Educational Psychology online community) and it will be advertised using the volunteer lists for staff or students maintained by IT Services. The research advert asks participants to email myself (via my university email address) if they would like more information about participation in the research. Participants will be emailed the link to the participant information and consent form before the interview. The email to participants will ask them to read through the information before deciding whether they wish to participate. Participants will be informed that they can ask any questions via email. Participants will be asked to reply to the email with a couple of convenient dates and times for the interview to take place if they wish to participate.

The Participants will be given the options whether to participate in an interview either in person, or online via google meet. The options have been created with the hope of addressing any accessibility needs and to ensure they feel as comfortable as possible. It also allows flexibility so participants can shape their own interview to suit them, this is important as they are discussing a personal and potentially sensitive topic. The interviews will last around an hour, however this might be longer or shorter depending how much the interviewee would like to talk. The researcher will ask the participants when they are available; the researcher will work around the participants schedules. If the interviews are in-person then the Participants will be given the option to conduct them at their home, or I can organise a confidential and comfortable venue to support the interview. If the interview is on google meet then I will set up an online invitation and send this through to the participants.

The participant will be informed that after they have asked the set questions I may reply with follow up questions. All participants will be sent a participant information form and consent form when they first register their interest in participating. I will ensure the consent form is completed before the interview begins.

The information form and consent form will make it clear to participants that if they consent to participate their interviews will be audio recorded. At the start of the in-person or the google meet interview participants will be asked again if they are happy to be audio recorded, if they agree this will be done via Google meet with cameras turned off before the recording begins. If they do not agree the interview will not go ahead. The participants will also be reminded that they are able to stop the interview whenever they want and if there are any questions, they do not want to answer there is no obligation to answer.

The Tree of Life tool will be used to guide the interviews and support potentially sensitive topics. This visual tool helps participants map out their life experiences, focusing on key events, relationships, and turning points.

Interviews will be transcribed using a university approved transcription tool. I will then listen to the interviews recording numerous times to ensure that the the interview is transcribed verbatim (word for word) and there are no errors. Participants will be asked to read through the transcript and check to make sure they are happy with it. Participants will be able to withdraw at any time up until the 31st November, 2024, without giving a reason. After this date the research report will be written making it difficult to remove participants' input. The transcripts will then be analysed using Narrative Oriented Inquiry (Hiles & Čermák, 2008): This involves examining participants' stories as narratives, focusing on how they structure their experiences and the meaning they make of them. This particular narrative analysis approach follows several possible steps, but the main focus is not only on the story being 'told' (Fabula), but also the 'telling', or how it is being told (Sjuzet), (Hiles & Čermák, 2008).
Participants names and any personal details mentioned in the interviews will all be changed in order to keep them anonymous.

Optional Second Stage:
Participants will be offered the opportunity to participate in a second stage of the research. This stage will involve creating an artefact, such as a drawing, poem, or other creative product, that reflects their experiences as Young Carers. Participants can choose to keep this artefact for themselves or share it with current Young Carers through support groups or charities. Depending on the nature of the artefact I will select an appropriate narrative data analysis approach which is appropriate.

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

Yes

Raises personal safety issues?

Yes

The main issue that I envisage is the affect the research may have on myself and my family due to the the topic and area being of personal relevance to me. My partner has Fibromyalgia and I have a daughter who may become a Young Carer in the future, this has the potential to cause some psychological harm to me as a researcher. However, I do not believe that this will be an issue or that any of the research I am proposing to undertake would be detrimental towards my mental health. I am aware of my personal limits and what I can and cannot reasonably cope with, and I would not propose anything I think would be harmful to myself or anyone else, so I don't believe personal safety issues will arise.

There could be risks to my mental well-being as the content of the research could be potentially sensitive, upsetting, or traumatic. Appropriate support and coping strategies are in place throughout the university. I can contact Student Support Services department within the university. I can also talk to our supervisors and the head of the department. It will also be possible to debrief via research supervision.
I also all have personal tutor and a year 3 mentor I can contact for support if required as well as colleague on the course who have offered peer supervision if I feel I need it.

I will ensure that any interviews will be organised for the start or middle of the day and that I space interviews out, this is to limit the psychological impact of the research, give me time to process any content and avoid travelling later in the day when I may be fatigued, or have less capacity to cope with difficult topics.

As there is a potential of conducting the interviews in peoples homes I have completed a risk assessment (see appendix). The main risks and strategies to mitigate/manage the risk will be:

1) a)Lone working risk. b)Travel to location risk. Potential psychological risk to participants. c)The topic may be sensitive- talking about previous difficult experiences of being a young carer. d)Risk of psychological harm to researcher- Potentially emotive topic as I share some characteristics similar to the participants.
2) a)I will ensure that I have told emergency contacts of my plans and will set a time to call them following a visit. I will also ensure my mobile phone is charged in case of an emergency. b) I will ensure my car is in good repair, there are no issues and there is enough fuel. I will also check to see if the route is clear before setting off and plan the route in advance.
c) I will have provided the participants with an information sheet and obtained informed consent. I am using the 'The Tree of Life' tool to help support the interview and limit the impact of the interview. I will ensure the participants are aware that they can withdraw at any point. I will also provide information for support groups and charities such as Samaritans for them to access if required. I will also offer debriefs and will make sure the participants have an opportunity to de-stress immediately after the interview by talking about other things.
d) I have carefully considered the impact on myself and my family and I have been reading lots of literature around insider research and the possible risk. I do not envisage that I will be psychologically harmed but I will ensure I take steps to limit the potential. I will ensure that I do not complete interviews close together, so it gives me time to process and not become overwhelmed. I will also ensure that I completed any interviews during the daytime to prevent emotional burnout. I will also use colleagues, friends and family to talk about anything that I find difficult. I will also use supervision to gain support.
3) I will have supervision every 4/6 weeks but will schedule this around the time of interviews

Section D: About the participants

1. Potential Participants

I aim to recruit 3-4 participants, this is a realistic number of participants for the aims and methodology of the research.

There is three criteria that participants will need to meet. 1) They will have previously identify themselves as a Young Carer who cared for someone who was diagnosed with Fibromyalgia. 2) They will no longer be living with someone with Fibromyalgia and 3) They will be over 18 years of age.

Justification for criteria-
The research is focussed on 'former' Young Carers who cared for someone who has a diagnosis of Fibromyalgia. The aim of the research is to explore stories of 'former' Young Carers and how they retrospectively make sense of their experience and it what way it may have shaped their adulthood. Therefore, it is important for participants to not be providing care presently and have had time to reflect on their experience. In order for Participants to reflect on how their experience may have shaped their adulthood, they will need to be adult and therefore over 18.

As participants are not currently Young Carers and are adults retrospectively reflecting on their experience, and because they are adults choosing to participate suggests that they are no longer considered as vulnerable. However, if the interview 'triggers' previous traumatic events then participants will be offered a debrief following the interview and will be signposted/provided with contact details of support groups, in the participant information sheet and following the interview/debrief. In using the Tree of Life tool, I am hoping that it may safeguard against this risk by providing a support/framework to enable more positive aspects of their narratives.

If I am struggling to find participants who cared for someone with Fibromyalgia I intent to widen my criteria and include any 'chronic pain conditions'.

2. Recruiting Potential Participants

My main recruitment strategy will be to approach the gatekeeper (admin for the group) for Young Carer and Fibromyalgia Facebook support groups in order to post an advert in the form of a poster (This will be to reach Former Young Carers who are still members of these groups). I will also approach local Young Carer and Fibromyalgia support groups not on Facebook. This will be through gatekeepers (main contacts) via telephone and/or email and I will send the poster to them electronically to share with prospective participants. I will also attempt to recruit using through the university volunteer list for staff and students. I will also use the EPNet group (Online Educational Psychology online community) to attempt to recruit if I have no success with other recruitment strategies.

The research advert asks participants to email myself (via my university email address) if they would like more information about participation in the research. Participants will be emailed the link to the participant information and consent form before the interview. The email to participants will ask them to read through the information before deciding whether they wish to participate. Participants will be informed that they can ask any questions via email. Participants will be asked to reply to the email with a couple of convenient dates and times for the interview to take place if they wish to participate.

2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by IT Services? Yes

It may be difficult to recruit through support groups as the target participants are no longer Young Carers. Fibromyalgia support groups may offer some difficulties in relation to sufferers of FMS may put pressure on family members to participate/not participate.

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

If participants respond to the advert/poster by emailing myself, I will proceed to email them back with a link to both the participant information sheet and electronic consent form. I will ask them to read through the information sheet before deciding whether they wish to participate. Participants will be informed that they can ask any questions via email.

When participants choose to participate in the study, they have the option of clicking on a link provided via email that then redirects them to an online informed consent form via a Google form registered to my University account. On the informed consent form, they will be given the choice to either opt in or out of the study by indicating their decision on the checkbox. Participants who choose to opt out of the study will be thanked for their time while those who choose to proceed will be proceed on to a Google Form to complete the consent form. Once consent is gained via the Google form, the researcher will save the forms on their secure University U Drive and erase it from their University account Google drive, where it will be automatically saved. These will be stored in a separate folder from other research data collected.

Participants will be asked to reply to the email with a couple of convenient dates and times for the interview to take place if they wish to participate.. Participants will be made aware of their right to withdraw at any point during the research process. They can request that their data be withdrawn from the research up until the 30th of April 2025. This is made clear in the consent form.

4. Payment

Will financial/in kind payments be offered to participants? No

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

I do not anticipate any physical harm to anyone involved in the research. However there is a potential for psychological harm to participants because of the content of interviews and revisiting difficult and emotive times in their lives. It is hoped that the process will be helpful and support sense making, however there is a risk that it may retraumatise, or cause mental discomfort to participants.. Specifically, reflecting on challenging experiences as a Young Carer, especially if emotionally charged, could trigger feelings of stress, anxiety, or sadness. The nature of Fibromyalgia and its impact on the family dynamic might also be a difficult topic for participants to revisit.

In participating in the study, participants will be required to provide their time, this is envisaged to be around 1-2 hours for the 1st interview and if participants decide to take part in the optional 2nd phase(this involves creating an artefact) it will be a similar amount of time; this would total 4 hrs+ which could be an inconvenience. It may also impact participants who may find it challenging to stay engaged, or feel fatigued.

How will this be managed to ensure appropriate protection and well-being of the participants?

The information pack will be explicit and break down clearly what is involved in the research and what the expectation of them is. They will be aware of their right to withdraw from the research at any point. Interview questions will follow a narrative approach and I will ensure that I am aware of any emotive or difficult topics. If I feel there is significant harm being experienced by then I will be sensitive and move the conversation on, and participants will be clear that if they do not want to answer a question they do not need to. I will continuous check consent and remind the participants of their right to withdraw at any point. I will also ensure there is a health warning at the beginning of the interview. I will remind the participations of anonymity and they will be assigned a Pseudonym within the interview and analysis. I respect that remembering stressful events can be discomforting and bring unwanted thoughts and feelings that can last longer than the length of the interview and could be experience for a time afterwards. At the beginning of the interview and optional 2nd phase activity I

will co-create some shared 'ground rules' to promote feelings of safety. I will also inform participants at the beginning of the sessions I will remind participants of the support available to them should they need it. As well as the right to withdraw, there are measures in place to support a participant for whom distressing feelings have arisen; for example, I will be available for them to speak with them afterward to debrief. My contact details will be provided for them on the information sheet. I will ensure that all interviews and the 2nd phase do not last an excessive amount of time (participants will be able to decide how long the sessions are. Regular breaks will also be offered.

The following charity will be included in the information sheet and at the end of the interview/as part of the debrief with contact details-
- Mind- Mental health charity.
- The Samaritans- Emotional support and distress charity

6. Potential harm to others who may be affected by the research activities

Which other people, if any, may be affected by the research activities, beyond the participants and the research team?

Potentially family members who may have been affected by the narratives told by participants if they can recognise who participants identity.

What is the potential for harm to these people?

In accordance with the University's Preventing Harm in Research & Innovation (Safeguarding) Policy, consideration must be given to whether there may be other people present during the research, who may be affected by it (i.e., beyond the research participants and the research team), and what steps will be taken to minimise the risk of harm to these people. As the research is focussing on the role of a Young Carer, the experiences discussed will likely be about family members.

How will this be managed to ensure appropriate safeguarding of these people?

Participants will be adults and they will make a decision as to whether they discuss the participation and what details they share with family members. All data will be anonymised and participants will not be identifiable when presented with the research. I will make it clear to participants that they can share the information sheet with their families. The information sheet will make it clear what the aims of the research are, and that the family or other supporters are not being judged or assessed as well as why we are carrying out this research. I will also make it clear that it is participants right to discuss the research with who ever they like, however, we will discuss the potential harm that could be caused and whether sensitivity may be supportive.

Support groups such as Mind and Samaritans will be provided in the participant information sheet and participants will be informed that if family members are 'triggered'/affected by the research then they should provide the details. This will be discussed at the end of the interviews/in the debrief.

As mentioned earlier, there is a risk of harm to my family. To mitigate this risk, I will ensure that my partner (suffers from FMS) knows how to access the support groups and that she has other forms of support such as her friends and parents. I also plan to be sensitive in what I discuss with her and how I look after myself (see previous section: Personal safety for strategies).

7. Reporting of safeguarding concerns or incidents

What arrangements will be in place for participants, and any other people external to the University who are involved in, or affected by, the research, to enable reporting of incidents or concerns?

Contact details of our university supervisor, director of the course and designated safeguarding contact will be provided.
This is written in the information sheet and consent form in the following way: you have the right to complain and raise concerns. This can be done at any time via my research supervisor and joint course director Penny Fogg-(p.fogg@sheffield.ac.uk). The other contact you can approach is Professor Rebecca Lawthom (DSL and Head of the School of Education)(r.lawthom@sheffield.ac.uk).

Who will be the Designated Safeguarding Contact(s)?

Professor Rebecca Lawthom

How will reported incidents or concerns be handled and escalated?

Any incidents or concerns will be dealt with inline with the University's safeguarding policy. All concerns would be discussed with Penny Fogg (my University Supervisor). Any concerns that were required to be escalated would then be shared with the Designated Safeguarding Lead: Professor Rebecca Lawthom (DSL and Head of the School of Education)(r.lawthom@sheffield.ac.uk). Following this, if the concern requires further attention then it will be escalated to the Research Ethics and Integrity Manager, Lindsay Unwin.

Section E: Personal data

1. Use of personal data

Will any personal data be processed or accessed as part of the project?
Yes

Will any 'special category' personal data be processed or accessed as part of the project?

Yes

Provide the number of people whose personal data you expect to process or access.
3

Approximate number of people with special category personal data
3

2. Managing personal data

Which organisation(s) will act as data controller(s) of the personal data?
University of Sheffield only

Who will have access to the personal data?
Only myself and my supervisor will have access. Personal will include data collected to facilitate the research, such as, information sheet, any addresses, email addresses and phone numbers obtained through the recruitment process. This will be stored securely and GDPR legislation will be followed. Audio recording (through university approved software), transcriptions of the interviews and data analysis will be stored on the my 'U' drive. The information will be anonymised by myself and pseudonyms will be used to protect identity.

What measures, processes and/or agreements will be put in place to manage the personal data?
We will ensure the security of the data processed. Data will be anonymised and kept securely on the university security protected 'U' drive. The laptop will be password protected. Informed consent with be obtained via Google forms and will automatically be saved to my google drive. I will save this to the 'U drive' and delete from my Google drive to ensure it is secure. Once data has been transcribed, audio recordings will be destroyed as soon as possible. Any data will then be anonymised and pseudonymised and participants will not be identifiable. I will ask for permission to use any parts of the transcription for any publication or report that may emerge from the research.

Will all identifiable personal data in digital or physical format be destroyed within a defined period after the project has ended?
Yes

When will the identifiable personal data be destroyed?
All data will be destroyed 3 years following completion of the viva.

3. Third-party services

Will any external third-party services not provided by the University be used to process or access personal data during the project?
No

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4. Security of computers, devices and software

Will personal data be processed or accessed on any computers or devices that are not managed by the University of Sheffield?
Yes

Will all computers and devices that are not managed by the University of Sheffield be secured in accordance with the IT Code of Connection?
Yes

Will any software not approved by the University of Sheffield be used to process or access data?
No

Will any software be written or developed in order to process or access the personal data?
No

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?
Yes

Document 1137964 (Version 3) All versions

Document 1141590 (Version 1) All versions

3rd version- to include information around right to withdraw

Consent forms relevant to project?
Yes

Document 1137963 (Version 2) All versions

Additional Documentation

Document 1141588 (Version 1) All versions
Risk Assessment- document

External Documentation

- not entered -

Section G: Declaration

Signed by:
Simon Dixon
Date signed:
Tue 25 June 2024 at 00:47

Official notes

- not entered -

Appendix N-

Ethics Approval documentation

Downloaded: 01/02/2026
Approved: 15/07/2024

Simon Dixon
Registration number: 220110345
School of Education
Programme: DEdCPsy

Dear Simon

PROJECT TITLE: Former Young Carers retrospective narratives of living with someone with a diagnosis of Fibromyalgia
APPLICATION: Reference Number 059789

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 15/07/2024 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 059789 (form submission date: 25/06/2024); (expected project end date: 15/07/2025).
- Participant information sheet 1137964 version 3 (10/06/2024).
- Participant information sheet 1141590 version 1 (25/06/2024).
- Participant consent form 1137963 version 2 (10/06/2024).

The following amendments to this application have been approved:

- Amendment approved: 17/01/2025
  - Participant_information_sheet__Amendment_.docx

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

James Bradbury
Ethics Admin
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Admin (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix O-

Recruitment Advert

"Share Your Story: Exploring the Parenting Journey of Raising a Child with Chronic Pain"

- ***Are you are a parent or carer of a child/young person who experiences Chronic Pain?***
- ***Is your child aged 5-17 and currently on roll at school or college?***

If you can answer yes to the above questions, then please read on.

Hello, my name is Simon Dixon, and I am completing a Doctorate in Educational Psychology at The University of Sheffield. My thesis research intends to explore the experiences of parents who have a child who experiences Chronic Pain.

The research will involve an interview (either face-to-face, or online) which is expected to last approximately 1-2 hour, but could be shorter or longer depending on how you are feeling.

Potential benefits-

By participating, you'll have the opportunity to share your experiences and contribute to a better understanding of what it is like to be a parent of a child with chronic pain.

The findings will help provide valuable insights into how parents understand and experience their child's chronic pain. It is hoped this will help improve the way healthcare and education systems work together to support families. Your contribution could influence future policies and practices, making a difference for other children and families living with chronic pain.

How to Participate:

- **Contact me at:** stdixon1@sheffield.ac.uk to discuss further.

This research has been approved by the University Research Ethics Committee (UREC) via The University of Sheffield. The Doctorate in Education and Child Psychology course directors are Dr Penny Fogg and Dr Sahaja Davies, the course sits within the School of Education, of which Dr Rebecca Lawthom is the Head of School. If you require their contact details please contact me.

Appendix P-

Participant Information Sheet

Hello! My name is Simon and I am training to be an Educational Psychologist at the University of Sheffield. As part of the Doctoral training course, I am carrying out some research.

The working title of the research is: *'The narratives of parents with a child who experiences Chronic Pain.'*

You are being invited to participate in a project which is intended to explore the stories of parents' experiences of being a parent of a child or young person who experiences Chronic Pain (CP). Before you agree to participate it is important that you fully understand why the research is being done and how you would be involved. Please read the following information carefully before deciding whether or not you would like to take part. I am happy to go through this with you and to answer any questions that you may have.

What is the purpose of the research project?

This study is about listening to the stories of parents/carers who have a child who experiences Chronic Pain (CP), giving them space to explore their experience and share their perspectives.

By hearing the stories and making sense of these, the research aims to help support professionals when working with children who experience CP with a hope to inform future practice.

Why have you been chosen?

You have been chosen to take part in this research project alongside 2/3 other participants. You have been invited because you contacted me to express interest in participating in the research and you meet the studies sampling criteria:

- You are a parent or carer of a child/young person who experiences Chronic Pain.
- Your child is aged 5-17 and is currently on roll at school or college.

*Within this research Chronic Pain is defined as: *'Pain that persists for more than three months and continues beyond the normal period of tissue healing, and may include, but not limited to, the following conditions; juvenile idiopathic arthritis (JIA) or inflammatory bowel disease (IBS), complex regional pain syndrome (CRPS), widespread musculoskeletal pain (juvenile fibromyalgia), recurrent abdominal pain (RAP), and chronic headache.'**

Do you have to take part?

No. It is your decision whether or not you decide to take part. If you do decide to take part, this information sheet will be yours to keep and you will be asked to sign a consent form.

You can withdraw from the research at any time and you do not have to give a reason for making that decision. I will continually seek your consent to be involved with the research, verbally, at each stage of the project. If you wish to withdraw from the research, please contact me (see below for email address).

What will happen to me if I take part? What do I have to do?

After you have fully understood the purpose of the research, read this information sheet, asked any further question you may have and signed the consent form you will be asked to participate in an interview. It is imagined that the interview will last approximately 1-2 hours, however, you are under no obligation to stay for this whole length of time. Equally, you are free to continue over this time period if you feel there is more you would like to share. This will be at a mutually convenient time in a comfortable and confidential space. This could be at your home or alternatively I can find a different appropriate location, it could also be facilitated virtually if required. The interview will take place between February - March 2025.

The interview will follow a **narrative approach**, which means that you will be invited to share your experiences and stories in your own words. This approach allows you to reflect on and explore your journey in a way that feels natural and meaningful to you. There are no right or wrong answers, and you can decide which aspects of your story you would like to focus on. During the interview, if you feel it would be helpful, we can use some narrative tools, such as visual or metaphorical activities (e.g., creating a timeline or using the "Tree of Life") to help structure or express your thoughts. These tools are entirely optional and will only be used if you feel they support your storytelling. The aim is to provide a safe, flexible, and supportive space for you to share your story.

Audio recordings of each interview will be made so that I can listen back to the stories you chose to share. Your audio recordings will only be listened to by the myself and the supervising research tutor for the project. They will be stored on my university secure 'U drive' and will be deleted as soon as the interviews have been transcribed.

Once your interviews have been written up, you will be given the opportunity to review and edit your interview transcripts before they are analysed. You will be given 2 weeks in which to do this.

After the interview transcripts have been analysed you will also be given the opportunity to read and reflect upon my interpretations before they are shared with anyone else. Again, you will be given 2 weeks in which to do this.

What are the possible disadvantages and risks of taking part?

My aim is to provide you with a safe and enjoyable opportunity to talk about your experiences. However, it is possible that you may experience some level of discomfort, with some of the stories that you choose to share evoking emotional thoughts and feelings. It is important that you are aware of this before you agree to participate in the research.

As part of this research, we are mindful of your child's wellbeing, both now and in the future. To protect your family's privacy, all information will be anonymised, and pseudonyms will be used to ensure no one can be identified. You will also have the opportunity to review your story to ensure it feels accurate and respectful. Before participating, you may wish to consider discussing the research with your child, including the possibility that they could read the thesis in the future. Support services will be available if reflecting on your experiences brings up any distressing feelings.

Throughout the interview you do not have to answer any questions that you find uncomfortable, you can take a break or you can stop the interview altogether.

If you become distressed at any point before, during or after the research process please remember that your GP, family and friends can all be immediate sources of comfort and support, as well as charities such as Mind and The Samaritans.

After the interview, you will be offered a debrief, with the chance to ask questions or talk in more detail about any difficult topics that were discussed. At the end of the research process you will also be given a debriefing sheet. This will contain information signposting you to available support services in the area should you feel you need it.

What are the possible benefits of taking part?

By taking part in this research, you will have the opportunity to share your experiences and contribute to a better understanding of what it is like to be a parent of a child with chronic pain. Your voice and perspective are important, and this research aims to highlight the unique challenges and strengths of parents like you.

The findings will help provide valuable insights into how parents understand and experience their child's chronic pain. It is hoped this will help improve the way healthcare and education systems work together to support families. Your contribution could influence future policies and practices, making a difference for other children and families living with chronic pain.

What happens if the research study stops earlier than expected?

If the research needs to be stopped earlier than originally intended, you will be fully informed as to the reasons for this.

What if something goes wrong?

If you are unhappy with, or uncertain about any part of the research process please contact me directly to explore whether I can be of help, or support in any way (Simon Dixon: stdixon1@sheffield.ac.uk).

If you would prefer to talk to somebody else about your concerns please contact the supervising research tutor for this project, Penny Fogg via email: p.fogg@sheffield.ac.uk or Professor Rebecca Lawthom (DSL and Head of the School of Education): r.lawthom@sheffield.ac.uk

Will my taking part in this project be kept confidential?

Your involvement in the research project will be kept strictly confidential. Your name will not be used at any point within the research.

When writing up your interviews, relationships and professional roles that are mentioned may be referred to (i.e. brother, mother or teacher), however no identifiable information will be included for example names of people, organisations or schools.

What is the legal basis for processing my personal data?

According to data protection legislation, I am required to inform you that the legal basis I am applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice: http://www.sheffield.ac.uk/govern/data-protection/privacy/general.

As I will be collecting some data that is defined in the legislation as more sensitive information about health conditions, I also need to let you know that I am applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

Who is organising and funding the research?

The research project does not have any sponsorship or funding and is part of the requirements for completion of the Doctorate in Educational and Child Psychology.

Who is the data controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

The research project has been ethically approved by the University of Sheffield Ethics committee.

What will happen to the results of the research project?

The results collected will be discussed within my thesis which will be presented to colleagues at the University of Sheffield and published on White Rose E-thesis online.

The result may then be included within a shorter report for publication in an academic journal. It is possible that in the future the findings of this research may also be presented to other professionals and organisations.

Who should I contact for further information?

Please contact Simon Dixon, the lead researcher if you would like further information regarding the research project (stdixon1@sheffield.ac.uk).

Alternatively, you can contact Penny Fogg, the supervising tutor for this research project (p.fogg@sheffield.ac.uk).

Course Directors: Dr Penny Fogg (p.fogg@sheffield.ac.uk) and Dr Timothy Sahaja Davies, (t.s.davies@sheffield.ac.uk).

Designated Safeguarding Lead: Professor Rebecca Lawthom (DSL and Head of the School of Education)(r.lawthom@sheffield.ac.uk).

Thank you for taking the time to read this information.

Kind regards,

Simon Dixon

Trainee Educational and Child Psychologist

University of Sheffield

stdixon1@sheffield.ac.uk

Appendix Q-

Participant consent form

Participant Consent Form

Working title of Project:

'The narratives of parents who have a child who suffers with a Chronic Pain condition.'

Name of lead researcher: Simon Dixon

If you agree to participate in this research, please read each statement below and indicate your response by placing your initials in the box.

1. I confirm that I have read and understand the information sheet for the above project and have had the opportunity to ask any questions. Insert ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study any time before my interviews, during my interviews, and up to a date to be agreed with the researcher prior to the analysis of the data. I understand that I do not need to give any reasons for why I no longer wish to take part and that there will be adverse consequences if I choose to withdraw (Contact Simon Dixon via email stdixon1@sheffield.ac.uk). I also understand that I can decline to answer certain questions during the interview process. ☐

3. I understand that my responses will be anonymised using my chosen pseudo name before analysis. ☐

4. I give my permission for other members of the research team to have access to my anonymised transcripts and for these to be included within the appendices of the lead researcher's thesis. ☐

5. I understand that my interviews will be audio recorded, that these will be stored on a the University of Sheffield secure 'U drive', on a password protected computer and that they may be listened to by other members of the research team. ☐

6. I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs and that my identity will remain anonymous. ☐

7. I understand my personal details such as my name, address and email address etc. will not be revealed to people outside of the research project. ☐

8. I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield so that the information I provide can be used legally by the researchers. ☐

Please read each statement below and write either 'yes' or 'no' in the box provided.

I would like the chance to review and edit the transcripts of my interviews before they are analysed.

I would like the chance to read, and reflect upon the researcher's interpretations of my data before it is shared with others.

_____ _____ _____

Name of Participant **Date** **Signature**

Copies: 1 for participant and 1 for research project's main record which will be kept in a secure location

Please contact Simon Dixon, the lead researcher if you would like further information regarding the research project (stdixon1@sheffield.ac.uk).

Alternatively, you can contact Penny Fogg, the supervising tutor for this research project (p.fogg@sheffield.ac.uk).

Designated Safeguarding Lead- Professor Rebecca Lawthom (Designated Safeguarding Lead and Head of Department (r.lawthom@sheffield.ac.uk).

Appendix R

Narrative Interview Guide (NIG) and prompts

Research Question: *What are the experiences of parents caring for a child with chronic pain?*

Introduction (Creating the Relational Space)

Purpose: To establish trust, explain the research, and invite the participant into the storying process.

"Thank you again for taking the time to talk with me today."

"This interview is part of a research study exploring the stories of parents who care for children experiencing chronic pain."

"I'm really interested in hearing your experiences, in your own words. You're the expert on your life, and I'd like to listen to your story without judgment or interruption."

"Everything we talk about is confidential, and you can stop or skip anything you're not comfortable with. The interview will be recorded to help me remember your words accurately."

"There are no right or wrong answers. I'd just love to hear about your experiences - whatever comes to mind."

✓ Ask for consent.

✓ Begin with a little relational small talk to ease into the space.

2. Opening the Story (The Narrative Invitation)

Purpose: Invite the participant to tell their story in their own words - start broad, listen actively, don't interrupt.

Narrative Prompt:

"Can you tell me the story of when you first noticed something was different - when you began to realise your child was in pain?"

Let the participant speak without interruption - use encouraging gestures (e.g., nodding, "mhmm," "take your time") to signal active listening.

3. Expanding the Narrative (Gently Opening the Dimensions)

Purpose: After the initial story, ask follow-ups that deepen understanding through the lens of Clandinin's three-dimensional narrative space.

Temporality (Past–Present–Future)

"How have things changed since then?"

"What did a typical day look like for you before all this started - and what does it look like now?"

"Looking ahead, what do you hope for yourself, or your family?"

Sociality (Inner world, relationships, emotions)

“What has this journey been like for you emotionally?”

“How have your relationships - with friends, family, or even healthcare professionals - been affected?”

“Can you share a moment when you felt particularly supported… or not supported?”

Place (Spaces, settings, environments)

“Are there particular places - like home, hospital, school - that stand out in your memory as part of this story?”

“What’s it like being in those spaces now, compared to before?”

4. Reflective Questions (Meaning-Making)

Purpose: Invite deeper reflection on identity, change, and personal growth.

“How has this experience shaped you as a parent?”

“Has this journey changed how you see yourself, or what you value?”

“If you were talking to another parent just starting out on a similar journey, what might you want them to know?”

5. Wrapping Up (Closure and Next Steps)

Purpose: Signal the end, affirm their participation, and outline what comes next.

“Is there anything else you’d like to share that we haven’t talked about?”

“Thank you so much for sharing your story. I know this can be a very personal topic, and I really appreciate your openness.”

“The next step is that I’ll transcribe the interview and analyse the stories across participants. Your name will not appear in anything I write.”

“If you’d like, I can share the transcript or any write-up with you for your input.”

- Offer emotional grounding or support if needed.
- Thank them again - acknowledge the courage it takes to tell personal stories.

Appendix S:

Extracts from reflexive research diary

Extract 1 – Alder Hey Showcase: Realising the Space for Qualitative Work

Date: 22nd March 2025 – After Alder Hey Experimental Arthritis Treatment Centre Showcase

Today I attended the showcase event at Alder Hey for the Experimental Arthritis Treatment Centre for Children. It was impressive and, if I'm honest, a little overwhelming. The majority of presentations were firmly rooted in biomedical and quantitative paradigms: disease activity scores, imaging endpoints, cytokine profiles, trial design, adherence statistics. There was a palpable sense of urgency around cure, remission, and optimisation of treatment protocols.

What struck me most, however, was what sat at the edges of the programme. There were a couple of panels with young people and parents, and these were consistently described as "patient voice" sessions that would "bring the numbers to life". The young people and parents were powerful and articulate; their stories clearly moved the audience. Yet the structure of the day positioned these contributions as illustrative rather than analytic, as colour added to the "real work" of biomedical research, not as work in their own right.

I had a long conversation with a science researcher, **** **** from Liverpool, who is seeking funding to explore affective implications of treatment using a patient-centred "dual target" framework. I found this exciting: she seemed genuinely committed to capturing emotional and relational outcomes, not only joint scores and lab results. At the same time, our discussion underlined how far apart our ontological and epistemological homes are. Her starting point is still measurement and modelling; mine is storied experience and co-constructed meaning.

Several people, both researchers and charity representatives, expressed interest in my thesis when I explained that I was exploring parents' narratives of caring for a child in chronic pain. They often responded with some version of "We really need that side as well" or "We don't hear nearly enough from parents". Yet when I probed what "hearing from parents" might look like, the focus was usually on improving adherence to treatment, identifying barriers to clinic attendance, or fine-tuning patient information materials. In other words, lived experience framed primarily as a route to better biomedical outcomes, rather than as an important object of inquiry in itself.

On the drive home I found myself both encouraged and unsettled. Encouraged, because there does appear to be a genuine appetite for including patients and families more centrally; unsettled, because the dominant research culture still seems to conceptualise participation in instrumental terms. I wrote in my notebook: "Is there room here for research that starts from narrative, not from outcome? Will colleagues trained in positivist traditions be able, or willing, to make the ontological and epistemological shifts required to treat stories as knowledge, not just data to feed back into trials?"

I also noticed my own defensiveness creeping in during some presentations that dismissed "anecdote" in favour of "evidence". Sitting in a children's hospital, funded by medical charities whose logics are understandably cure-oriented, it is perhaps inevitable that medical model thinking dominates. But I kept wondering: where would my work sit in this ecosystem?

Adjacent? Marginal? Could a narrative study like mine be seen as legitimate contribution, or would it be relegated to "nice but soft" add-on?

This experience sharpened my conviction that my thesis is not just "nice to have" but fills a genuine gap. At the same time, it reminded me that if I want to speak into this world, I need to articulate my contributions in ways that are intelligible and compelling to colleagues whose default evidence hierarchies differ profoundly from mine.

Extract 2 – Insider Position: Partner's FMS/RA and Being a Parent

Date: 14 March 2025 – After second participant interview

Today's interview with Maddy left me more shaken than I expected. Listening to her describe the relentlessness of her daughter's pain, the constant recalibrating of family life, I found myself thinking about [partner's name] and the early years of their FMS and RA diagnosis. I recognised the weariness in Maddy's voice when she talked about "never really having a day off from thinking about it". That line could have been lifted straight from our kitchen-table conversations.

I noticed, mid-interview, that I was nodding more vigorously when she spoke about not being believed, and offering longer empathic responses ("that sounds incredibly hard") than I had planned. On the one hand, this probably helped build trust; she visibly relaxed after I shared a little about my own experience of living alongside chronic pain. On the other hand, I am uneasy about how much my insider positioning might have steered the narrative towards certain emphases, dismissal, battle, exhaustion, because those are the elements that resonate most strongly for me.

Later, reading the transcript, I could see moments where I tacitly encouraged elaboration on system failures ("Tell me more about that meeting…") but did not follow up as fully on more ambiguous or hopeful comments (for example, when she mentioned a particularly understanding school nurse). I am left asking: to what extent am I co-producing a particular genre of story, struggle, injustice, advocacy, because it fits my existing schema of what life with chronic pain "should" look like? How many alternate storylines (adaptation, joy, ambivalence) am I failing to invite?

As a parent myself, I also felt activated when she described the impact on siblings and the guilt she carries. I caught myself slipping into a comparative mode, "Would I cope as well?", rather than staying purely with her meaning-making. I wrote "over-identification?" in the margin of my reflexive journal as soon as the call ended. In analysis I will need to hold this tension deliberately: allowing shared experience to deepen my understanding, while actively checking where my interpretations might be projections rather than grounded in the data.

Extract 3 – Realising/identifying projection in Coding

Date: 19th December 2025 – Revisiting early codes

I re-read my initial coding of Kelly's transcript today and was startled by how much of my own frustration is embedded in the labels I chose. Segments where she talks about repeated GP visits and school meetings were coded "SYSTEM FAILURE – BATTLE MODE", "WARFARE WITH SCHOOL", "CONSTANT FIGHTING".

On re-listening to the audio, her tone is weary, yes, but also careful and measured. She doesn't actually use "battle" or "war" metaphors often; those are mine. When she does talk about "fighting", it is as much with herself ("fighting the urge to give up") as with services.

I realised, uncomfortably, that I have been hearing her through the filter of my own long-standing anger at how my partner has been treated in rheumatology and pain clinics. For me, healthcare and education systems often do feel like battlefields. There is a risk that I am scripting these mothers into similar war narratives because that is the story I am primed to hear.

In supervision last week, [supervisor's name] asked: "What would happen if you looked for moments of collaboration, or uncertainty, or resignation, instead of only battles?" That question has stayed with me. Today I went through the transcript with a different highlighter, marking instances where professionals tried (however imperfectly) to respond, where Kelly expressed ambivalence, or where there was no clear villain. These passages had barely registered in my first pass.

The tension here is tricky: I do not want to minimise or sanitise the very real injustices these families face. At the same time, I need to be wary of over-simplifying complex relational dynamics into a neat antagonistic binary. My insider status gives me rich, embodied understanding of what these mothers are dealing with, but it also gives me a script that can drown out quieter, less familiar notes in their stories. The analysis needs to make space for both.

Extract 4 – Doubts About "Narrative Labour" as Original Concept

Date: 7th January 2026 – Writing the Discussion

I am hesitating over how boldly to present "narrative labour" as a contribution. The more I read, the more I see its family resemblance to existing ideas: Hochschild's emotional labour, Baines' work on unpaid care, disability studies work around advocacy burden. I am wary of claiming too much originality for something that may be, in essence, a re-labelling of known dynamics in a specific context.

At the same time, when I look at the transcripts, there is something distinctively narrative about the work these mothers are doing. It is not just that they feel a lot (emotion work) or do a lot (care work); they are constantly telling, retelling, editing, translating, and curating stories for different audiences, clinicians, schools, family members, even themselves. The labour is in the storytelling itself: anticipating which details will be believed, which will be dismissed, how to pitch their accounts to avoid the 'mad mother' stereotype.

Maybe the honest contribution here is not "I have invented a new concept" but "I have named and elaborated a narrative-specific dimension of existing labour frameworks in the context of paediatric pain." That feels more accurate and less grandiose. I need to write this section in a way that situates narrative labour clearly within these literatures, acknowledging the shoulders it stands on, while still arguing that paying attention to stories as work adds something important for EP practice.