#### LIST OF APPENDICES

Appendix	Name of Appendix	Page no
No.		
1	The knowledge, skills and values required by practitioners to	312
	develop relationship centred care-	
	after Tressolini et al 1994	
2	Example of data analysis – unitising data	315
3	Example of information of preliminary category headings	321
	used in member checking in case study 1	
4	Filling in patterns using individual grids and preliminary	326
	categories from case study 2	
5	Developing understanding of the data -case study 1	329
	combined with case study 2.	
6	Example of sensitising concepts used in case study 3	338
7	Information and consent forms used in the research	341
8	Ethical approval from the local NHS Research Ethics	351
	Committee	
9	Organisational approval from the local PCT	352
10	List of conference papers, articles and book chapters arising	353
	from this thesis	

#### APPENDIX 1

The knowledge, skills and values required by practitioners to develop relationship centred care from Tressolini et al (1994).

AREA	KNOWLEDGE	SKILLS	VALUES
Self-awareness	Knowledge of self Understanding self as a resource to others	Reflect on self and work	Importance of self-awareness, self-care, self-growth
Patient experience of health and illness	Role of family, culture, community in development Multiple components of health Multiple threats and contributors to health as dimensions of one reality	Recognize patient's life story and its meaning View health and illness as part of human development	Appreciation of the patient as a whole person Appreciation of the patient's life story and the meaning of the health-illness condition
Developing and maintaining caring relationships	Understanding of threats to the integrity of the relationship (e.g. power inequalities) Understanding of potential for conflict and abuse	Attend fully to the patient Accept and respond to distress in patient and self Respond to moral and ethical challenges Facilitate hope, trust, and faith	Respect for patient's dignity, uniqueness, and integrity (mind- body-spirit unity) Respect for self- determination Respect for person's own power and self-healing processes
Effective communication	Elements of effective communication	Listen Impart information Learn Facilitate the learning of others Promote and accept patient's emotions	Importance of being open and nonjudgmental

**Table 1**Areas of knowledge, skills, and values for the patient-practitioner relationship

Tressolini et al (1994), p.30

AREA	KNOWLEDGE	SKILLS	VALUES
Meaning of community	Various models of community Myths and misperceptions about community Perspectives from the social sciences, humanities, and systems theory Dynamic change—demographic, political, industrial	Learn continuously Participate actively in community development and dialogue	Respect for the integrity of the community Respect for cultural diversity
Multiple contributors to health within the community	History of community, land use, migration, occupations, and their effect on health Physical, social, and occupational environments and their effects on health External and internal forces influencing community health	Critically assess the relationship of health care providers to community health Assess community and environmental health Assess implications of community policy affecting health	Affirmation of relevance of all determinants of health Affirmation of the value of health policy in community services Recognition of the presence of values that are destructive to health
Developing and maintaining community relationships	History of practitioner-community relationships Isolation of the health care community from the community at large	Communicate ideas Listen openly Empower others Learn Facilitate the learning of others Participate appropriately in community development and activism	Importance of being open-minded Honesty regarding the limits of health science Responsibility to contribute health expertise
Effective community- based care	Various types of care, both formal and informal Effects of institutional scale on care Positive effects of continuity of care	Collaborate with other individuals and organizations Work as member of a team or healing community Implement change strategies	Respect for community leadership Commitment to work for change

**Table 2**Areas of knowledge, skills, and values for the community-practitioner relationship

Tressolini et al (1994), p36

AREA	KNOWLEDGE	SKILLS	VALUES
Self-awareness	Knowledge of self	Reflect on self and needs Learn continuously	Importance of self-awareness
Traditions of knowledge in health professions	Healing approaches of various professions Healing approaches across cultures Historical power inequities across professions	Derive meaning from others' work Learn from experience within healing community	Affirmation and value of diversity
Building teams and communities	Perspectives on team-building from the social sciences	Communicate effectively Listen openly Learn cooperatively	Affirmation of mission Affirmation of diversity
Working dynamics of teams, groups, and organizations	Perspectives on team dynamics from the social sciences	Share responsibility responsibly Collaborate with others Work cooperatively Resolve conflicts	Openness to others' ideas Humility Mutual trust, empathy, support Capacity for grace

Table 3
Areas of knowledge, skills, and values for the practitioner-practitioner relationship

#### APPENDIX 2 Example of data analysis – unitising data from case study 1

#### RESIDENTS

#### The value of knowing (what can I tell you)

Personal knowledge of carers

knowing what time it is - watch being on wrong time

Personal knowledge of other residents

not being kept informed

Being kept informed

Informing each other

keeping links with friends/ family outside the home

knowing what's going on – being able to give information to others

I know what I know

She says I know everything - I only know what they tell me

Being seen as knowing

Knowing events outside the home – Goose Fair

developing knowledge about other residents

Eye for detail – other visitors routines with other residents

knowing is a key to other relationships

#### Helping where I can

helping not being acknowledged

supporting others

feeling I'm not too much trouble

Being involved in wife's care

Looking out for other residents

Helping where I can

doing my jobs

helping with the family – helping with other residents now

personal feedback between residents - what's my hearing like today?

I'll help where I can

Doing what I can to help

I don't want to be a bother

#### Finding common ground (we are here but not by choice)

common interests

Common bonds

facilitation of interests – by carers

introducing residents with common conditions (e.g. stroke0 – by RGN

interested in plants

Introducing residents, sitting them beside each other

sharing ideas

#### 'Being me'

being part of the community of the home - more than a resident proud of what I can do

I know what I know; Being seen as knowing

Personal touch – making it special between us what's important to me today
What's important in my care
Being personal to me

#### 'Waiting? - you have to here you know!'

waiting to go to the toilet always waiting Having to wait waiting - wasting time

#### CARE WORKERS

#### Motivation for caring

I'm a very hands on person - I like to get involved

I do it without making them conscious of the fact they can't do it

I try not to take away their last bit of independence

If I can help her enjoy what she's got left in life

I'm a doing person

It's very satisfying what you do when you think that you're helping them

Having a caring attitude

Your heart's got to be in it

Wanting to give, does that make a difference?

It might just be a personality thing

You've either got it – the initiative, the willingness to do that little bit more than the straightforward job

#### 'Do unto others'

We all want to feel that somebody loves us, we do

If it's my mum or my dad.. but if you've been there and given them the support, then that's very satisfying

We don't know if we will be like that one day

I think to myself, give what you can now because in later years, you'll be wanting someone to do it for you

It was their way of giving something back because they (Mum and Dad) would always say they were fit and healthy for their ages and it rubbed off on me

#### Feeling valued by other staff

They appreciated it and asked my opinion

They say you seem to know what you are doing

I feel my opinions are valued

They ask me about different creams

She said thank you and how much it was appreciated and how hard it was

#### Leading by example

I did it slightly different and these are tips they seem to be picking up

They way you are with people, determines if they want to do things the way you are suggesting

We hope to encourage that with new staff, by our example You try and do that by example

#### Seeing it from the residents perspective

If you just sat and did nothing all day, it would be really boring wouldn't it?

If it's something you'll enjoy then you'll get a kick out of it

It's only attention seeking to relieve a boredom they might feel

They worry for the future – how is it all going to end? And those things you just can't answer

It's a big issue for her because she knows it's going to take two or three of us, so I can see her reasoning behind it

#### The extra mile (as a reciprocal gesture)

You only need someone to say something like that and it's all worthwhile, you want to go that extra mile and do extra for her without her having to ask for things, you do, you want to put yourself out for her.

She was so grateful for what you did for her, anything she asked, I wanted to do it for her and I wanted to do more and she thrived on the fact that was someone was there and prepared to help her, prepared to care for her

#### This is their home now

I tried to make her feel at home and to look on it as her home

Their room is important – leaving it as they would leave it with their special cushions or toys on the bed

You like to feel comfortable, you like to feel special in your own home

It's up to us to make them feel special

We try and make a homely environment here

#### Giving them responsibility as part of the relationship

She understands that we are busy but she still moans behind our back

That annoys me because she knows we're busy and why we can't do it

She can ask if they forget and that will save me an extra job

They ring for the others, but she stopped ringing for him because she worked him out She would say shall I ask (Matron) or shall you?' and I'd say whatever you think Maybe sometimes they do (misuse this responsibility) but it's only attention seeking to relieve a boredom they might feel

#### Getting to know residents

You will get some feedback from them which is important and that affects how you would approach them

Sussing them out – what they thought of me and how I could approach them I think it's most important talking to them really

She would get cross from time to time if things weren't done the way she wanted things done

They're their own person and they have done things with their life and what you see now is nothing like what they used to be

#### Getting to know residents as individuals

Putting some make up on, doing her hair, whatever made her happy She likes to talk so it's listening really She likes to talk about her sons so I ask her about them and what they're doing

Sometimes she asks for the toilet for attention or just to see someone

It's a good thing that at 00/08 she's still interested in how she looks

It's a good thing that at 99/98 she's still interested in how she looks

And we have this little discussion about what jewellery to wear and what looks best

#### Attention to detail

Is when you're looking after the person and doing things the way they like it Leaving the room with the tie backs in place and the special cushions or toys on the bed

Making sure they look smart - appropriate clothing for them

Not letting people leave the table with food around their mouths

Taking time to match jewellery with the outfit - because it's important to her

Its important to her because she knows she looks the best she can

At least she knows you've tried for her, you've done as much as you can

Little details make all the difference

You try to do what you say you will do because they depend on it

#### Anticipating needs

Arranging care routines to suit residents

Altering routines to address needs of different residents – like giving them a piece of fruit if they want it

She really appreciated me asking if she needed it

If you beat her and take her to the toilet before she asks, she will always remember that

#### **Routines**

With our shift patterns, you need to work around that, so we came to a compromise — we said you choose what you want — it's worked out perfectly for out routine, for their routine

Being flexible when things don't go according to plan

Making judgements to change routines when circumstances dictate based on personal knowledge of residents side, that there's not really an hour now we can have undisturbed and say we can spend this with you, it's really, really sad

Everyone's going to need the toilet at some point, it will inevitable happen, so it's in

Everyone's going to need the toilet at some point, it will inevitable happen, so it's in the forefront of her mind

#### The little things

They are not an extra but an integral part of care

You're going to do for them what they can no longer do for themselves, everyday, ordinary things but things that are important if you can't get them done

Little things, little details, make all the difference

It's the little things as well as the general caring that ahs to be part of it That's just the way nursing Home life is, the little things

#### Making it special

They deteriorate quickly without the mental care

Having special names that may be unorthodox – it tells her I'm an idiot just like her

When I had to stop calling her that (the owners intervened) she thought I didn't care any more

When I wasn't there, she would call for me

It makes her feel special to hear about our social lives

#### Effect of agency workers

That's the first thing the residents pick out, they ask who is on and when it's agency it's a downfall for them

They lose confidence (the residents); they worry

G (resident) was crying and it's not fair but what can we do?

(residents) not trusting the agency staff

Their ways are different – their manner is abrupt sometimes

They have no idea who the resident is or what they are about and obviously they can't take the time out to know the resident

They (residents) aren't as relaxed or as happy as they used to be

#### Recognition of relationships between residents

Allowing residents to build own relationships

They talk about nothing really, but it's nice to see them communicating

The way things are in that room (lounge) is to be on stand by for them

She said to me, do you think she's asleep? And I said she's resting her eyes, because she won't admit it, but then she 9other resident) said but at least it's quiet

She will ask me where's X? and I'll say guess, and she'll roll her eyes and laugh

If we're busy I might hear them saying, do you think they've forgotten about us? And they'll say oh no, A said she'll come, shall I ring my bell?

You want to put two like minded people together

#### Looking after the families

We should be considering the feelings of the relatives – I think we sometimes overlook this

He wasn't a well person himself

I always felt he was looking for a little bit of support, of kindness from us

I think sometimes the relatives must feel things

#### The extra mile

I think to do something with her on a particular day, like the nuts and the bird things and that breaks up the monotony for her and she enjoys it

I'll go and put a feeder up and tell her and the next time she's up there, she's looking for it

They were sat in the garden and I decided we would have a sort of flower arranging competition

I took each vase up to their room, so it wasn't wasted and it was there for them when they went up

Taking a group of residents to care worker's parents for an afternoon tea

#### **FAMILIES 12/02/04**

#### Relatives being involved in the home

Helping out when the staff are busy - doing teas

Using visit to get to know other residents

Carrying on conversations with other residents

Coming to social events

Taking the initiative and changing the radio station to something the residents would like

#### Awareness of relationships between residents

She visits her each day and I encourage that

She speaks to the others; she never used to speak about them

Long live G!

It's a bit like a village, everyone sharing information about each other and their close families

#### Relatives being made to feel welcome

Staff greeting you by name

Being included in the fun

Staff getting to know you

Seeing relatives as individuals, getting to know them personally

Feeling cared for

Sharing personal information – relatives to staff and vice-versa

#### Staff being personal in the residents' care

Making it special

Having fun

Being able to turn a situation around

Knowing their likes and dislikes

Knowing about what they used to do and be like

Maintaining links with church

Knowing what television programmes they may like to watch

#### Individuality

They treat them as individuals

Respecting the need for their private space

They are treated with dignity and respect

They are aware that they have different interests

Their well being is considered

#### APPENDIX 3

Example of information of preliminary category headings used in member checking in case study 1

#### SUMMARY OF REPORT

#### IT'S THEIR HOME NOW

Providing a homely atmosphere was important that included the furnishings, flowers and layout of communal rooms. Residents identified it as their home and staff wanted the residents to feel special as they would in their own home and communicated this within their care routines. This was also communicated in a welcoming atmosphere with both residents and families identifying how they felt welcomed both on initial visits and when they moved in. The home was chosen due to its rural location and because it was smaller than others. Easy access to the village also helped families take residents out in wheelchairs, to move beyond the grounds which was also seen as positive. Having access to gardens and wildlife was also important with care staff taking residents out for walks when weather permitted and encouraging residents to take an active interest in attracting wild birds near their windows.

#### **BEING TOGETHER**

The lounge and dining areas allowed residents to talk with each other and families would also be able to arrange furniture to provide small family groupings during visits. Families, who may have been visiting the home for a long period, also used communal times as an opportunity to develop relationships with residents other than those whom they were visiting. Staff were aware of relationships between residents and would facilitate conversations by where residents were seated, however, there appeared little time for staff to be involved themselves in conversations outside of the care routines. However there were times in the day when little conversation occurred between residents although they were able to hold conversations. Families who were visiting may involve a group of residents within their conversation to stimulate this level of conversation.

#### **RECOGNISING THE PERSON**

Everybody involved in the study considered this very important. Older people enjoyed discussing areas of their life experience and families encouraged this as they felt it

this information to make the care routines more individual and to help the residents pursue previous interests when they were able. This approach moved beyond asking people what they wanted to wear and saw what was important about what they were wearing to that individual. This also supported care staff in maintaining independence but also recognising that residents may also exercise choice in the level of independence they wished to exercise on a day to day level. Understanding that people had good days and not so good days was an important part of the care. But also seeing how people may have been as people before they came in gave the care staff insight as the reasons why they residents may make different choices.

#### ATTENTION TO DETAIL

Little things are important to people. Staff remembering to set someone's watch to the right time of putting in a person's earrings may seem inconsequential to them but can have a major impact on the resident's day. Families also saw the detail of someone's appearance as important. Many residents took an interest in how they looked and this was an important aspect of their care – being supported to wear matching sets of clothes, putting on makeup and jewellery, having nails done and the weekly visit from the hairdresser. Within the Manor, this attention to detail was the norm, not because staff were told to do it but because they saw how important it was to the residents they cared for.

#### **ANTICIPATING NEED**

Residents appreciated staff knowing what they needed and approaching them before they needed to ask. Care staff identified an intimate knowledge of what residents liked to do when and they were often in the vicinity when that resident required attention. This contributed to the residents feeling cared for, they could relax a bit, they didn't need to always be thinking what needed to be done next, because they felt able tot rust the staff that were on not to leave them until they were in discomfort.

#### **BUILDING TRUST**

For residents, it was important that they knew if someone said they would be back, that they could rely on this. All staff were aware of this and did everything they could to ensure they would return when they said they would. Families felt that they could

trust the staff to do anything they may request between visits and felt confident that the care being delivered was of a high standard. They also felt that the residents themselves could voice any concerns although would take this up if they felt it was necessary.

#### MAKING IT SPECIAL

For residents, this was about staff going out of their way to speak to them at different times of the day, not just when involved in care. It was also about making an extra effort because it was important to them, this may include changing a hearing aid battery even when it might not be strictly needed, because it may help. In care routines, having a special name or being referred to in a certain way to make them feel important to that person. Having a bit of fun as part of the routine, or being included in the fun was also important with some residents. Knowing the little routines people liked such as having biscuits and cheese of an evening when you move up to your bedroom. Families identified the importance of knowing such routines especially when residents were unlikely to ask for them. Families also worked very hard to make visits special by maintaining links with the wider social network such as bringing old friends to visit or taking their relative to see other family members. Sharing photographs and speaking of family events also made visits special as well as supporting a continued recognition of themselves beyond the immediate context of the Home.

#### WORKING TOGETHER

There was a sense of teamwork that went beyond the care staff. Ancillary staff were well known to residents and families who took an active role in contributing to the positive experience of residents and families. There appeared no demarcation between care staff and ancillary staff with a mutual level of respect for the job they all had to do. Some residents were actively involved in contributing to the running of the home by laying tables and delivering mail. Even residents who were unable to engage in these activities made efforts to support care staff by doing what they could to help such as undoing buttons and taking off earrings. On some occasions when residents could see staff were busy, they would wait until they saw people rather than ring for attention. They may also give advance warning about their needs to enable the staff to plan their care given the busy context in which they were working. Families also saw

themselves as supporting care in providing toiletries and clothes, working with the staff to identify the most appropriate types of clothing that still enabled the resident to wear the style of clothing they were used to.

While there were many positive aspects of care within the Manor, there were occasions where aspects of care adversely affected the experiences of the residents, their families and care staff.

#### HAVING STAFF WE KNOW

It was important to both residents and families that intimate care was being delivered by staff known to them. While on occasion, this was accepted as not always possible, it became a problem when there was a lot of agency staff who were only coming in for isolated shifts. Care staff also found working with staff who did not know the home or residents difficult as they felt it took their focus away from the residents and would still undertake many of the small specialised routines that were special tot hat residents as the agency staff would not know what they were. Residents also found it tiring if they had to tell the agency carer every little detail of their care, such as where the night clothes are kept or when to start running the water. On occasions when there is a lot of staff not known, it becomes unsettling to both residents and families as they are all conscious of the economic climate that care homes are operating within and it makes them fearful of their own futures.

#### HAVING TO WAIT

Waiting appears a feature of life for older people within care homes. Care can not always be delivered exactly when it is required and there may be days when waiting appears more apparent than other days to individual residents. At the Manor, every effort is made to explain to residents the reasons why they wait, but for the individual resident, it may result in pain or incontinence. One aspect of waiting which was a regular feature was meal times when residents would be seated at the table 15 or 20 minutes before the meal was served. While staff explained this was to ensure everyone made it to the table in good time and allowed them to support residents who required full assistance with their meals, it was still a wait. Families identified that on these occasion, there was limited conversation even between people who were able to

speak together. On family member timed her visits to stimulate conversation at the dinner table when she was able. Families identify the feeling that residents are waiting for something to happen to them and suggest encouraging residents to be more proactive in the running of the home or organising activities.

#### NOT HAVING TIME TO TALK

Residents enjoyed talking and families were aware of the benefits to the residents of being involved in conversations. Outside of care routines, there was little opportunity for care staff to sit and speak with the residents. Care staff identified that they would appreciate more opportunities to do activities that would stimulate conversation between the residents but found that changing dependencies of residents meant that care routines encroached on what had once been time set aside to do this with residents. Families recognised the difficulties faced by staff as residents did not always want to be engaged but felt that with encouragement, they would get a lot out of short periods of time with someone speaking to them.

APPENDIX 4 -Filling in patterns using individual grids and preliminary categories from case study 2

Theme/ categories		
GETTING TO KNOW THE		
PERSON		
what's important to us		she always beams, I think you get
		back what you give out
		who brings the flowers it's either
		J and W the nurse and I say you
		shouldn't bother because some
		days they are just so pulled out
		but he always says thank you to
		her
being personal	we met the chef and he told us he	we thanked the chef for making
	was getting married, he had a new	him nice dinners
	job and a new wife	
	they tell me things about their	we try to be pleasant and friendly
	lives occasionally, I'm old enough	with them and we have fun and a
	to be their grandmother	joke
Understanding what is important	he did ask N on his own if he	he'd rather be doing something
to him	could be moved down here	than nothing
	because he thought N, who he	
	refers to as the captain was going	
	to give him a job, he was applying	
	for a job really	
	he used to walk around and carry	
	the musical instruments for K the	
	activities lady and he found out	
	they had an entry to open space,	
	the garden and he could also walk	

		along to help clean the budgerigars out	
BUILDING TRUST	you make a point of greeting the care staff by name, yes because they are friends to me	we'd only been here a week or so and G had a chest infection and when I got in G was in a terrible state, and they'd had one doctor, R took one look and said it was penicillin, he was allergic and they'd accidentally given him a dose of penicillin. Well I've never forgotten that and neither has G	R is a great favourite with us because she was the first true friend we made here
		anyway they tell me the truth and L said he was all right and when it gets tot eh second day he starts looking for me but now he's stopped doing that so shortly I shall be able to take three days away	I've started for the first time taking two consecutive days, I tired it and I was very anxious but I don't ring up because they have enough to do
ATTENTION TO DETAIL OF CARE			
what's right for us	I'm a great believer in routine and it works well for us		he carries my bag to the door and he won't let me go without that, it's our ritual, it is as we say our fond farewells it is special for both of us
		they do it quietly and efficiently, no shouting	when I am leaving that is when sometimes our little friend is offensive but the staff don't fuss, they come up and guide her away and then there's no offence.  Anything that that interferes with routine is upsetting fro me

continuity of staff	when were at the QMC, they said you'll have the same people to look after you in the days and the same ones at night the difference here was we were getting a great change of staff	when it's the same ones, they may not know them by names but they know them by looks. I think it is the fact that they recognise them	I do like it here because we've had more regular staff and that's what settled G
		they get used to people by habit	if a was to walk in, /g would automatically put his foot up as G associates him with the dressing
little things		you get the tone of the voice, that's when you get the signal sometimes, when he gets a bit of depression or he's a bit down his voice changes	they play football with him sometimes, he was playing with L the other day and he was kicking it quite hard in the corridors—accidental of course! (from G's perspective)
		when L come in and sets his drink down and talks to G I see his eyes, he's checking to see if he's been shaved, his hearing aid to see if it s been switched on, he's chatting to him but he's not wasting time	
having the right team on	when there is friction between carers you can sense it, when you come for four hours these things become obvious	they are willing to work together, there is no friction	there are others that are very good but they are really excellent

## APPENDIX 5: Developing understanding of the data -case study 1 combined with case study 2.

#### TASK AS FOCUS

Routines as a vehicle for getting the job done	The job gets done, they get the proper care	Checking that the job gets done
(agency staff) to come into a new situation, the building is new, the residents are new, the staff are new, you can't remember them all by name, it's very hard to take it all in 1S5	yes, like on the weekend they weren't happy because of the way things were; our own staff not being on, not trusting the agency because their ways are different and their manner is abrupt at times I have found and because they have no idea who the resident is or what they are all about and obviously they can't take the time out to know the resident, it makes them very unsettled, it makes them very unhappy ,whereas we do, we are continuously here and we know them and what they need 1S1	Sometimes I go in the evening, I wait for mother to have her tea and then I go and mother's up in her room. I think I've been there twice now and once I'd been there, she was cold and I thought the room was cold, she didn't have a rug over her and she didn't have her alarm there and I thought this is ridiculous, she is sitting there with no buzzer and cold. I spoke to someone I don't know who, she should be made comfortable and made warm and she really should have the alarm system with her and that's happened more than once. well it was rectified that time and I haven't been back since. 1F1
At this point, Louie came in and examined Win's face and commented (rather loudly) on her 'tache and whiskers and that he would sort this out. He returned with a razor, a bowl of water and a towel. He proceeded to shave her in the lounge. She said to me after that Darrel would be mad if he knew that they weren't doing that p.8	today I noticed with EN about agencies because we've had a bad weekend, she says he gets fed up with having to remember to tell them every little thing and I said well we've got to explain every little thing to them, but she says she has to say like the nightie is under the pillow and to turn the tap on when we go in, for us, it's automatic that we get the nightie	most important and that is what worries me at the moment as I don't see how it can be resolved at the moment, you can offer higher wages, but it doesn't mean better staff, it means you can get staff, but that means higher costs but it's a concern for my mother and it's also a concern if I was to have to try and get her into another home and mother would

NUSCOSOCI AS FOCUS Socing the part person to relation to the present person	out from the pillow and turn the tap on 1S3	probably sufferand there's the disorientation and the hassle, I don't really want it, we'll see and just hope it can be resolved 1F1
I have dinner more or less on my own, although I sit with somebody they can't speak with me the carers speak but they're always in a mad rush as though they haven't got time to do itir3	The only staff at lunch are the kitchen staff. Once everyone is seated, the carers move to the small dining room and throughout the home to feed residents that require assistance p.16	I haven't seen any staff sit and talk to the residents, or you know, get involved with the families, 1F2
that nobody has time, you know to talk to them and make little groups1F2	Well I think routine is a very good thing people do become used to a routine of going to the loo at a certain time and making them comfortable and god she was dreadful when they bathed her1F7	the one thing that I think Granny can't really cope with, that the staff are there but they've got their duties: 'I haven't seen any one all day' I think in some ways she thinks that some one should come and speak to her for half an hour or even an hour each day 1F5

Seeing the past person in relation to the present person	Understanding how a resident approaches life	Attention to detail of care routines because it's important to the person
MS won't say a lot, she might have a little grumble sometimes, but she won't say a lot. I put rubber gloves in this bag and washing up liquid and a little squeezy mop and it got her talking about washing the pots, and this sort of thing	I would say it's the individual, and what they're nature is like and how they react and if they have been a person who has given or a person who has taken in their previous life then if they have been a person who has taken, they want you to be doing for them, and you know they are still like that and it doesn't matter what is going off around them, it's me, me who needs attention, me who needs to be looked after, it depends on what you're like yourself. I can't, I know people are like that, but I couldn't be like that but that's just the way I am, but there is one person who has always been like that and she' always be like that if you understand what I mean, you just go with what's there and do your best1s6	you're going to look after them and you're going to do for them, what they can no longer, now, do for themselves, ordinary, everyday things but things that are important if you can't get them done and you do it, willingly 186
well I last night I had some pudding and got told off at tea time wry laugh and then when I came to bed you see A was with me, she's my keyworker and she says you shouldn't have had that pudding after she helped to lift me backwards into bed, they hoick me round wry laugh and put me backwards into bedIRI	Well I think it was me, I was just determined, I'd got to settle really (in moving into the home) IRI	well sometimes when you have an issue with G's hearing aid and sometimes they might not need a new battery, but I'll say I'll go and get a new one and try to see if that makes them a bit louder, she knows they don't fit very well because she hads something wrong with her ears but if she knows you've put a new batteyr in, at least she knows you've tried for her, and you've done as much as you canise
went downstairs that morning and D said you	this is what's annoying me sometimes when	from experience, I knew, because I've come

are going to sing today, but I said I'm not, I can't sing, I've had an operation, I literally can't. I said where am I going to sing, he said at Church. I said how am I getting there, he said in your wheelchair, I said who is taking me, he said A. and I was going to say I enjoyed it but it's a funny thing to enjoy, er. It was, er, a lovely (memorial) service, (for one of the other residents) but I let her down at the end by crying, well it was the day after my, the second anniversary of my husband's death, it was too closeiri	she is moaning about it and she understands that we are busy but she is still moaning that we're not taking her behind our back and I say to her w you know we're busy so why are calling us behind our back? She does know and that's what annoys me with W, we're ding our best and she knows we are but she's still there, giving it his (opening and closing his fingers to indicate someone talking) 1S3	was so sore down below in her bottom area and what that was about and why and she
ever since I heard G talking to you I've been feeling really ashamed, well all the things she did and I was nothing she was the WI and she drove that minibus and did things for the community and I did nothingand what did you do after you retired. What did I do hobbiesiri	'I would never say I disliked any of them because they've all got something about them that you can like' 1S2	talking on attention to detail, the room is also important, as you leave the room, and just making sure they look smart and when they are at the table, make sure you don't take them way with food around their mouths for example 1S3
it's blowing you know, those trees I can see them from my bed, blowing IRI M (son) said what do you want in this home and my immediate reaction was trees IRI I said trees, and birds and goodness how many I've got I've seen a few blue tits on those nutsiri	Some residents are more demanding than others and sometimes these demands can prevent care being given to others. However, Gill sees it is important to understand that if some have been selfish all their life, they are not going to be different now they are older 1S2	'like knowing that some residents like their earrings in and if they don't have them, it upsets them, so it is programmed in your own mind to become part of their care.' 152
you've got to get to know that person as quickly as possible, and if you get on with	you observe them, you know from their habit what their habit will be, like how you	it's about getting to know them quickly and forming relationships with them and gaining

them straight away, you can do good for that person 288	normally react to a situation. There is a man who if there is an obstacle in his way will confront it, then there's another man who sees an obstacle and will go round it 2510	their trust 2S8
she's been a spinster all her life, how must she feel when she hears a man's voice, I'm going to get you ready for bed? 2S1	es pe that year to liquided in what one year use the track in a so important and I think it's important that you help them days y to do it use.	with g, she really doesn't want me to be there, she doesn't like getting changed by blokes but if I have to change her, I'll stand behind her and slip her nightie over her clothes so she has her dignity 288
it doesn't always follow to ask families, he could be opposite and in some ways he is, he used to be volatile but now he's quite placid apart from when he's back in his war years 254	he believes in God, so I'll say God Bless, if he says he's seeing angels, I'll acknowledge him 252252	it's the little things like knowing he wears glasses and a hearing aid. The other day I came in and found it in a toffee tin, now if they don't know they won't know to look for that and then it will get lost 2F7
If a vicar comes in and asks to see B, if B is not a believer, he wouldn't have invited a vicar into his home, I can't say because you're living here now, you have to do things like this, this is his home. 2812	I won't ask him about being a POW because that would upset him 2s2	there are signs about what she can eat, but they are not read, that's not a big thing to read the signs. 2F3

#### RELATIONSHIP AS FOCUS

Understanding how we all fit into the community

onderstanding now we are no mito the community	ity	
Anticipation of need in care routines / knowing the right thing to do at the right time for the person and their family	Putting yourself in their shoes / seeing the other perspective	Seeing what is important to all of us
so I picked all the flowers and went and got	I'm a doing person and I feel that everyone	think in W's case we're lucky there because
about 5 vases and got the tables and s tuck it	should be allowed and helped to do the things	her family are so supportive and you don't get
in front of them (smiling) and they looked at	that they want to do, because if you just sat	that a lot,she probably wouldn't agree that in

me as though to say do I have to do this? and	and did nothing all day, it would be really	one way she's lucky but she knows that they
then W said well I've only got one hand and I	boring wouldn't it? and if it's something that	look after her and she knows that they are
said come on of course you can, you're going	you enjoy well then you'll get a kick out of it	always there and they will help her. I wouldn't
to be in this competition and I sorted out the	and even if you're limited, if you get to the	think you could find a more supportive family
colours of the flowers so they looked	stage that you're limited in what can you can	than them and they're always interested 186
reasonable and I fetched them a little pot, and	do in life, the things that you can still do I	
they were all sticking so many flowers in their	think are so important and I think it's	
little pot and they were all looking at what	important that you help them enjoy to do it. 156	
each other had done, oh and then I fetched		
Matron and I said 'Matron, can you come and		
judge this competition' and she picked put one		
she liked best and I think we had a little prize		
for who'd won it but I couldn't remember		
what it was and then when we finished, I took		
each vase and put it into each of their rooms		
for them, so when they went back upstairs, it		
was just there for them and it wasn't wasted,		
but it passed an hour on for them, and then		
they got chatting and talking about it		
afterwards which made communication		
between that group and I think that's so		
important186		
yes and with her lipstick, she'll say you are the	I think that it's right and fair that we should	With HG they all knew that HG was poorly
only one who does that now and when she has	tell ourselves that we're not just looking after	and we just said we couldn't do things because
her lipstick and I always give her a tissue to	the residents here but we should also be	HG was poorly and they accepted that 1S3
blot and I maker sure she has it before she can	considering the feelings of the relatives 156	
ask186		
yeh but I always find with W if you beat her	I think sometimes that the relatives must feel	well she missed her home because she was
and take her to the toilet before she asks she	things and to us, just take as an example,	very very sad when she had to come in and

will always remember that, oh D has taken me to the toilet, she remembers that more and she'll say to BPL and G oh D's taken me to the toilet and she'll remember it was at 3 o'clock and then if you say, do you want to go just before tea, and beat her, she remembers and then it's as though you're saying when she'll go to the toilet and she appreciates that, it's as though you're looking after her which is what you are 1S3

Dthy, you're looking after Dthy, you're doing for Dthy, and to us, dthy is how as she is now, but prior to coming here, she was a different person and to her daughter, she's that different person, and likewise Dly, when they come to visit, it can't be easy for them, seeing how they are and I think in certain cases, we must show as much compassion as we can to them.

sell her home. During the period, she was selling it and waiting for a buyer, she would say do you think Matron will let you take me to the bungalow to fetch one or two things, so we went to the bungalow and we fetched a few things and then when it came to the point of selling, she was very upset and wanted to talk, she just wanted someone to listen, because she felt so emotional inside, and she said 'I know, I've got to, I know I can't look after myself anymore' because she had had a stroke, it was on her right side and she said, 'I know I've got to do it but it hurts so much' and she was so with it, so grateful for what you did for her, anything she asked, I wanted to do it for her and I wanted to do more and she thrived on the fact that someone there was prepared to help her, prepared to care for her186

he always does what the others don't do as soon as he gets into the room he goes straight for the creams, he does diprobase on the good leg if I can call it good, because the ankle is a bit swollen and he does the movelat on the bad leg and the bad arm and I've got some very sore places on the groin and, and the thigh and he put cream on there last night and again this morning right through... it's really sore at bed time it helps, it helps you get to sleep..if you've got something that's soreir

it must be hard for her daughter 186

He helps out with the mail and taking it around to the residents in the mornings. He also sets the tables fro lunch and dinner and helps out with the tea trolleys. These are his jobs that he feels he is making a contribution with. He said you can't get too involved with some of them like the other residents as they keep falling asleep and can't really talk very much to you, so he doesn't say much p.9

W is left to last and this is a conscious decision on B's part because she requires a particular ritual that once is achieved enable her to go to sleep better. While it doesn't bother him in the night to answer her buzzer and take her cups of tea and drinks as she wants, he is conscious that she is then not sleeping and this is going to have a negative impact on her the following day. So he spends additional time her rubbing the creams into W's arms and legs. She is appreciative of this and says how much it is needed. He rearranges her pillows, removing a head rest pillow to the chair for the morning. This is done without asking W and she immediately says how much more comfortable she is now. We say goodnight and I explain when I will be in next and in what capacity. She tells me that G always asks her when I will be in next and I respond that is the reason I tell W. As we leave, B turns out a light and she asks for the other one to be left as she can't see the clock otherwise. He thought it was the other way round but W was very clear that the larger standing lamp being on was her preference rather than her small side lamp. B turned off the side lamp and left the standing lamp on as W requested. She appeared to then settle for the nightp.50

at the end of the day, it's the residents who are suffering, after all, they don't ask to come somewhere like this to stay, they can't help it and we don't know if we will be like that one day and I think to myself, give what can you give now because maybe in later years, you'll be wanting someone to do it for yourse

Care for them hopefully in every way that they would like whether it's attending to a cold, whether it's a physical problem or I think it's most important is talking to them really too and you will get some feedback from them which is important and that affects how you would approach them and you can have a bit of banter with them and they enjoy that as well1S1

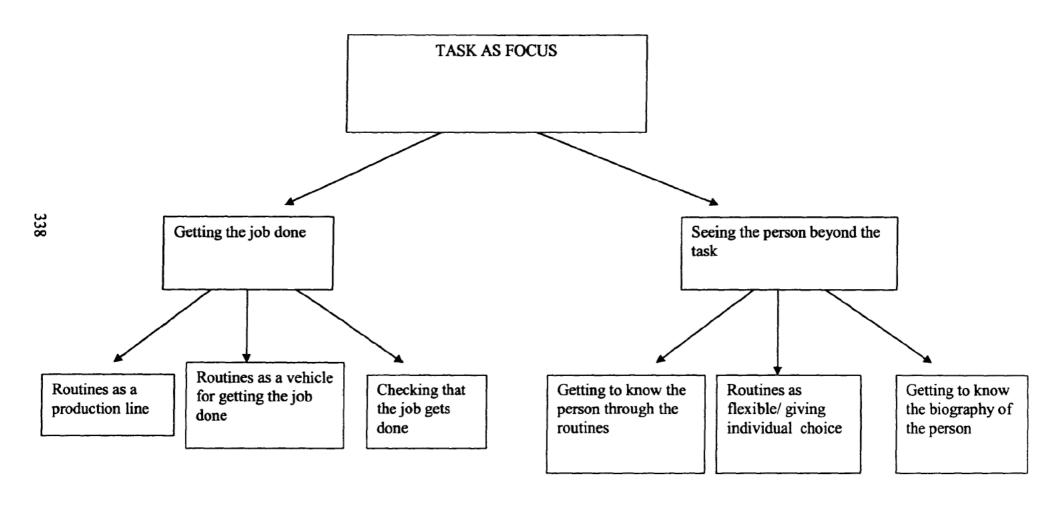
it's about knowing what is important to that

families want the best for their relatives and

you notice a calmness when she's on, with the

person on that day 2810	you can't blame them for that, it would be the same if it was my dad, it makes me care more 2S2	staff and the residents you can pick up on it as soon as you walk in. You come out feeling better, like you've had a proper conversation and some special time with him 2F2
We have two chairs together but we have no divine right to that corner but it does make it nice to be like that. It's important for me to know where we are and when I go to know we will be there. There's no reason why we shouldn't be accommodated in that respect as it doesn't adversely affect the other residents.	when we have the door open and we might be laughing because someone has said something funny as they have walked past, he'll get annoyed because he's not part of the laughter and he doesn't understand 2F2	there's routine between 3 and half four and I figured that was the best time to visit because after lunch they all nod off and then they wake at three and then they go in for their tea at half four, so when he used to say are you leaving now, I could say well you're going in for your tea now 2F4
we were walking back to the central seating area and john was singing. R (RN) came in and began singing with him, she was followed by Dennis who also joined in with a good harmony. 2FOP.20	families need somebody to talk to, it's like being a counsellor sometimes but you've got to spend that time with them even if it's only five minutes if you spend time listening to families, they'll know you will spend time caring for their relative 282	families need to have a good rapport with you and trust what youa re doing 284
he likes to feed himself but he makes a right mess, but he is content to do it for himself, if he gets frustrated, I'll step in and ask him if he wants help and he'll say yes or know. Oned ay his daughter came in right after lunch and he was in a right mess, she was mad but it didin't take two minutes to change him, he was like an imp grinning 2S2	Even Y said he should be out in the sun but they haven't got the right chair and it's time consuming because they all have to be hoisted 2F2we understand with the staff ratio they couldn't do it (take their relative outside on a hot day) for him to be out seeing the birds and flowers, that would make a real difference to him 2F2	they (families) observe what is going on, what we are doing and they learn, if that's the right word, how to approach the problem 2S4
Mr. H also says how important it is that someone who is looking after Margaret knows her as an individual and he said how good L was because he really knows her 2FO P.24	the families pick up on the changes from the staff but they don't always accept them, it's not cut and dried 2S4	we know he needs a lot of time, but we know he gets it, they never walk past him if he needs something 2F6s

#### APPENDIX 6-EXAMPLE OF SENSITISING CONCEPTS USED FOR CASE STUDY THREE



# APPENDIX 7- INFORMATION SHEETS USED EXPLORING RELATIONSHIP CENTRED-CARE WITHIN CARE HOMES INFORMATION SHEET FOR OLDER PEOPLE LIVING IN A CARE HOME

UNIVERSITY OF SHEFFIELD LIBRARY

#### **BACKGROUND**

This research project is part of an independent study being undertaken by Christine Brown Wilson, as part of her Ph.D. at the University of Sheffield. Christine lives in Nottingham and has worked in Nursing Homes as well as in Community hospitals. You are being invited to give your views about what are the important relationships to you; who are they with and how this contributes to your well-being and care, as part of this research project. Before you agree to take part in the study, it is important that you understand what is involved. If you are unsure about any part of this information, please don't hesitate in contacting Christine whose details are at the end of this information sheet.

#### WHY IS THE RESEARCH BEING DONE?

The purpose of this project is to explore the contribution relationships between yourself and those important to you make to the overall life of the home. The views of other residents, family members and staff will also be taken into consideration. This will provide a complete picture of how the relationships between the residents, their families and staff contribute to the giving and receiving of care. This information can then be used to support the future development of care practice within care homes.

#### WHO WILL BE INVOLVED?

As well as you, I will be inviting members of your care team and other residents within the home to be involved. I will also ask some members of your family if they would like to contribute.

#### WHAT WILL YOU BE ASKED TO DO?

The study will involve Christine visiting the Home initially to get to know everyone. She will be spending her time chatting to you informally and is very interested in what you consider to be important about the relationships you have. Christine will also be available to participate in the care routines of the home as an extra pair of hands. This will take place during different shifts and on different days of the week. As a nurse herself Christine will be sensitive to your needs and will try not to approach you at times you may find difficult.

#### WHAT WILL BE THE BENEFITS?

Christine will discuss your part within the research with you personally and will be happy to talk about the full report to the home with you. She would also be interested in how you think the study could be used to influence the care older people receive generally. This study will give you an opportunity to identify what you think are important issues about how relationships form and are developed within care homes. You will also have contributed to a piece of research that seeks to identify what older people themselves see as important in contributing towards care as well as receiving care.

#### ARE THERE ANY RISKS IN TAKING PART?

It is hoped that this will be a positive experience for you and those involved within your Home. Disruption to the normal routines of the home will be minimal.

## WHAT HAPPENS IF I DO NOT WISH TO BE INVOLVED IN THE PROJECT?

Taking part in this study is entirely up to you. If you do not wish to be involved you do not need to give a reason and your wishes will be respected. Also if at any time throughout the project, you wish to withdraw, you may do so again without needing to give a reason.

#### WILL TAKING PART BE CONFIDENTIAL?

All information relating to you as a result of this research will be strictly confidential. Any contribution you make will not be identified.

#### WHAT WILL HAPPEN TO THE RESULTS?

This project is part of a higher educational degree being undertaken by Christine. The report will form part of a thesis and may be used for publication at a later date.

#### Contact for further information

If you have further questions or wish to discuss this research project in more detail, please contact:

Christine Brown Wilson

School of Nursing and Midwifery

**Humphry Davy House** 

Golden Smithies Lane

**Manvers** 

Rotherham S63 7ER

Tel: 0114 2229221

I hope you will be able to be part of this study and thank you for your interest.

## CONSENT FORM FOR OLDER PEOPLE LIVING IN CARE HOMES

Please	tick as appropriate	YES	NO
1.	I understand that the project is looking at relationships that I think are important to life within a care home		
2.	I understand that I may be interviewed to find out my views on how relationships contribute to the life of the care home		
	I understand that my family may be approached to be involved in the project	1	
4.	I understand that care staff will be involved in the project		
5.	I understand that Christine will be visiting the homes at different times to chat and observe what is going on in the home		
6.	I understand that Christine will work sometimes as a pair of helping hands		
7.	I understand that I will not be referred to by name in the final report		
8.	I understand that I can choose not to participate in the project		
9.	I understand that I can withdraw at any time and do not need to give a reason		
10	I have read the information sheet and am happy that I understand the aims of the project and what is required and am willing for my home to be part of the project		

ı	Mio or the out rothe		
3.	I understand that my family may be approached to		
	be involved in the project		
4.	I understand that care staff will be involved in the		
	project		
5.	I understand that Christine will be visiting the		
	homes at different times to chat and observe what		
	is going on in the home		
6.	I understand that Christine will work sometimes	1	
	as a pair of helping hands		
7.	I understand that I will not be referred to by name	1	
	in the final report		
8.	I understand that I can choose not to participate in		•
	the project		
9.	I understand that I can withdraw at any time and		}
	do not need to give a reason		
10	. I have read the information sheet and am happy		
1	that I understand the aims of the project and what		
	is required and am willing for my home to be part		
	of the project		
Partic	ipants name:		
	· · · · · · · ·		
Signa	ture:		
Date:			
Dute.			
•	I have given a clear explanation of the study to the	resident and	I am satisfied
	that they have given informed consent		
	, ,		
Witne	and have		
withe	essed by:		
Name	e in Capitals:		

## EXPLORING RELATIONSHIP CENTRED-CARE WITHIN CARE HOMES INFORMATION SHEET FOR FAMILY CARE GIVERS OF OLDER PEOPLE LIVING IN A CARE HOME

#### **BACKGROUND**

This research project is part of an independent study being undertaken by Christine Brown Wilson, as part of her Ph.D. at the University of Sheffield. Christine lives in Nottingham and has worked in Nursing Homes as well as in Community hospitals. You are being invited to give your views about what are the important relationships to you; who are they with and how this contributes to your role within the home, as part of this research project. Before you agree to take part in the study, it is important that you understand what is involved. If you are unsure about any part of this information, please don't hesitate in contacting Christine whose details are at the end of this information sheet.

#### WHY IS THE RESEARCH BEING DONE?

The purpose of this project is to explore the contribution relationships between yourself and those important to you make to the overall life of the home. The views of the person you care for within the home, other residents and their family members as well as staff will be taken into consideration. This will provide a complete picture of how the relationships between the residents, their families and staff contribute to the giving and receiving of care. This information can then be used to support the future development of care practice within care homes.

#### WHO WILL BE INVOLVED?

As well as you, I will be inviting members of the care team and other residents within the home to be involved. I will also ask the person you care for within the home if they would like to contribute.

#### WHAT WILL YOU BE ASKED TO DO?

The study will involve Christine visiting the Home initially to get to know everyone. She will be spending her time chatting to you informally and is very interested in what you consider to be important about the relationships you have. Christine will be available during different shifts and on different days of the week within the nursing home and would be happy to visit you at your home if that was more convenient for you.

#### WHAT WILL BE THE BENEFITS?

Christine will discuss your part within the research with you personally and will be happy to talk about the full report to the home with you. She would also be interested in how you think the study could be used to influence how family caregivers are involved within the life of the home. This study will give you an opportunity to identify what you think are important issues about how relationships form and are developed within care homes. You will also have contributed to a piece of research that seeks to identify what older people and their families see as important in contributing towards care.

#### ARE THERE ANY RISKS IN TAKING PART?

It is hoped that this will be a positive experience for you and those involved within your Home. Disruption to the normal routines of the home will be minimal.

## WHAT HAPPENS IF I DO NOT WISH TO BE INVOLVED IN THE PROJECT?

Taking part in this study is entirely up to you. If you do not wish to be involved you do not need to give a reason and your wishes will be respected. Also if at any time throughout the project, you wish to withdraw, you may do so again without needing to give a reason.

#### WILL TAKING PART BE CONFIDENTIAL?

All information relating to you as a result of this research will be strictly confidential. Any contribution you make will not be identified.

#### WHAT WILL HAPPEN TO THE RESULTS?

This project is part of a higher educational degree being undertaken by Christine. The report will form part of a thesis and may be used for publication at a later date.

#### Contact for further information

If you have further questions or wish to discuss this research project in more detail, please contact:

Christine Brown Wilson
School of Nursing and Midwifery
Humphry Davy House
Golden Smithies Lane
Manvers
Rotherham S63 7ER

Tel: 0114 2229221

I hope you will be able to be part of this study and thank you for your interest.

#### **CONSENT FORM FOR FAMILY CARE GIVERS**

Please t	ick as appropriate	YES	NO
r	understand that the project is looking at elationships that I think are important to life within a care home		
1 1	understand that I may be interviewed to find out my views on how relationships contribute to the life of the care home		
	understand that my relative within the care home may be approached to be involved in the project		
1	I understand that care staff will be involved in the project		
1	I understand that Christine will be visiting the homes at different times to chat and observe what is going on in the home		
	I understand that Christine will work sometimes as a pair of helping hands		
1	I understand that I will not be referred to by name in the final report		
I .	I understand that I can choose not to participate in the project		
9.	I understand that I can withdraw at any time and do not need to give a reason		
	I have read the information sheet and am happy that I understand the aims of the project and what is required and am willing for my home to be part of the project		

my views on how relationships contribute to the		
life of the care home		
3. I understand that my relative within the care home		
may be approached to be involved in the project		
4. I understand that care staff will be involved in the		
project		
5. I understand that Christine will be visiting the		
homes at different times to chat and observe what		
is going on in the home		
6. I understand that Christine will work sometimes		
as a pair of helping hands		
7. I understand that I will not be referred to by name		
in the final report		
8. I understand that I can choose not to participate in		
the project		
9. I understand that I can withdraw at any time and		
do not need to give a reason		
10. I have read the information sheet and am happy		
that I understand the aims of the project and what	1	
is required and am willing for my home to be part		
of the project		
Participants name:		
Signature:		
Date:		
I have given a clear explanation of the study and I given informed consent	am satisfied th	nat they have
Witnessed by:		
Name in Capitals:		

# EXPLORING RELATIONSHIP CENTRED-CARE WITHIN CARE HOMES INFORMATION SHEET FOR STAFF WORKING WITHIN CARE HOMES

#### **BACKGROUND**

This research project is part of a PhD being undertaken by Christine Brown Wilson, a lecturer at the University of Sheffield. Christine lives in Nottingham and has previously worked in Nursing homes. You are being invited to give your views about what you see as the important relationships within care homes and how they contribute to the care experience within the home. Before you agree to take part in the study, it is important that you understand what is involved. If you are unsure about any part of this information, please don't hesitate in contacting Christine whose details are at the end of this information sheet.

#### WHY IS THE RESEARCH BEING DONE?

The purpose of this project is to explore the contribution relationships between yourself and others within the home make to the overall life of the home. In addition, this research will consider the views of residents, family members and other members of staff towards how they see the contribution of relationships within the home. This will provide a clear picture of what is important within care homes to the residents, their families and staff, to support how care homes can be developed in the future.

### WHO WILL BE INVOLVED?

As well as yourself, I will be asking other members of your care team to be involved. I will also ask older people and members of their family if they would like to contribute. Other homes from the area will also be approached to be involved.

## WHAT WILL YOU BE ASKED TO DO?

The study will involve Christine visiting the Home initially to get to know everyone. The timing of this will be negotiated with the manager and will take into consideration the needs of the home, the staff and older people. Christine will also be available to participate in the care routines of the home as an extra pair of hands. This again will be negotiated but is anticipated to take in a variety of days and shift patterns. Christine will also come in and chat to the residents, the staff and yourself. At this point, Christine will be sensitive to the needs of all involved. Christie will spend approximately one to two days a week within the home in this way for 4-6 weeks.

### WHAT WILL BE THE BENEFITS?

The home will receive a report of Christine's findings and at the end of the project. It is hoped that the information will support you as a team in identifying what it is that you do well as well as areas that you may identify could be improved. You will also have contributed to a piece of research that will raise the profile of the good work you do.

## ARE THERE ANY RISKS IN TAKING PART?

It is hoped that this will be a positive experience for you and those involved within your Home. Disruption to the normal routines of the home will be minimal.

## WHAT HAPPENS IF I DO NOT WISH TO BE INVOLVED IN THE PROJECT?

Taking part in this study is entirely up to you. If you do not wish to be involved you do not need to give a reason and your wishes will be respected. Also if at any time throughout the project, you wish to withdraw, you may do so again without needing to give a reason.

### WILL TAKING PART BE CONFIDENTIAL?

All information relating to you as a result of this research will be strictly confidential. Any contribution you make will not be identified. The home will not be identified in the final report.

### WHAT WILL HAPPEN TO THE RESULTS?

This project is part of a higher educational degree being undertaken by Christine. The report will form part of a thesis and may be used for publication at a later date.

#### Contact for further information

If you have further questions or wish to discuss this research project in more detail, please contact:

Christine Brown Wilson
School of Nursing and Midwifery
Humphry Davy House
Golden Smithies Lane
Manvers
Rotherham S63 7ER

Tel: 0114 2229221

I hope you will be able to be part of this study and thank you for your interest.

## **CONSENT FORM FOR CARE STAFF**

Please tick as appropriate		YES	NO
1.	I understand that the project is looking at how relationships within the home contribute towards the care given		
2.	I understand that I may be interviewed to find out my views on how I think relationships influence the care given within the home		
3.	I understand that residents and their families will be approached to be involved in the project		
4.	I understand that Christine will be visiting the homes at different times		
5.	I understand that Christine will work at specified times as a pair of helping hands		
6.	I understand that myself and the home will not be referred to by name in the final report		
7.	I can choose not to participate in the project		
8.	I can withdraw at any time and do not need to give a reason		
9.	I have read the information sheet and am happy that I understand the aims of the project and what is required and am willing for my home to be part of the project		

of the project		
Participants name:		
Signature:		
Date:		

## INTRODUCTORY INFORMATION SHEET RELATIONSHIPS WITHIN CARE HOMES

To introduce myself, I am a Registered General Nurse with experience of working with older people in a variety of settings and am currently working at the University of Sheffield, studying towards my PhD in nursing. I would like to invite you, your staff and the residents and their families within your home, to be involved in a research project that explores the importance of relationships within the giving and receiving of care.

My own experience in working in nursing homes has shown me the importance of valuing residents, their families and the staff that care for them. By inviting people from within nursing homes to participate within this study, I hope I will be able to give a voice to all involved in this important sector of nursing older people. There is a lot of change in the care of older people initiated from recent policies and guidelines. I believe it would be of value to have the voice of those working in and cared for by the independent sector as part of the debate.

This research proposes to explore the contribution that relationships between residents, staff and family members make to the life and care within the home. This will be one of the few studies that involve everyone in the home at the same time. By involving residents, their families and staff, the perspectives that each group of people have can be shared with the others while always maintaining confidentiality. This will help each of these groups understand what is important to the others about relationships within the home. These shared understandings can then be used if wanted to feed into the planning and delivery of future care within the home. As this research is looking at the views of so many people within the home, it would be important that the staff, the residents and their families were prepared to be involved within the study.

This research will take an in depth case study approach. I will visit the home for a period of time that covers at least three months. Before the study began, I would spend some time becoming known to everyone to make sure they understood what I would be doing. Information sheets would be provided to everyone and consent received from anybody wishing to be involved. Following this time, I would be spending 1 or 2 days per week on different days and different times either sitting and chatting to the residents or as an extra pair of hands helping out when I can. These would be negotiated in advance. I would also ask older people, their families and staff who wish to be involved to be interviewed at convenient times. These interviews would be taped and a written copy given to the person being interviewed. At the end of the research, I would provide a report to the home. This would not contain any reference to those who took part, just the information gathered. It is hoped that the involvement of the Home would be a positive experience with disruption being minimal.

The broad areas that will be of interest to the study include things like: working together; involvement of families and older people themselves in the life of the home; how the residents interests are catered for and how people build up social networks within the home. The contribution of the values and philosophy of the home, social events and activities will also be considered. These are only general ideas, anything else that those involved feel are important would also be included.

If you feel you would like more information or to discuss becoming involved, please contact Christine Brown Wilson on 0114 2229921

## APPENDIX 8- ETHICAL APPROVAL

## Trent Health Authority



Please ask for: Linda Ellis, Administrator Ext: 49435. E-mail <u>linda.ellis@rushcliffe-pet.nhs.uk</u> Nottingham Local Research Ethics Committee 2

1 Standard Court
Park Row
Nottingham
NG1 6GN

Tel: 0115 912 3344 Fax: 0115 912 3300

REC **P2070301** 

(please quote this number on all correspondence)

07 November 2003

Ms Christine Brown-Wilson Lecturer School of Nursing and Midwifery Humphry Davy House Golden Smithies Lane Manvers Rotherham S63 7ER

Dear Ms Brown-Wilson

## Re: Exploring relationship-centered care within care homes

The Chair of the Nottingham Research Ethics Committee 2 has considered the amendments submitted in response to the Committee's earlier review of your application on 28 July 2003 as set out in our letter dated 04 August 2003. The documents considered were as follows:

- . Application Form
- . Protocol
- . Information Sheet for Older People First Revision
- . Information Sheet for Families of older people First Revision
- . Information Sheet for Staff First Revision
- . Consent Form for Older People
- . Consent Form for Familes of Older People
- . Consent Form for Staff
- Interview Schedule for Residents

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study. On behalf of the Committee I am, therefore, happy, to give full approval for this study on the understanding that you will follow the conditions set out below:

- 1. The Project must be started within three years of the date on which REC approval is given.
- 2. You must not start your project in any institution until you have received written approval from their R&D department. You should have submitted your original application to the R&D office and parallel reviews will have been taking place. Approval should therefore be imminent.

If your study is to take place in any of the following units then you do not need further ethical approval but you do need R&D approval.

- . Queen's Medical Centre
- · Nottingham City Hospital
- · Nottingham Primary Care Trusts
- · Mental Health Care Trust

If your study is to take place in units outside of Nottingham but still within the boundaries of the Strategic Health Authority, then you do not need further full ethical approval. You will however need your study approved by the R&D unit of the institution concerned and an assessment of 'locality issues.' These 'locality issues' (such as appropriate status of research aspects of local research subjects, information sheets) are usually addressed and reviewed by the local ethical committee and you should clarify this point with the administrator of your local REC. These reviews should take place quickly.

- You must not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate immediate hazards to research participants or when change involves only logistical or administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.
- 4. You complete and return the standard progress report form to the REC one-year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.
- 5. If you decide to terminate this research prematurely you send a report to this REC within 15 days, indicating the reason for the early termination.
- 6. You advice the REC of any unusual or unsuspected results that raise questions about the safety of the research.

Yours sincerely



Dr M Hewitt/Mrs L Ellis Chair/Administrator Nottingham Research Ethics Committee 2

cc Research and Development

## APPENDIX 9-CORRESPONDENCE FROM PCT WITH ORGANISATIONAL APPROVAL

## Nottinghamshire Primary Care Trusts (excluding Bassetlaw PCT)



R&D Department Hucknall Health Centre Curtis Street Hucknall Nottingham NG15 7JE 0115 859 0773

8<sup>th</sup> July 2004

Mrs CR Brown Wilson
Lecturer
School of Nursing and Midwifery
Humphry Davy House
Golden Smithies Lane
Manvers
Rotherham
S63 7ER

Dear Mrs Brown Wilson

**Ethics Reference Number: P2070301** 

Project Title: Exploring Relationship Centred Care Within Care Homes

Thank you for submitting the above project to the Nottingham Primary Care R&D office. The project has now been given organisational approval by:

Cheryl Clements, R&D lead, on behalf of Nottingham City PCT. Dr Clive Richards, R&D lead, on behalf of Rushcliffe PCT.

Although organisational approval has been given for this study it does not guarantee that independent contractors such as GPs, dentists, optometrists and community pharmacists will be able to take part in your study.

You must not commence your research until you have written ethical approval from the relevant LREC(s)/MREC as required for your study.

## Conditions of approval

- To complete yearly/final reports as requested
- To endeavour to publish and/or disseminate research findings on completion of the project
- To inform the R&D department of any changes that occur eg project not started for any reason, change in personnel etc

• That you have read and agree to abide by the Research Governance Framework (RGF) for Health and Social Care.

The Research Governance Framework sets out the responsibilities of all those involved in research in order to enhance the ethical and scientific quality of health research and to safeguard patients and the public. The lead investigator and all involved in the research have a responsibility to comply with Research Governance.

Full details can be found in the RGF document available at <a href="www.doh.gov.uk">www.doh.gov.uk</a> or via the R&D office.

You may be aware that every quarter we are required to send basic project details to the National Research Register. If you or your sponsor do not wish us to divulge this information because of intellectual property rights or confidentiality constraints, you must inform us immediately if you have not already done so. For your information, the details sent to the NRR are as follows:

Reference Number:
MREC Number
Project Title
Principal Research Question
Methodology eg RCT, Qualitative interview study
Sample Group Description
Outcome Measures (Measurable End Points)
Start and End Dates
NHS R&D Programme (Yes/No)
Multicentre Research (Yes/No)
Project Related Web Site
Contact Person
Funding Organisation
Supplementary Information

Yours sincerely,

Death of the

Rachel Illingworth Research and Development Manager

Copy to:

R&D lead as applicable Nottingham Ethics Office, Standard Court Mailstore usage: 0.81MB / 40.00MB (2.01%)

Date: Fri, 21 May 2004 17:15:35 +0100

From: Illingworth Rachel <rachel.illingworth@broxtowehucknall-pct.nhs.uk>
To: "c.brown-wilson@sheffield.ac.uk" <c.brown-wilson@sheffield.ac.uk>

Subject: Exploring relationship-centered care within care homes

Dear Christine

Further to our conversation on 13th May I can confirm that you approached me in May 2003 to discuss your proposal for your PhD. As you were intending to undertake your research in private nursing homes I advised at that time that PCT organisational approval for research governance purposes was not required.

You contacted us again in April 2004 to let us know that one of the nursing homes you had recruited within Rushcliffe PCT boundaries had NHS continuing care residents. You had only discovered this after spending some orientation/observation time at the home. We agreed that PCT approval from Rushcliffe PCT was now required and that you would send us the required information to process your study.

We agreed over the phone on the 13th May that you would have no further contact with the residents at the home until organisational approval from Rushcliffe PCT had been obtained. You notified us that you were planning to recruit a nursing home within Nottingham City PCT boundary and that you wished to apply for organisational approval for this PCT now.

As agreed on the phone your study has been expedited for organisational approval (at Rushcliffe and Nottingham City PCTs) and we will write to you formally once the process is complete. Thank you for sending through your CRB certificate.

I do appreciate that you have contacted us/kept us informed about your study over the past year and have sought our advice on research governance issues.

Yours sincerely,

Rachel Illingworth
Research and Development Manager
Broxtowe and Hucknall Primary Care Trust (Host for R&D)
Hucknall Health Centre
Curtis Street
Hucknall
Nottingham
NG15 7JE
Tel: 0115 859 0773

DISCLAIMER: This e-mail is confidential and privileged. If you are not the intended recipient please accept our apologies; please do not disclose, copy or distribute information in this e-mail or take any action in reliance on its contents: to do so is strictly prohibited and may be unlawful. Please inform us that this message has gone astray before deleting it at helpdesk@nottingham-his.nhs.uk. Thank you for your co-operation.

WARNING: Though this email has been scanned by Network Associates GroupShield Anti Virus software the recipient should still check this Email and any attachments for the presence of viruses. Nottingham Health Informatics Service accepts no liability for any damage caused by any virus transmitted by this Email.

## **APPENDIX 10**

## List of conference papers, articles and book chapters arising from this thesis

Brown Wilson, C. (2004) Exploring relationships in care homes: the ethical dimension. 2<sup>nd</sup> International Summer School- Nursing Research focused on Gerontological Nursing Research. University of Maribor, Slovenia. 28<sup>th</sup> June 2004-2<sup>nd</sup> July 2004.

Brown, Wilson, C.(2004) Exploring Relationships in care homes: the process of constructivist research. Presentation to the British society of Gerontology conference

Brown Wilson (2004) Exploring rigour in constructivist research. Presentation to the 5<sup>th</sup> Europena Doctoral Conference in Nursing Science, Charite-Universitatsmedezin Berlin. 1-2 October 2004.

Brown Wilson (2005) Towards relationship centred care in care homes. The RCN 2005 International Nursing Research conference, Belfast, 8-11<sup>th</sup> March 2005.

Cook, G., Brown Wilson, C. and Forte, D.(2006) The impact of sensory impairment on social interaction between residents in care homes. International Journal of Older People's Nursing 1, 216-224.

Davies, S., and Brown Wilson, C. (2007) Creating a sense of community. In National Care Homes Research and Development (NCHR&D) Forum 'My Home Life'. Quality of Life in Care Homes: a review of the literature. London. Help the Aged.

Davies, S., and Brown Wilson, C. (2007) Shared decision making in Care Homes. In NCHR&D Forum 'My Home Life'. Quality of Life in Care Homes: a review of the literature. London. Help the Aged.