

**“It made me see him in a different light.”  
The use of life story work with older people  
who have dementia in health and social care  
practice.**

**Jane McKeown**

**Volume 2**

**Appendices**

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## **APPENDIX 1:**

**Reflective question used to guide critical appraisal of literature**



## **Reflective question used to guide critical appraisal of literature**

1. Is the research discussed in relation to the underlying philosophical and theoretical bases?
2. Does the researcher describe their interests in the research? Is this transparent, with reference to professional and personal backgrounds, prejudices and beliefs?
3. Does the research illuminate the subjective meaning, actions and context of those being researched?
4. How are ethical issues approached and discussed and how do service users influence the research process?
5. Is there evidence of the adaptation and responsiveness of the research design, to the circumstances and issues of real life social settings met during the course of the study? Are blocks and false steps described?
6. Does the sample chosen, produce the types of knowledge necessary to understand the structures and processes within which individuals or situations are located?
7. Is the description (narrative) provided detailed enough to allow the researcher or the reader to interpret the meaning and context of what is being researched? Is the reader taken on a journey?
8. How are the different sources of knowledge about the same issue compared and contrasted?
9. How does the research move from a description of the data, through quotation or examples, to an analysis and interpretation of the meaning and significance of it?
10. What claims are made for the generalisability of the findings to either other bodies of knowledge or to other populations or groups?

Adapted from Popay et al (1998) and Jones (2003)

## **APPENDIX 2:**

**Letter to family carers inviting participation in research protocol  
development**



Sheffield Care Trust



Mental Health and Wellbeing

Older Adult Mental Health Care Group  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH  
Tel: 0114 226 3965  
Fax: 0114 226 3451

E-Mail: [Jane.McKeown@sct.nhs.uk](mailto:Jane.McKeown@sct.nhs.uk)

27<sup>th</sup> January 2005

Dear

Let me introduce myself. My name is Jane McKeown and I am the Practice Development Nurse working with Sheffield Care Trust Older Adult Mental Health and Social Care Group.

Part of my work last year involved helping to identify the learning and development needs of the qualified nurses working on \*\*\*\* Ward. This information will help the ward to ensure that staff continue to receive the necessary skills and training to care for the patients on \*\*\*\* Ward.

I am now hoping to continue working with \*\*\*\* Ward to carry out a small piece of research in relation to improving the understanding that all staff have of the patients they care for on the ward. This research links to my role as Practice Development Nurse and also links to a research degree I am undertaking with the University of Sheffield.

At this stage I am wanting to encourage a range of people involved with \*\*\*\* Ward, including carers / family members, to help develop the research proposal. This will then be assessed by Sheffield Health Research Consortium, to ensure that the interests of patients are safeguarded, and to agree the research can go ahead.

Please take a few moments to read the accompanying sheet of paper. If you would like to become involved in developing the proposal at any level, or wish to ask me more about this research please make contact with me through any of the suggested means. Please leave me your telephone number if you wish me to ring you, as I work part time, and can be difficult to get hold of.

Thankyou for your time

Yours Sincerely

Jane McKeown  
(Practice Development Nurse)

## **APPENDIX 3:**

**Notes from research protocol development group meeting**

## **\*\*\*\*\* Research Development Meetings**

### **What are these meetings about?**

These are 3 meetings to develop a research proposal for a piece of Action Research on \*\*\*\*\* Ward. Jane McKeown is co-ordinating the meetings which evolve from her work on \*\*\*\*\* as a Practice Development Nurse and her interests as a research degree student.

### **What will be discussed in these meetings?**

The first meeting has already taken place and was aimed at generating ideas for a possible area of care to improve, change and research. It was attended by practitioners and carers, who discussed areas of good practice on \*\*\*\*\* and also a number of areas that might be improved.

The second meeting will aim to begin to agree on a focus for the research and discuss the practicalities. The third meeting will be a chance to look at and comment on a draft research proposal that will go to the necessary bodies for agreement and funding.

### **How can I contribute to these discussions?**

It is difficult for everyone who wants to be involved to attend these meetings. The general discussions and themes that come out of each meeting will be shared with anyone who registers an interest in finding out more, with Jane McKeown (details below). Action Research involves changes to practice to improve care for patients - so the views of everyone involved with \*\*\*\*\* Ward are valuable - and essential for the best chance of choosing an area for research that will benefit everyone.

The summary of each meeting will be pinned on the notice board just outside the entrance to the ward, on the board at the corridor junction at the bottom of the ward and at the back of the ward communication book. Jane will try and speak to people individually and possibly in handovers or staff groups. The summary will be e-mailed to people who use e-mail regularly.

**For more information please see Jane or contact her by phone 226 3963 or e-mail [jane.Mckeown@sct.nhs.uk](mailto:jane.Mckeown@sct.nhs.uk).**

## \*\*\*\* Research Development Group

### Meeting 1 Held on Tuesday 12<sup>th</sup> April 2005.

#### **Summary of Discussions:**

##### **The Research Themes**

Five members of staff and carers involved with \*\*\*\* met to begin to identify a possible focus for research on \*\*\*\*. The overall theme of "Understanding more about the patients cared for on \*\*\*\*\*" was proposed with a view to focusing discussions on patient care, and it was suggested that any ideas within this very broad remit were welcomed.

The type of approach to the research being considered is Action Research. This has an emphasis on the involvement of many different people throughout the research process. It is collaborative in the sense that the researcher is not seen as the expert - all viewpoints are equally important. It also seeks to make improvements in practice and "change" or "action" is just as important as "research results".

##### **Possible Areas for Research**

This discussion involved everyone at the meeting considering what some of the good aspects to care were on the ward and where there was scope for improvement and research. These are the views from individuals at the meeting, it is accepted that others may agree or disagree. The thoughts have been put into words pretty much as individuals at the meeting said them.

##### **What's Good?**

- The entertainment events are enjoyable and the staff make a big effort to ensure they are a success
- The care on the ward is good
- Some staff show genuine affection to the patients
- It's nice to see when staff act in an "ordinary" way with patients, like giving a hug or a kiss.
- Staff are generally friendly and approachable - this makes it possible to raise any issues of concern about patients

- Staff are responsive to suggestions or requests
- Staff seem willing to learn about patients
- Patients are cared for well in relation to personal care

### **Some suggestions for possible research ideas**

- More one to one activities with every person.
  - This discussion focussed on trying to work with every person, trying to find things that stimulate them individually. There was an awareness that this would not always be successful, depending on the person's mood and preferences at the time. It was seen that this was not just the role of one staff group but of all staff working on \*\*\*\*\*. It was seen as particularly relevant to people who had no visitors. This care should be seen equally as important as the basic physical care. The words that were used in this discussion were - "Quality Time", "Making people feel special", "A personal touch".
- Specific activities or techniques that might be used with people on the ward
  - This discussion was around a number of possible "interventions" such as multi sensory equipment (lights, sounds, Snoezelen) and pets as therapy... that might be available. The discussion moved to other "research" that advocated certain activities such as collage, life story work and reminiscence. It was thought that these "interventions" may be very valuable but it was also possible that it was the time spent with the person and the relationship that was central. Some of these interventions might be ways of spending time and developing closer relationships with people on the ward - and might also be enjoyable to staff.
- Finding more out about a person's personal biography - their likes, dislikes, things they enjoyed doing, holidays, work...
  - The discussion touched on the question that although we know past interests, how can we find out if the person still enjoys these things today.

### **Next Steps**

Time ran out and the meeting ended. It was agreed that others involved with \*\*\*\*\* should be asked to offer their ideas on areas for possible change and improvement. Jane would share the discussions from this meeting and gather opinions. The next meeting would aim to try and agree on some priorities and consider some of the practicalities. The next meeting will take place on a Tuesday between 12 and 1.30 - hopefully avoiding Brunch and allowing nursing staff to attend.



## **APPENDIX 4:**

**Letter to Alzheimer's Society requesting their involvement**



# Sheffield Care Trust

Mental Health and Wellbeing



Older Adult Mental Health Care Group  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH  
Tel: 0114 226 3965  
Fax: 0114 226 3451

E-Mail: [Jane.McKeown@sct.nhs.uk](mailto:Jane.McKeown@sct.nhs.uk)

23<sup>rd</sup> September 2005

Dear \*\*\*\*\*,

I am writing to inform you about a proposed piece of research I hope to undertake on \*\*\*\*\* Ward within Sheffield Care Trust. I would value the comments and contributions the Alzheimer's Society may wish to make about the research and would also be interested in your thoughts of how the Society may be able to collaborate in the research. I know the Society has had some involvement following the Service Evaluation of last year and although many service users have relatives, some people have no relative or advocate.

I enclose the notes to date on the direction of the research, I have had to focus this following advice from the University of Sheffield, although I hope it still captures the essence of what staff and carers feel is important. I would hope to ensure we take into consideration the Service Users views of the research, this will clearly be challenge and I would value the skills and experience that your Society members/staff may be able to offer.

Please read through the notes to date and if you feel it would be worthwhile I would be happy to meet up and discuss this in more detail.

Many Thanks  
Yours Sincerely

Jane McKeown  
(Practice Development Nurse)

## **APPENDIX 5:**

**Written update on research protocol progress**

### **\*\*\*\* Research Update**

Just to update you regarding the proposed research on \*\*\*\* – incase you thought it had been forgotten about! The research involves understanding how a more detailed understanding of the people cared for on the ward can benefit their care.

I am relatively new to research and am quickly learning how much work is needed before actually making a start. Believe me – I have not forgotten about the research – here is a summary of where we are:

1. The Care Group Practice and Service Development Group have agreed in principle to the research going ahead, a full proposal will be presented to them in December 2005
2. A short research proposal is nearly complete – I will be passing this out for comments in early October – this should help clarify what is actually involved as I know up to know the fine details have not been available. This proposal will bid for some funds to help make the research a reality.
3. My University supervisors will contribute to the details of the research and this will inform a more detailed proposal.
4. The proposal then has to be consulted on by service user groups before being sent to a group of researchers to comment on its value and quality.
5. The proposal then has to go to another panel to be agreed upon and also has to be presented at an ethics committee.

This may seem time consuming and tedious; but is important to ensure the research will ultimately benefit the ward, patients and carers. It ensures that people who do not wish to be involved can opt out with no question and ensures that those who do wish to be involved know what they are “signing up to”.

If you have any questions please do not hesitate to speak to me: Jane McKeown  
(Practice Development Nurse) 226 3965

## **APPENDIX 6a:**

**Research governance approval confirmation letter**

Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

15 March 2007

Ms Jane McKeown  
Practice Development Nurse  
Sheffield Care Trust (AMH)  
Fulwood House  
Old Fulwood Road  
Sheffield S10 3TH

Tel: 0114 271 8804  
Fax: 0114 271 6736  
Email: shsrc@sct.nhs.uk  
www.shsrc.nhs.uk

Dear Ms McKeown

**Consortium Reference: ZF24**

**Full Project Title: A multiple case study exploring the impact of using a Life Story Work approach with people with dementia and 'challenging behaviour'**

Following our earlier letter of 18 December 2006 concerning funding, you now have **Research Governance approval from this Consortium** to carry out research as described in documentation you have supplied to us.

Please check the attached financial schedule against the previous letter, as nothing in this letter may be construed to increase the total amount of funding mentioned in the earlier one. Please check also that the schedule is consistent with any revised start and end dates since you drafted the schedule. If necessary, amend the amounts in any one financial year, provided the overall total remains unchanged. Then please sign the contract and ask whoever is authorised to countersign it on behalf of your organisation to do so. Finally, please sign and return to me the second copy of this letter, including the financial schedule and contract page.

Please note that end of project accounts must be forwarded to the Consortium Management Accountant and that amendments to the financial schedule should not be made without prior permission.

We also advise you of the following conditions which apply to all receiving Research Governance Approval through the Consortium:

1. Please inform us of the actual project start date immediately you do start and at that time inform us also of the expected end date.
2. In order to comply with the NHS Research Governance Framework, please copy the Consortium into all future project monitoring forms that you send to the relevant Research Ethics Committee, including the "Declaration of End of Study".
3. The Consortium recommends the attached format for maintenance of your project site file to ensure all documentation is readily accessible.

4. You will also need to seek approval for every future change to protocol or project title and I suggest you do this by sending us a draft of the submission you will also have to make to the NHS REC and that you do so **at the same time as that submission to the REC**. See the following web reference for details:  
<http://www.corec.org.uk/applicants/apply/amendments.htm>
5. As Chief Investigator, you have an obligation to report all research-related adverse events directly to the Consortium.
6. You need to seek Consortium approval for any additions to your research team not already included in documentation sent to us. For this purpose, please send a short CV, preferably in the format required by the NHS REC.
7. This Research Governance approval is given on the understanding that the findings of the research will be appropriately disseminated in peer-reviewed journal(s) and to research participants and any organisations representing their interests.

We wish you every success with the project and please feel free to contact us if you need further assistance from the Consortium.

Yours sincerely



Dr Robert Dixon  
Consortium Manager

Enc. Contract and Financial schedule (2 copies)  
Site file guidance

cc Olga Lycett, Assistant Principal Accountant  
Andrea Wilson  
Jane McKeown (For SCT Older Adults records) ✓  
Jonathan Boole  
Project File

## **APPENDIX 6b:**

**Ethical approval confirmation letters**





**North Sheffield Ethics Office**

1st Floor Vickers Corridor

Direct Line: 0114 271 4894 or 271 4011

Fax: 0114 256 2469

Email: sue.rose@sth.nhs.uk

**Northern General Hospital**

Herries Road  
Sheffield  
S5 7AU

21 February 2007

Ms Jane McKeown  
Practice Development Nurse  
Sheffield Care Trust (Older Adults Health and Social Care Group)  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

Dear Ms McKeown

**Full title of study:** A multiple case study exploring the impact of using a life story work approach with older people with dementia and 'challenging behaviour'.  
**REC reference number:** 06/Q2308/171

Thank you for your letter of 01 February 2007, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chairman.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised].

**Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

**Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		06 November 2006
Investigator CV		11 October 2006
Investigator CV		11 October 2006
Protocol	2	01 October 2006
Letter from Sponsor		17 August 2006
Peer Review		02 May 2006
Insurance details from University		15 January 2007
Interview Schedules/Topic Guides	2	11 October 2006
Interview Schedules/Topic Guides	2	11 October 2006
Letter of invitation to participant	staff (version 2)	01 February 2007
Letter of invitation to participant	carer (version 2)	01 February 2007
Letter of invitation to participant	proxy (version 2)	01 February 2007
Participant Information Sheet: Staff	4	20 January 2007
Participant Information Sheet: proxy	4	20 January 2007
Participant Information Sheet: Relatives	4	20 January 2007
Participant Consent Form: Staff	4	20 January 2007
Participant Consent Form: Relatives	4	20 January 2007
Participant Consent Form: Proxy	4	20 January 2007
Response to Request for Further Information		01 February 2007
Ward Information		12 January 2007
Life story work info	2	01 February 2007
Consent Monitoring		
Wellbeing Profile		
CBS Scale		
Data Collection Info		

### Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**06/Q2308/171****Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr C A Moore**  
**Chairman – North Sheffield Research Ethics Committee**

Email: april.dagnall@sth.nhs.uk

*Enclosures: Standard approval conditions [SL-AC1 for CTIMPs, SL-AC2 for other studies]*

Copy to: Mrs Greta Pearman  
University of Sheffield  
Research Office, University of Sheffield  
New Spring House  
231 Glossop Road, Sheffield  
S10 2GW  
  
R & D Consortium



## National Research Ethics Service

### North Sheffield Local Research Ethics Committee

1st Floor Vickers Corridor  
Northern General Hospital  
Herries Road  
Sheffield  
S5 7AU

Tel: 0114 271 4011  
Fax: 0114 256 2469

30 July 2008

Ms Jane McKeown  
Practice Development Nurse  
Sheffield Care Trust NHS Foundation Trust  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

Dear Ms McKeown

**Study title:** A multiple case study exploring the impact of using a life story work approach with older people with dementia and 'challenging behaviour'.  
**REC reference:** 06/Q2308/171  
**Amendment number:** 1  
**Amendment date:** 15 July 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 30 July 2008.

#### Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Information leaflet for carehome staff	1	12 July 2008
Carehome passport	1	12 July 2008
Notice of Substantial Amendment (non-CTIMPs)	1	15 July 2008
Covering Letter	1	15 July 2008

## Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

## R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2308/171:

Please quote this number on all correspondence

Yours sincerely



Dr C Moore

pp Chair

E-mail: april.dagnall@sth.nhs.uk

Enclosures

List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to:

University of Sheffield R & D Department

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within  
The National Patient Safety Agency and Research Ethics Committees in England



## National Research Ethics Service

North Sheffield Local Research Ethics Committee  
1st Floor Vickers Corridor  
Northern General Hospital  
Herries Road  
Sheffield  
S5 7AU

Telephone: 0114 271 4011  
Facsimile: 0114 256 2469

18 September 2008

Ms Jane McKeown  
Service Development Directorate  
Sheffield Health and Social Care NHS Foundation Trust  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

Dear Ms McKeown

**Study title:** A multiple case study exploring the impact of using a life story work approach with older people with dementia and 'challenging behaviour'.  
**REC reference:** 06/Q2308/171

At the meeting held on 15 September 2008 the Research Ethics Committee reviewed a supplementary application for approval of the above research study under Section 30 of the Mental Capacity Act.

The reviewers felt that the investigator had fulfilled the criteria for section 30 approval. The investigator assured the Committee that if it was necessary to appoint care staff as nominated consultee this would be decided at an MDT meeting and would not be anyone involved with the research project.

### Mental Capacity Act 2005

The members of the committee present approved the supplementary application on the basis described in the documentation submitted. I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

### Confirmation of ethical opinion

The research continues to have a favourable opinion from this committee. It should continue to be conducted on the basis previously approved by the committee, as amended by this supplementary application. The conditions of approval issued with the committee's original favourable opinion continue to apply.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	3	03 August 2008
Participant Information Sheet: Nominated consultee	1	01 August 2008

Participant Information Sheet	personal consultee (V1)	01 August 2008
Participant Consent Form: Nominated consultee	1	01 August 2008
Participant Consent Form: Personal consultee	1	01 August 2008
Summary of ethical framework		
Notice of Amendment: Application for Section 30		18 August 2008
MCA 1 Form	Supplementary Information for section 30	
Article		01 August 2008

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

<https://www.nationalres.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>

We value your views and comments and will use them to inform the operational process and further improve our service.

06/Q2308/171

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

  
Dr C A Moore  
Chair

E-mail: april.dagnall@sth.nhs.uk

**Enclosures**     *List of names and professions of members who were present at the meeting and those who submitted written comments*

**Copy to:**     Richard Hudson, University of Sheffield

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES directorate within  
The National Patient Safety Agency and Research Ethics Committees in England

## **APPENDIX 7:**

### **Life Story Work Research Timeline**



**Table showing Timeline of Research**

Date	1 2 / 0 6	0 1 / 0 7	0 2 / 0 7	0 3 / 0 7	0 4 / 0 7	0 5 / 0 7	0 6 / 0 7	0 7 / 0 7	0 8 / 0 7	0 9 / 0 7	1 0 / 0 7	1 1 / 0 7	1 2 / 0 7	0 1 / 0 8	0 2 / 0 8	0 3 / 0 8	0 4 / 0 8	0 5 / 0 8	0 6 / 0 8	0 7 / 0 8	0 8 / 0 8	0 9 / 0 8	1 0 / 0 8	1 1 / 0 8	1 2 / 0 8	0 1 / 0 9	0 2 / 0 9	0 3 / 0 9	0 4 / 0 9	0 5 / 0 9					
RG LEC	*			*															*			*													
Pilot																																			
Cs1																																			
Cs2																																			
Cs3																																			
Cs4																																			
RRG							#	#		#		#	#						#		#							#		#					

**Key:** LEC = Local Ethics Committee; RG = Research Governance; CS = Case Study; LSW W/S = Life story work workshop; + = LSW product completed; RRG = Research reference groups (also Jul 09, Nov 09 and Jan 10);

**APPENDICES 8 a, b, c, d and e:**

**Detail of each case study**

## **APPENDIX 8a:**

### **Pilot case study detail**

## Pilot Case Study Detail

Date	Pilot Case Study	Time (Hr/Min)
Apr 07	Meeting ward manager; negotiating access. Meetings with nurse, psychologist and OT re recruitment.	1.30
May 07	Recruitment and information giving continue.	2.00
Jun 07	Phoned to prompt progress, followed by e-mails.	0.15
Jul 07	Consent gathering. Person with dementia identified. Visits to meet person and wife; establish assent. Teaching to staff re LSW.	2.30
Aug 07	Interviews 1 – 5 pilot. “ interviews progress to case studies 1 and 2. Rating scales completed.	6.30
Sep 07	Visit to chat with staff re ward closure and discuss research. Ward Closure. Pilot ended. Re-negotiation of research follow up participants.	2.00
		14.45

## **APPENDIX 8b:**

### **Case study 1**

## Case Study 1

Date	Activity	Time (Hrs/Mins)
Oct 07	Phone calls and e-mails locating person with dementia and participants and negotiating entry to ward.	0.30
Nov 07	Visit to ward to re-establish contact. Visits to recruit gain consent and present teaching. Rang wife to re-establish contact.	3.00
Dec 07	Consent, information sharing with wider staff group and interview P1 (P3 previously interviewed in pilot). Rating scales completed.	2.30
Jan 08	Telephone call to enquire on progress and prepare for interviews, told staff member died and activity high, maintained e-mail contact.	0.20
Feb 08	Visited to monitor progress, LSW well under way, staff wanting direction.	1.00
Mar 08	No direct contact	
Apr 08	Life story book completed, visited to meet staff and view book	1.00
May 08	Interviews with P 1, 2, 3 & 4 and contact in field	4.00
Jun 08	Completion of rating scales and viewing of final version of LSB.	1.15
Jul 08	No direct contact	
Aug 08	No direct contact	
Sep 08	No direct contact	
Oct 08	Verbal update on progress	0.10
Nov 08	Care plan and medication card obtained.	0.20
Dec 08	Visit to new ward where person with dementia has moved. Conversation with P4.	0.30
Jan 09	Phone conversation with P3 re progress and use of LSB	0.15
Feb 09	Illness and ward closure due to infection meant cancelled meeting with P3	
Mar 09	FU discussion with P3. Collection of observational charts of use of LSW with person with dementia.	1.00
Jan 10	Planned meeting to discuss findings with P3 cancelled – person with dementia died, attended funeral.	
		15.50

## **APPENDIX 8c:**

### **Case study 2 detail**

## Case Study 2

Date	Activity	Time (Hrs/Mins)
Oct 07	Access negotiated in May by visits to ward manager and deputy. Follow up with P3 (who was in pilot). Recruitment visits, information and discussion re person with dementia participant.	3.00
Nov 07	Visits for recruitment and consent gathering. Met person with dementia and wife on 2 occasions. Delayed visits due to high ward activity. Teaching, negotiating assent with person.	3.30
Dec 07	Consent and interview with P1 and P2 (P3 used pilot interview). Rating scales completed. Support to get work underway. Conversation with person with dementia.	3.30
Jan 08	Telephone and e-mail contact. P1 withdrew off sick.	0.15
Feb 08	Visit to support staff and offer guidance. Later in the month discussion / supervision regarding issues arising. Person with dementia fell and fractured his leg is on general ward	1.45
Mar 08	E-mail contact	0.10
Apr 08	Pen picture completed, assisted in editing and presenting. Person with dementia transferred to general nursing home.	1.20
May 08	Pen picture presented to person with dementia in nursing home. Follow up letter to nursing home.	2.15
Jun 08	Interviews P2 and P3, phone contact with NH. Ethics amendment to allow visit to NH.	2.15
Jul 08	Phone contact with NH	0.10
Aug 08		
Sep 08		
Oct 08		
Nov 08	Phone contact with NH	0.10
Dec 08	Phone contact with NH, visit cancelled due to staff sickness	0.05
Jan 09	FU at nursing home and conversation with P5.	1.00
		17.25



## **APPENDIX 8d:**

### **Case study 3 detail**

### Case Study 3 Detail

Date	Activity	Time (Hrs/Mins)
May 08	Initial negotiation to consent began in February. Met with staff to discuss recruitment and identification of person with dementia.	1.15
Jun 08	Person identified but family declined as not happy with involvement. Visited ward to discuss progress and recruitment.	0.15
Jul 08	No direct contact.	
Aug 08	Person with dementia identified, went to visit her, gained assent and made contact with daughter. Recruited another staff member. Gathered consent.	1.30
Sep 08	E-mail conversation and information sharing with carer. Interviews with P1 and 2. Met with and interviewed P3	3.00
Oct 08	No contact	
Nov 08	E-mail contact re progress, visited ward and rating scales completed. Time spent with person and daughter, demographic information collected.	3.00
Dec 08	Life story book completed; visits and time spent with person and daughter observing use of LSB. P1 interview	3.00
Jan 09	Contact with daughter and ward; person moved to nursing home	0.20
Feb 09	No contact	
Mar 09	Interviews with P2 and 3. Made contact with and visited nursing home and conversation with care worker (P5) and with person with dementia	2.30
		14.50

## **APPENDIX 8e:**

### **Case study 4 detail**

#### Case Study 4 Detail

Date	Activity	Time (Hrs/Mins)
Jul 08	Negotiate access through conversation with manager, information sheets sent to P1 and 2.	0.30
Aug 08	Person identified	
Sep 08	Recruitment and consent/ assent of person with dementia and carer; conversation with them in person's home.	1.00
Oct 08	No contact	
Nov 08	Rating scales completed, consent and interviews with P1 and 2	3.00
Dec 08	Life story book completed, met with person with dementia to gather her views on the book and the process.	1.00
Jan 09	Interview P1, e-mail contact with P2 who has now left the service. Demographics collected.	1.00
Feb 09	Follow up at resource centre and discussion with P5.	1.00
Mar 09		
Apr 09	Interview with P3 and conversation with person with dementia	1.00
May 09		8.30

## **APPENDIX 9:**

**Flyer inviting participation in the LSW research**

## Life Story Work Research

This information is to let staff, carers, service users and visitors know about some research which is taking place on \*\*\*\* starting in June 2008.

### **Who is undertaking the research?**

I will be undertaking this research; I am a Practice Development Nurse for Sheffield Care Trust and have been working with older people with dementia for over 15 years. I will be supervised by staff from The University of Sheffield.

### **What is the research about?**

The research will explore the benefits of taking a Life Story Work approach with up to 6 selected older people across 3 wards. I am interested in the views of everyone involved in the care of the person. The research will provide a better understanding of the care we give to older people with dementia so that we can constantly improve our service, the research will also be part of a research degree I am doing at Sheffield University.

### **What does that mean in practical terms?**

The research will take about 18 months and people will be asked to become involved at various points during that time. Detailed life story information will be collated for the people selected to take part in the research; this will involve gathering information from relatives, carers, care-staff and care notes. The information will be shared in



a way that is agreed by everyone involved, especially the person and their relatives/carers. I will then meet to talk individually with everyone involved to hear their views of using the approach.

### **Will I (or my relative) be asked to take part?**

If you are invited to take part you will be given detailed information to help you to decide if you want to become involved.

### **Do I have to take part?**

No, there will be no pressure whatsoever; you do not need to explain why.

### **How can I become involved in this research?**

You may want to be part of the "Research Reference Group"; this small group would meet on a monthly basis to oversee the research, discuss the results and look at how the results can be put into action. If you do not want to attend meetings but still want to be kept informed you can ask to have regular updates. Please contact me about this.

### **I still have questions I want to ask**

If there is anything you want to ask more about, or you have any concerns I can arrange to meet you.

**Jane McKeown (Practice Development Nurse)**

**Tele: 226 3950 (You may need to leave a message as I work part-time but I will return your call)**

**E-Mail: [Jane.McKeown@sct.nhs.uk](mailto:Jane.McKeown@sct.nhs.uk)**

**APPENDICES 10 a, b and c:**

**Information Sheets**



## **APPENDIX 10 a:**

### **Information sheet care staff**



## **Information about research for care staff**

### **Life Story Work Research**

I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish. If you have any questions, please feel free to contact me (contact details below).

Part 1 tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

#### **PART 1**

##### **What is the purpose of the study?**

The purpose of this study is to take a life story work approach in the care of up to 6 selected patients across 3 wards and explore the effects of this approach on the care the person receives and everyone concerned with their care. The accompanying coloured leaflet describes what life story work is and how it can be used.

I will be undertaking this research; I am Practice Development Nurse for Sheffield Care Trust and have been working with older people with dementia for over 15 years. The research will provide a better understanding of the care we give to older people with dementia so that we can constantly improve our service, the research will also be part of a research degree I am doing at Sheffield University.

##### **Why have you been invited?**

A life story work approach will be taken to a patient on the ward with whom you are working. We are interested in your views about this approach.

### **Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do then you will be asked to sign a consent form. If you decide not to take part, your working conditions and professional development will be unaffected.

### **What will happen to me if I take part?**

Your involvement in the research would be for about 12 weeks with a follow up interview at 6 months, the whole research project is expected to last 18 months.

Below is a list of expected timescales and descriptions of what will happen:

- Week 1 – I will meet with you for 1 hour to interview you about the life story work approach.
- Weeks 2-3 – You **may** be asked to collate information on the patient's life story by talking to the person; meeting with relatives, friends, other staff and looking through care notes. You will receive training and support for this and have time out of your usual duties to do this and will undertake the work alongside another member of staff.
- Weeks 4-6 – You **may** be asked to meet with key people involved in the patient's care in order to agree how best to use and share this information to benefit the care the person receives. You will not have to do this alone.
- Weeks 6 – 12 – You **may** be asked to collate the life story information and use it with the person as agreed in their care plan.
- Week 12 – I will visit you for 1 hour to interview you about your views and experiences of using this approach.
- 6 months - I will visit you for 1 hour to interview you about your views and experiences of using this approach.

The interviews will involve me asking a few questions about your experience of the approach. This will be a fairly informal opportunity to talk about your work with the patient, this will be audio taped with your permission, which will allow me to listen to what you have to say instead of trying to also make notes. The interviews will last no more than an hour and can be in a place of your choice.

Some staff members will be asked to be involved in gathering the life story information. If you are asked and you prefer not to do this it is OK and we will approach someone else.

### **Expenses/Payments**

Time will be negotiated out from your usual duties to participate in the research. You will be paid any travel expenses incurred for meeting relatives in their homes if appropriate.

### **What are the possible disadvantages and risks of taking part?**

The risks with using life story work are very low, occasionally people can become upset by their memories and you may need to comfort and support the person and/or their carer. Sometimes painful memories for staff can be evoked and you would be offered supervision and support to overcome any distress. Generally people experience life story work as enjoyable.

### **What are the possible benefits of taking part?**

Generally people experience life story work as enjoyable. You will have the opportunity to get to know people with dementia and their carers better, you will also be contributing to nursing research.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2 of this information sheet.

### **Will my taking part in the study be kept confidential?**

The information you give will form part of the research study and as far as possible, it will be anonymised; however, this may be difficult due to the small numbers of people involved in the study. The steps that will be taken to address this are outlined in part 2 of this information sheet.

## **PART 2**

### **What will happen if I don't want to carry on with the study?**

You are free to withdraw from the research at any time without giving a reason. I would discuss with you what you wanted to happen to any information you had given – for example interviews, and this information would be destroyed if you wished.

### **What if there is a problem?**

If you have any complaints about how you are dealt with during the research you may report this to my University Supervisors Amanda Clarke 0114 2255931 or Julie

Repper 01949 851229. The research has indemnity from the University of Sheffield. If you have any complaints about the care any patient receives as a direct result of the research you may report this to the Care Trust Complaints & Litigation Lead Wendy Hedland 0114 2718956. If during the course of the research I have any concerns regarding the quality of care given by any member staff I will report through the usual Care Trust complaints processes. I would keep any information confided to me in the interviews confidential with the exception of information suggesting harm to self or others.

**Will my taking part in this research be kept confidential?**

Every effort will be made to maintain confidentiality; however, due to the small size of the study, this may not always be possible. If you have concerns about confidentiality these can be discussed and arrangements made for specific information to be kept only by me and shared only with my University supervisors. Any audio tapes will be kept in a locked drawer to which only I will have access and will either be returned to you or destroyed at the end of the study. Transcripts of taped interviews will be kept by me in a locked draw and on a password protected computer, this may be kept up to five years and after that time would be destroyed.

**What will happen to the results of the research study?**

The results of the research will be published in a thesis for my PhD, this will be accessible through Sheffield University library. The results are likely to be shared locally through a report and presentations to which you would be invited and nationally at conferences and through journal articles. You would not be identified in such presentations unless you specifically gave consent.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given a favourable opinion by North Sheffield Research Ethics Committee.

**What if I have more questions?**

I would be only too pleased to meet and discuss the project more fully with you and answer any other questions you might have. I can be contacted on 226 3950.

**Jane McKeown (Practice Development Nurse)**

## **APPENDIX 10b:**

### **Information sheet family carers**



## **Information about research for relatives**

### **Life Story Work Research**

I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish. If you have any questions, please feel free to contact me (contact details below).

Part 1 tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

#### **PART 1**

##### **What is the purpose of the study?**

The purpose of this study is to take a life story work approach in the care of up to 6 selected patients across 3 wards and explore the effects of this approach on the care the person receives and everyone concerned with their care. The accompanying coloured leaflet describes what life story work is and how it can be used.

I will be undertaking this research; I am Practice Development Nurse for Sheffield Care Trust and have been working with older people with dementia for over 15 years. The research will provide a better understanding of the care we give to older people with dementia so that we can constantly improve our service, the research will also be part of a research degree I am doing at Sheffield University.

##### **Why have you been invited?**

Staff will be taking a life story work approach in the care of your relative. We are interested in your views about this approach.

##### **Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do then you will be

asked to sign a consent form. If you decide not to take part, the care your relative receives will not be affected.

### **What will happen to me if I take part?**

Your involvement in the research would be for about 12 weeks with a brief follow up interview at 6 months, the whole research project is expected to last 18 months. Below is a list of expected timescales and descriptions of what will happen:

- Week 1 – I will meet with you for 1 hour to interview you about the life story work approach.
- Weeks 2-3 – Staff from the ward will meet with you for about an hour to talk to you about life story information of your relative/friend that might benefit their care.
- Weeks 4-6 – Ward staff will meet with you to agree how to best use and share this information to benefit the care your relative receives.
- Week 12 – I will visit you for 1 hour to interview you about your views and experiences of using this approach.
- 6 Months – I will contact you to ask you a few questions about the continued use of this approach

The interviews will involve me asking a few questions about your experience of the approach. This will be a fairly informal opportunity to talk about your relative, this will be audio taped with your permission, which will allow me to listen to what you have to say instead of trying to also make notes. The interviews will last no more than an hour and can be in a place of your choice.

### **Expenses/Payments**

Unfortunately, we do not have funds to pay for your time. However, you will be paid any travel expenses incurred for attending meetings on the ward specifically related to the research. Alternatively, myself and ward staff would be happy to meet you in your own home or at a place of your preference.

### **What are the possible disadvantages and risks of taking part?**

The risks with using life story work are very low; occasionally, people can become upset by their memories and may need comfort and support, the staff undertaking the life story work are experienced in dealing with people's emotions and will receive supervision. Generally, people experience life story work as enjoyable.



**What are the possible benefits of taking part?**

Generally, people experience life story work as enjoyable. You will have the opportunity to get to know people with dementia and their carers better, you will also be contributing to nursing research.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2 of this information sheet.

**Will my taking part in the study be kept confidential?**

The information you give will form part of the research and as far as possible, it will be anonymised, however this may be difficult due to the small numbers of people involved in the study. The steps that will be taken to address this are outlined in part 2 of this information sheet.

**PART 2****What will happen if I don't want to carry on with the study?**

You are free to withdraw from the research at any time without giving a reason. I would discuss with you what you wanted to happen to any information you had given – for example, from interviews with me, and this information would be destroyed if you wished.

**What if there is a problem?**

If you have any complaints about how you are dealt with during the research you may report this to my University Supervisors Amanda Clarke 0114 2255931 or Julie Repper 01949 851229. The research has indemnity from the University of Sheffield. If you have any complaints about the care any patient receives as a direct result of the research you may report this to the Care Trust Complaints & Litigation Lead Wendy Hedland 0114 2718956.

**Will my taking part in this research be kept confidential?**

Every effort will be made to maintain confidentiality, however due to the small size of the study this may not always be possible. If you do have concerns about confidentiality these can be discussed and arrangements can be made for specific information to be kept only by me and shared only with my University supervisors. Any

audio tapes will be kept in a locked drawer to which only I will have access and will either be returned to you or destroyed at the end of the study. Transcripts of taped interviews will be kept by me in a locked drawer and on a password protected computer, this may be kept up to five years and after that time would be destroyed.

**What will happen to the results of the research study?**

The results of the research will be published in a thesis for my PhD, this will be accessible through Sheffield University library. The results are likely to be shared locally through a report and presentations to which you would be invited and nationally at conferences and through journal articles. You would not be identified in such presentations unless you specifically gave consent.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given favourable opinion by North Sheffield Research Ethics Committee.

**What if I have more questions?**

I would be only too pleased to meet and discuss the project more fully with you and answer any other questions you might have. I can be contacted on 226 3950.

**Jane McKeown (Practice Development Nurse)**

## **APPENDIX 10c:**

### **Information sheet proxy family carer**



**Information about research for relatives on behalf of person with memory problems**

**Life Story Work Research**

I would like to invite your relative to take part in a research study. Due to their memory problems, they may not fully understand all that the research involves, so we are seeking your opinion about whether they should take part. To make this decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to care staff about the study if you wish. If you have any questions, please feel free to contact me (contact details below).

Part 1 tells you the purpose of the study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

**PART 1**

**What is the purpose of the study?**

The purpose of this study is to take a life story work approach in the care of up to 6 selected patients across 3 wards and explore the effects of this approach on the care the person receives and everyone concerned with their care. The accompanying coloured leaflet describes what life story work is and how it can be used.

I will be undertaking this research; I am Practice Development Nurse for Sheffield Care Trust and have been working with older people with dementia for over 15 years. The research will provide a better understanding of the care we give to older people with dementia so that we can constantly improve our service, the research will also be part of a research degree I am doing at Sheffield University.

**Why has my relative been invited?**

Your relative has been selected to take part in the research as their particular situation

will help us to add to the understanding on the use of life story work. A life story work approach will be taken in their care and we are interested in their experiences of this approach.

### **Do I have to agree to them taking part?**

No. It is up to you to decide whether or not they should take part, you might want to chat about this with care staff. If you agree then you will be asked to sign a consent form on their behalf. If you decide they should not take part, the care your relative receives will not alter in any way.

You may wish to think about the following questions and chat about them with other family members and care staff:

- Is the person someone who has been happy to talk about their life to others?
- Have there been any past indications of distressing or unpleasant memories the person may prefer not to relive?
- Do you think the person would have liked care staff to know more about their life to assist in their care?
- Is the person someone who has been happy to share their views and opinions with others if given the opportunity?

### **What will happen to my relative if they take part?**

Their involvement in the research would be for about 12 weeks, with a follow up assessment at 6 months, the whole research project is expected to last 18 months.

Below is a list of expected timescales and descriptions of what will happen:

- Week 1: I will meet with staff to ask their views on the overall wellbeing and observed behaviours of your relative.
- Weeks 2-6: Care staff will generally talk to the person during everyday care and interactions about any particular parts of their life story they seem interested in sharing.
- Weeks 7 – 11: After agreeing a suitable way of sharing the information it will be incorporated into the person's care and used with them. Their reactions will be observed.
- Week 12: I will meet with staff to ask their views on the overall wellbeing and observed behaviours of your relative.
- 6 Months: I will meet with staff to ask their views on the overall wellbeing and observed behaviours of your relative.

From your relative's point of view, any observations and discussions would not be intrusive and would appear the same as daily interactions between themselves and care staff. The life story work approach is used in many areas concerned with the care of older people, as a part of everyday practice.

**What are the possible disadvantages and risks of taking part?**

The risks with using life story work are very low, occasionally people can become upset by their memories and may need comfort and support, the staff undertaking the life story work are experienced in dealing with people's emotions and will receive supervision. Generally people experience life story work as enjoyable.

**What are the possible benefits of taking part?**

Generally people experience life story work as enjoyable. It is hoped this approach will help staff to better understand your relative and their needs.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2 of this information sheet.

**Will my taking part in the study be kept confidential?**

The information you give will form part of the research and as far as possible, it will be anonymised, however this may be difficult due to the small numbers of people involved in the study. The steps that will be taken to address this are outlined in part 2 of this information sheet.

**PART 2**

**What will happen if I don't want my relative to carry on in the research?**

You are free to withdraw your relative from the research at any time without giving a reason. Also staff may request this if their observations suggest the involvement was causing your relative any distress. I would discuss with you what you wanted to happen to any information that had been gathered – for example life story information, observations, and this information would be destroyed if you wished.

**What if there is a problem?**

If you have any complaints about how you are dealt with during the research you may report this to my University Supervisors Amanda Clarke 0114 2255931 or Julie Repper

01949 851229. The research has indemnity from the University of Sheffield. If you have any complaints about the care any patient receives as a direct result of the research you may report this to the Care Trust Complaints & Litigation Lead Wendy Hedland 0114 2718956.

**Will my relative taking part in this research be kept confidential?**

The information gathered from your relative will form part of the research. This may include age, diagnosis and medication taken. As far as possible, this will be anonymised. I will also look at your relative's care notes during the research and may make use of these written records. Once again, where possible, confidentiality will be maintained. Due to the small numbers of people involved in the study complete confidentiality may be difficult to achieve and if you do have concerns these can be discussed and arrangements can be made for specific information to be kept only by me and shared only with my University supervisors. Parts of your relative's life story information may be used in the research but will not be used to identify them individually.

**What will happen to the results of the research study?**

The results of the research will be published in a thesis for my PhD, this will be accessible through Sheffield University library. The results are likely to be shared locally through a report and presentations which you would be invited to and nationally at conferences and through journal articles. Your relative would not be identified in such presentations unless you specifically gave consent.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given favourable opinion by North Sheffield Research Ethics Committee.

**What if I have more questions?**

I would be only too pleased to meet and discuss the project more fully with you and answer any other questions you might have. I can be contacted on 226 3950.

**Jane McKeown (Practice Development Nurse)**

**APPENDICES 11 a, b and c:**

**Consent forms**



**APPENDIX 11 a:**

**Consent form care staff**



APPENDIX 9 b

CONSENT FORM (version 4 /staff/Mc/20/01/07) LIFE STORY WORK RESEARCH

RESEARCHER: Jane McKeown

PARTICIPANT: Staff

1. I confirm that I have read and understood the information sheet version 4/staff/JMc. 20/01/07 for the above study

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand my participation is voluntary and I am free to withdraw at anytime without giving a reason.

4. I agree to take part in the above study.

Name of Participant: ..... Signature: ..... Date: .....

Name of person taking consent (if not researcher): ..... Signature: ..... Date: .....

Researcher: ..... Signature: ..... Date: .....

## **APPENDIX 11 b:**

**Consent form family carer**



CONSENT FORM (version 4 /relatives/Mc/20/01/07) LIFE STORY WORK RESEARCH

RESEARCHER: Jane McKeown

PARTICIPANT: Relatives/Carers

1. I confirm that I have read and understood the information sheet version 4/relatives/Jmc. 20/01/07 for the above study.

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand my participation is voluntary and I am free to withdraw at anytime without giving a reason and without the care or rights of my relative being affected.

4. I understand that patient information such as date of birth, diagnosis, gender and medication taken will be collated as part of the research, this information will not be used to identify individuals

5. I agree to take part in the above study.

Name of Participant: ..... Signature: ..... Date: .....

Name of person taking consent (if not researcher): ..... Signature: ..... Date: .....

Researcher: ..... Signature: ..... Date: .....

**APPENDIX 11 c:**

**Consent form proxy carer**



CONSENT FORM (version 4 /proxy/Mc/20/01/07) LIFE STORY WORK RESEARCH

RESEARCHER: Jane McKeown

PARTICIPANT: Proxy

- 1. I confirm that I have read and understood the information sheet version 4/proxy/Jmc. 20/01/07 for the above study.
- 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3. I understand the participation of my relative is voluntary and I am free to withdraw them at anytime without giving a reason and without their care or rights being affected.
- 4. I understand that patient information such as date of birth, diagnosis, gender and medication taken will be collated as part of the research, this information will not be used to identify individuals
- 5. I agree for my relative to take part in the above study.

Name of Participant: ..... Signature: ..... Date: .....

Name of person taking consent (if not researcher): ..... Signature: ..... Date: .....

Researcher: ..... Signature: ..... Date: .....

## **APPENDIX 12:**

**Record of data collection across all case studies**

**Summary of Data Collected Across 4 Case Studies**

Feature	Pilot Case Study	Case Study 1	Case Study 2	Case Study 3	Case Study 4	Total
Interviews with care staff	3 (+1)*	4 (1a 3b)	5 (3a 2b)	4 (2a 2b)	3 (2a 1b)	16
Interviews with family carers	0 (+1)*	2 (1a 1b)		2 (1a 1b)	1 (b)	5
<b>Total Interviews</b>	<b>3</b>	<b>6 (2a 2b)</b>	<b>5 (3a 2b)</b>	<b>6 (3a 3b)</b>	<b>4 (2a 2b)</b>	<b>21</b>
Discussion / observation with person (notes maintained)	1	2	2	3	3	10
Discussion / observation with other (notes maintained)		1	1	1	1	4
<b>Total number of discussion notes</b>						<b>14</b>
Rating scales (WBP & CBS)		2	2	2	2	8
Other		Observation chart; Care plan	Care plan		Care plan	4
Field notes maintained in research diary specific to each case study (No of A3 hand written sheets)		40 (inc pilot)	22	18	13	93
More generic field notes / reflections (no of A3 hand written sheets)						157
<b>Total Field Notes (no of A3 hand written sheets)</b>						<b>250</b>
Time in the field	15 Hours	16 hours	18 hours	15 hours	9 hours	73 hours
Research Reference Group Meetings x 12						18 hours
Other meetings where LSW was the focus (inc LSW workshop) in hours – notes maintained						20 hours
<b>Total hours of activity directly related to data collection (not including transcription of all interviews)</b>						<b>111 hours</b>

\*5 Interviews were conducted in the pilot case study, 2 (one staff member and one carer) were subsequently carried forward for use in case studies 1 and 2. Other interviews from pilot not included in total. Interviews: a = interview before LSW commenced ;b = interview after LSW completed



## **APPENDICES 13 a, b, c and d:**

### **Topic guides for interviews**

## **APPENDIX 13 a:**

**Topic guide care staff before LSW**

## Semi Structured Interview – Schedule for questions and prompts

### For Care Staff (pre)

#### Opening Sentence

As you are aware are going to be taking a Life Story Work approach with (person's name \*\*\*\*). This will involve us gathering detailed information about \*\*\*\*'s life history, work, interests, likes dislikes etc. I would like to ask you a few questions about your thoughts on taking this approach with \*\*\*\*. Although I will be asking questions I do hope this feels more like a conversation than an interview please let me know if you wish to stop at anytime.

- 1) Can you tell me how you feel about being involved with this approach with \*\*\*\*?
  
- 2) What are you hoping will be the main benefits of taking this approach?
  
- 3) Do you have any particular concerns or can you see any particular difficulties in taking this approach with \*\*\*\*?
  
- 4) Can you tell me a little about what you know about \*\*\*\* as a person?  
Prompts:  
How have you found out about him or her?  
Have you talked to his or her family or visitors...?  
How does the assessment you use help in gathering this information?
  
- 5) What is your view on the overall care \*\*\*\* presently receives?
  
- 6) How could it be improved?
  
- 7) Is there anything else you would like to say about this LSW approach?

## **APPENDIX 13 b:**

**Topic guide care staff after LSW**

## Semi Structured Interview – Schedule for questions and prompts

### For Care Staff (post)

#### Opening Sentence

As you are aware we have been taking a Life Story Work approach with (person's name \*\*\*\*). This has involved us gathering detailed information about \*\*\*\*'s life history, work, interests, likes dislikes etc. I would like to ask you a few questions about your experiences of taking this approach with \*\*\*\*. Although I will be asking questions I do hope this feels more like a conversation than an interview and please let me know if you wish to stop at anytime.

- 1) Can you tell me about your experience of being involved with this life story approach?
- 2) What have been the main benefits of taking this approach from your point of view?
- 3) Have there been any particular concerns or difficulties in taking this approach with \*\*\*\*?
- 4) What (if anything) do you think you have learned about \*\*\*\* by taking this approach?
- 5) Have you noticed any changes in the care \*\*\*\* receives since taking this approach?
- 6) Is there anything else you would like to say about how this LSW approach has affected you, other staff, \*\*\*\* or \*\*\*\*'s carers/relatives?

## **APPENDIX 13 c:**

**Topic guide family carer before LSW**

## Semi Structured Interview – Schedule for questions and prompts

### For Relatives / Carers (Pre)

#### Opening Sentence

As you are aware we are going to be taking a Life Story Work approach with (person's name \*\*\*\*). This will involve us gathering detailed information about \*\*\*\*'s life history, work, interests, likes dislikes etc. I would like to ask you a few questions about your views about us adopting this approach with \*\*\*\*. Although I will be asking questions I do hope this feels more like a conversation than an interview please let me know if you wish to stop at anytime.

- 1) Can you tell me what you understand by this life story approach?
- 2) How do you feel about \*\*\*\* being involved with this?
- 3) What are you hoping will be the main benefits of taking this approach?
- 4) Do you have any particular concerns or can you see any particular difficulties in taking this approach with \*\*\*\*?
- 5) What do think care staff generally know about \*\*\*\* as a person?  
Prompts  
How do they find out?  
Have the asked you for any information about \*\*\*\*
- 6) What is your view on the overall care \*\*\*\* presently receives?  
How could it be improved?
- 7) Is there anything else you would like to say about how this LSW approach?

## **APPENDIX 13 d:**

**Topic guide family carer after LSW**



## **Semi Structured Interview – Schedule for questions and prompts**

### **For Relatives / Carers (Post)**

#### **Opening Sentence**

As you are aware we have been taking a Life Story Work approach with (person's name \*\*\*\*). This has involved us gathering detailed information about \*\*\*\*'s life history, work, interests, likes dislikes etc. I would like to ask you a few questions about your views as \*\*\*\*'s (wife, daughter, husband...). Although I will be asking questions I do hope this feels more like a conversation than an interview and please let me know if you wish to stop at anytime.

- 1) Can you tell me about your experience of being involved with this life story approach?
  
- 2) What have been the main benefits of taking this approach from your point of view?
  
- 3) Have there been any particular concerns or difficulties in taking this approach with \*\*\*\*?
  
- 4) What (if anything) do you think care staff have learned about \*\*\*\* by taking this approach?
  
- 5) Have you noticed any changes in the care \*\*\*\* receives since taking this approach?
  
- 6) Is there anything else you would like to say about how this LSW approach has affected you, \*\*\*\*, or the care staff?

## **APPENDIX 14:**

### **Informal topic guide for conversations with participants**

## Conversation Topic Guide

Taken from the ethics notice of substantial amendment submission dated July 2008.

I would wish to visit the nursing/care home to enquire what their views are on the LSW for the person admitted to them. In a general discussion I would ask a small group of staff who wanted to talk to me:

- Have you seen the pen picture / life story book?
- What are your thoughts on it?
- What did you find particularly helpful (if anything) –
  - prompts about getting to know the person,
  - being able to strike up a conversation,
  - is it of any value?
- Have you used any of the information in it to interact with or care for the person?
- Anything else they want to say about it.

## **APPENDIX 15:**

### **Challenging Behaviour Scale**

## THE CHALLENGING BEHAVIOUR SCALE (CBS) FOR OLDER PEOPLE LIVING IN CARE HOMES

Name .....

Age ..... Sex ... M/ F      Diagnosis of Dementia ... Y/ N/ Don't know

Residence ..... Date .....

Checklist Completed By .....

**PHYSICAL ABILITY** (delete as applicable)

1. Able to walk unaided / Able to walk with aid of walking frame / In a wheelchair
2. Continent / Incontinent of urine / Incontinent of faeces / Incontinent of urine + faeces
3. Able to get in or out of bed chair unaided / needs help to get in or out of bed chair
4. Able to wash and dress unaided / needs help to wash and dress
5. Able to eat and drink unaided / needs help to eat and drink

Over the page is a list of challenging behaviours that can be shown by older adults in residential or nursing settings. For each behaviour listed consider the person over past 8 weeks and mark:

**INCIDENCE:** Yes / Never. If Yes move to Frequency

**FREQUENCY:**

- 4: This person displays this behaviour **daily or more**
- 3: This person displays this behaviour **several times a week**
- 2: This person displays this behaviour **several times a month**
- 1: This person displays this behaviour **occasionally**

**DIFFICULTY:**

Then *for each behaviour shown* mark down how difficult that behaviour is to cope with, when that person shows it, according to the following scale:

- 4: This causes a lot of problems
- 3: This causes quite a lot of problems
- 2: This is a bit of a problem
- 1: This is not a problem

**N.B.** If a person does not show a behaviour no frequency or difficulty score is needed.

If the person causes a range of difficulty with anyone behaviour, mark down the score for the worst it has been over the last few (eight) weeks.

	CHALLENGING BEHAVIOUR	INCIDENCE		FREQUENCY		DIFFICULTY		CHALLENGE	
		Yes	Never	1-occasionally 2-several/month 3-several/week 4-daily or more	1-no problem 2-bit of problem 3quite a lot of problem 4-lots of problem	Frequency	Difficulty		
1	<b>Physical Aggression</b> (hits, kicks, scratches, grabbing, etc.)								
2	<b>Verbal Aggression</b> (insults, swearing, threats, etc.)								
3	<b>Self Harm</b> (cuts hits self, refuses food starves self, etc.)								
4	<b>Shouting</b>								
5	<b>Screaming/Crying out</b>								
6	<b>Perseveration</b> (constantly repeating speech or actions, repetitive questioning or singing)								
7	<b>Wandering</b> (walks aimlessly around home)								
8	<b>Restlessness</b> (fidgets, unable to settled down, pacing, 'on the go', etc.)								
9	<b>Lack of motivation</b> (difficult to engage, shows no interest in activities, apathy, etc.)								
10	<b>Clinging</b> (follows holds on to other residents /staff, etc.)								
11	<b>Interfering with other people</b>								
12	<b>Pilfering or Hoarding</b> (possessions, rubbish, paper, food, etc.)								
13	<b>Suspiciousness</b> (accusing others, etc.)								
14	<b>Manipulative</b> (takes advantage of others, staff, etc.)								
15	<b>Lack of Self Care</b> (hygiene problems, dishevelled, etc.)								
16	<b>Spitting</b>								
17	<b>Faecal Smearing</b>								
18	<b>Inappropriate Urinating</b> (in public, not in toilet, etc.)								
19	<b>Stripping</b> (removes clothes inappropriately, flashes, etc.)								
20	<b>Inappropriate Sexual Behaviour</b> (masturbates in public, makes inappropriate 'advances' to others, etc.)								
21	<b>Sleep Problems</b> (waking in night, insomnia, etc.)								
22	<b>Non-compliance</b> (deliberately ignores staff requests, refuses food, resists self care help, etc.)								
23	<b>Dangerous Behaviour</b> (causes fires or floods, etc.)								
24	<b>Demands Attention</b>								
25	<b>Lack of Occupation</b> (sits around doing nothing, etc.)								
	<b>TOTALS</b>	Add scores (1 – 25) for each column		25		100		100	400

## STAFF `PROMPT` SHEET

HOW OFTEN DOES THE PROBLEM / BEHAVIOUR OCCUR?

- 4: This person displays this behaviour **daily or more**
- 3: This person displays this behaviour **several times a week**
- 2: This person displays this behaviour **several times a month**
- 1: This person displays this behaviour **occasionally**
- 0: This behaviour is **never** displayed by this person

HOW MUCH OF A PROBLEM IS THIS BEHAVIOUR?

- 4: This causes **a lot** of problems
- 3: This causes **quite a lot** of problems
- 2: This causes **a bit** of a problem
- 1: This is **not** a problem

WE ARE INTERESTED IN THE WORST THE RESIDENT HAS BEEN OVER THE LAST TWO MONTHS.

If a person does not show a behaviour no difficulty (or problem) score is needed.

If the person causes a range of difficulty with any one behaviour, mark down the score for the worst it has been over the last few weeks.

## Instructions for use of the Challenging Behaviour Scale

### Background

1. This scale was initially derived as the Problem Behaviour Checklist (Inventory) and used in a staff training study. Reference: Moniz-Cook, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Elston, C. and Win, T. (1998) 'Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally Ill?' *International Journal of Geriatric Psychiatry*, 13, p.149-158.
2. On the basis of initial reliability and validity studies it was changed and re-labelled – The Challenging Behaviour Scale (CBS).
3. Reliability and validity studies were carried out in Continuing Care Hospitals and residential and nursing homes. Although you can use the scale for non-demented institutional populations its global properties will be of little use. For example people with a depressive illness may present with self harm whereas this is not often seen in dementia.
4. This scale was developed on the basis of staff report : hence eating problems do not feature strongly and were included under the 'non-compliant' category. You may wish to add some items of eating problems for your own use but the norms will have to be adjusted.
5. This is a global scale and although it has been subject to factor analysis, other scales for aggression, agitation and eating problems are more useful for specific behaviours. This scale does have a category for 'apathy' / depression / doing nothing which may be of use in monitoring.
6. The Incidence and Frequency ratings are useful in measuring 'actual behaviour' if guidelines are followed (see later). The Difficulty and Challenging scores are more measures of staff coping / management / perception. The Difficulty domain is only required to calculate Challenge scores whilst the Challenge score is a measure of management difficulty or coping.

### Contract

1. I would be grateful if you would supply me with information of use of this scale, (i.e. if you decide to use it and how). I wish to develop it further and keep a database of it's use.
2. Please do not circulate the Scale and Staff Prompt Sheet without my permission, as I am currently negotiating detail publication with a test agency.
3. Please refer to Moniz-Cook, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S (2001) 'The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes'. *British Journal of Clinical Psychology*. 40 (3): 309-322 for detail of development, reliability and validity. Please turn over for specific instructions.

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© E. Moniz-Cook 2001



## CHALLENGING BEHAVIOUR SCALE INSTRUCTIONS

1. Use as a structured interview with at least 2 members of staff (one qualified and one unqualified), for individual clinical work or for 'research' work / monitoring.
2. If you hand these out then make sure that one person who knows the person well (key worker), a qualified member of staff and one other do the checklist in a group.
3. If a staff member is stressed out this may influence the results (especially on some items and the Difficulty and Challenge rating).
4. Repeat testing is best done with the same staff group, but reliability is not bad if group is different as long as it is a group and not one person.
5. You need to wait approximately 8 weeks before you repeat testing because of wording of frequency items.

### Scoring

1. Multiply each Frequency x Difficulty item to get a Challenge item score.
2. Add Challenge score to make total Challenge (do not add Frequency, add Difficulty and then multiply for Challenge).  
By this method the maximum Challenge score is 400.
3. If you want to measure the (more reliable) actual behaviour use total Incidence and total Frequency on their own.

### Notes

1. The Incidence and Frequency domain are fairly stable measures of actual behaviour. The Difficulty domain is not often used on its own but is used to calculate the Challenge domain, which is a measure of staff coping / management. This latter domain (Challenge) is very sensitive and is only reliable if you follow the rules.
2. It is useful in assessing behaviour in whole environments, e.g. a ward – ask the person in charge to complete with at least the key worker and one other.
3. Measurement of individual cases – use as a structured interview with the same pair of staff pre and post / at least one staff member of the baseline pair.

### References

MONIZ-COOK, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Elston, C., and Win, T. (1998) 'Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally Ill?', *International Journal of Geriatric Psychiatry*, 13, p.149-158.

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MONIZ-COOK, E.D., Gardiner, E. & Woods, R.T. (2000) 'Staff Factors Associated with the Perception of Behaviour as 'Challenging' in Residential and Nursing Homes'. *Aging and Mental Health*, 4(1), p.48-55.

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MONIZ-COOK, E.D., Woods, R.T. & Richards, K. (2001) 'Functional Analysis of Challenging Behaviour in Dementia: The Role of Superstition'. *International Journal of Geriatric Psychiatry*, 16: p.45-56.

MONIZ-COOK, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S. (2001) 'The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes'. *British Journal of Clinical Psychology*. 40 (3): p.309-322.

COLE, R.P., Scott, S. & Skelton-Robinson, M. (2000) 'The effect of Challenging Behaviour and Staff Support on the Psychological Wellbeing of Staff Working with Older Adults'. *Aging and Mental Health*, 4(4): p.359-365.

## **APPENDIX 16:**

### **Wellbeing Profile**

**Well-being Profiling – Individual Profile Sheet**

Wellbeing Profile for (name): ..... Date: .....

Profile Completed by: .....

When filling in the profile refer to the guidelines describing the meaning of each item.

Well-being Indicators

0 = No sign  
 1 = Some signs  
 2 = Significant signs

Indicator	0	1	2
1. Can communicate wants, needs and choices			
2. Makes contact with other people			
3. Shows warmth and affection			
4. Shows pleasure or enjoyment			
5. Alertness, responsiveness			
6. Uses remaining abilities			
7. Expresses self-creatively			
8. Is co-operative or helpful			
9. Responds appropriately to people/situations			
10. Expresses appropriate emotions			
11. Relaxed posture or body language			
12. Sense of humour			
13. Sense of purpose			
14. Signs of self-respect			
<b>Total of Scores</b>			
<b>Final Well-being Score</b>			

## **APPENDIX 17:**

### **Observation recording chart**

**Monitoring the Use of Life Story Work – to be completed after using life story work with patient**

<b>Person's Name: -</b>				
<b>Encounter</b> (Record date time and details)	<b>Verbal</b> (Record anything person says that might be positive or negative)	<b>Non-Verbal</b> (Record any signs such as smiling, grimacing, sighing that might indicate a positive or negative reaction)	<b>Behaviours</b> (Record any agitation, withdrawal, pacing more than usual or positive behaviours)	<b>Signature</b> (Indicate who has completed this)
<i>Example:</i> 30/03/2008 14.00 hours Looking at LSW book with Bob	<i>"It was grand"</i> <i>"What a lovely time"</i> <i>"Who's that man?" - seemed upset</i>	<i>Smiling, nodding, animated</i>  <i>Frowning towards end and restless</i>	<i>Seemed attentive for 5 minutes then became agitated so stopped</i>	<i>Jane McKeown (Researcher)</i>

**APPENDICES 18 a, b and c:**

**Research reference group notes**

**APPENDIX 18a:**

**Record of meeting dates and attendance**

### LSW Details of Reference Groups

No	Date	Focus	No. attendees	Location
1	21 <sup>st</sup> June 2007	Introductions / ground rules	5	Beighton
2	17 <sup>th</sup> July 2007		4	Beighton
3	20 <sup>th</sup> September 2007		3	Beighton
4	8 <sup>th</sup> Nov 2007		2	Grenoside
5	29 <sup>th</sup> January 2008		5	South Memory
6	18 <sup>th</sup> July 2008		4	South Memory
7	23 <sup>rd</sup> October 2008	Introduced data analysis	7	South Memory
8	5 <sup>th</sup> March 2009		5	South Memory
9	7 <sup>th</sup> May 2009	Data analysis issues	6	South Memory
10	16 <sup>th</sup> July 2009	Data analysis issues	4	South Memory
11	5 <sup>th</sup> Nov 2009	Consideration of findings	4	South Memory
12	21 <sup>st</sup> January 2010	Discussion of Findings into practice	4	South Memory
13				



## **APPENDIX 18 b:**

**Notes from research reference group Jan 2008**

## Life Story Work Reference Group Meeting

Tuesday 29<sup>th</sup> January at South Memory Service – Lyndhurst Road

**Present:** (Names changed for confidentiality) Staff nurse; support worker; specialist dementia nurse (sdn); service manager; Jane McKeown

**Apologies:** carer; Lecturer; OT; OT

### Notes from meeting in September 2007 and matters arising

It was noted that no notes had been written from November's meeting as only Jane and OT had been present. Jane had cancelled the December meeting due to proximity to Christmas.

#### Recruitment

Support worker was welcomed and her attendance represents a support worker point of view; Support worker has some experience of using LSW when working in the day hospital.

Jane has asked the manager at the Alzheimer's Society to see if she knows of any carers who may be interested in joining the group.

Staff nurse suggested the daughter of a service user on \*\*\*\* ward may be interested – Jane will liaise with ward manager regarding this.

Jane has been considering how the views of people with dementia could influence the research – Sdn mentioned a forum with the Alzheimer's Society that *may* be a useful forum- Jane will ask manager. It was also agreed as early findings begin to emerge there may be forums attended by people with dementia that these could be shared discussions encouraged. Possible presentations at the Memory Services Cafes could be considered.

#### Training

Lecturer and Jane had discussed two possible dates to offer a training session to staff – perhaps based at \*\*\* and \*\*\* initially – although offering invites to staff within the Directorate. Jane will liaise with relevant Ward Managers. Jane had mentioned this in a meeting with Assistant Clinical Director– who had welcomed the idea.

#### Ground Rules

These were confirmed as being helpful

#### Update on current research

Jane presented the current update (Doc 1A Update January 208)

**Progress** was reported on. Locations suggested to commence the third case study included (range of teams). Jane will refer to her original protocol to see if community services are included. She will contact the new ward manager at \*\*\*\*. There was a short discussion on integrating LSW with a palliative care approach with people with

dementia. Sdn gave an example of her own experience of using LSW with a person with cancer (not with dementia).

Jane commented on the **enthusiasm** of staff involved; although noted support workers who had shown an interest were not actively involved in the LSW gathering. Jane would explore this more.

The **difficulties** of staff gathering LSW information were discussed. It is hoped the training might help staff see the benefits. Staff nurse suggested staff gathering the information could be encouraged to visit the person's home when gathering information from the relatives as this may help them see the person in a different light. Jane will encourage staff to be supported in doing this. Service manager agreed this could be encouraged – staff would need to ensure their motor insurance covered “travel within work” if going in their own car – this could usually be added to the motor policy at no extra cost. Jane has money for transport until the end of March.

Service manager suggested Jane liaise with Discharge Facilitator – to keep updated on any imminent discharges of people involved in the research.

**Early findings** – as these emerged Jane wanted to share them at relevant forums so that the research influenced practice and people were kept informed. Service manager suggested the Directorate Meeting that took place on the 1<sup>st</sup> Friday in the month would be a good forum. Also the Dementia Brief was read by many staff and a short piece in there might be relevant.

### **Research Funding**

The research money Jane secured from the Consortium needs using by the end of March.

Staff nurse time in the Directorate – Jane reported she had e-mailed managers with the financial code for this and urged them to make use of the money before the end of March – even if it was to offset some of the research overspend of the Directorate.

Materials – Jane will explore purchasing some Memory Books; boxes; photo albums

Service manager suggested buying a photo scanner and printer – they were less than £100 and would allow staff to take copies of personal photos leaving relatives with the originals.

Jane would buy some biscuits to use with staff on the training events

### **Date of Future Meeting:**

The date of Thursday 10<sup>th</sup> April had been proposed – but 2 people were unable to attend – the new date proposed is:

**Tuesday 15<sup>th</sup> April 12.00 – 1.30** at the Memory Service (if a room is available – confirmation nearer the time) **Please let Jane know if this is convenient for you.**

## **APPENDIX 18 c:**

**Notes from research reference group October 2008**

## Life Story Reference Group Meeting

Thursday 23<sup>rd</sup> October 2008 at South Memory Service Lyndhurst Road

**Present:** Staff nurse, carer, Lecturer, Jane McKeown, carer, service manager, OT

**Apologies:** Ward manager; OT

**Resignations:** Lecturer,

### 1: Apologies and Membership

It was noted that lecturer has left Sheffield to work at Aberdeen University; another lecturer from the University of Sheffield attended instead. Occupational Therapists have shown an interest in joining the group and will attend to see if they wish to become regular members, as is a carer.

### 2: Notes from meeting in July 2008.

The notes from last meeting were briefly reviewed and agreed as a fair reflection of the issues covered.

### 3: Matters Arising

Those matters arising that were not on the agenda included:

**Photo scanner** – used by \*\*\*\* – to reside on \*\*\* Ward

**LSW Training** – Jane and lecturer delivered a workshop to a range of staff from the Dementia Directorate – the workshop was very enthusiastically received and evaluated very well.

**Directorate Meeting** – Jane presented current progress to the Directorate Meeting comprising Directorate and team / ward managers – people seemed interested in the work and some useful discussion took place. The Directorate meeting will be a good place to take findings when it comes to putting the research into everyday practice.

### 4: Research Progress Update (dated 6<sup>th</sup> October 2008) – Paper A Update Oct 2008

Steady progress in data collection was noted with 4 case studies at differing stages of development.

### 5: Early Results

Jane provided some of the early results in the form of transcriptions from some of the interviews and had ordered these under the headings that had been developed for the "Framework Approach" being used to analyse the research data. After taking some time to read through this the group began to discuss some of the findings. Some of the discussion included:

- Group members may need time to become familiar with the Framework Approach to analysis and Jane will try different approaches to see what best suits the group.
- There was general agreement with how data fit into the Framework
- There was possibly a need to consider a new category of "Carer / Caring Satisfaction / Experience"
- It was unclear where the "Emotional" aspects of using life story work should be reflected – one suggestion was under "Ethics or Difficulties" – but Jane did not feel the emotional side always presented as a difficulty
- There was a discussion about the sharing of private and / or distressing memories and different views were aired such as: the need for staff supervision; trying not to talk too deeply – but equally these memories were sometimes shared even when talking about quite superficial areas of life; the benefits and the disadvantages of relatives being told or about them wanting to know or not wanting to know; understanding past preferences, wishes, upsets before using life story work.
- A story is often told differently depending on the audience – a story told to work colleagues may be different to the story told to friends and different again when told to different family members

## **6: Next Steps**

- Case study 1- Jane will revisit as patient has moved to a new ward and it is timely to review whether the LSW is still in use and what impact it is having
- Case study 2 – Jane to visit the Nursing Home to get their views on the picture of the patient that moved there
- Case Study 3 and 4 – Data collection and life story work continuing
- Analysis – Jane to bring more data in a different format to next research reference group

## **7: Any Other Business**

None noted

### **8: Date and Time of the Next Meeting**

This was agreed as Thursday January 8<sup>th</sup> 2009 – however Jane is unable to make this meeting and now proposes:

**Thursday 5<sup>th</sup> February 2009 12.00 – 13.30 at the South Memory Service Lyndhurst Road**

## **APPENDIX 19:**

### **Development of the thematic framework**



## Development of Thematic Framework for Life Story Work Research

Practice Development Project – October 2000

Using Life Story Work with People with Dementia on a Ward for People with Dementia



### Systematic Review of Life Story Work Literature

McKeown, J. Clarke, A. & Repper, J. (July 2006)

#### Key Themes

Understanding the Person; Communication and Relationships; Implications for Practice; Ethical Issues



### Specific Research Questions – March 2006

The study aims to explore the experience of using a LSW approach with people with dementia and complex needs. More specifically, it will investigate the ways in which LSW:

- Shapes the care that the person with dementia receives; for example, does LSW lead to improved understanding of the person with dementia? In what ways may it effect challenging behaviour?
- Effects the relationships between the person with dementia, carers and staff; for example, do those participating in LSW experience more collaborative working between staff, carers and the person with dementia?
- Is understood and developed in practice; for example, what are the difficulties of adopting such an approach from the perspective of all concerned?

### Research Commenced March 2007

- Formation of Research Reference Group – July 2007
- First pilot data collected July 2007
- Began considering Thematic Framework August 2007 – based on pilot data, systematic review and experience from practice.
- First full data collected November 2007
- Revisions of Thematic Framework though applying the data; through academic supervision and through collaboration with research reference group.



### LSW Thematic Framework 1 - July 2008

#### **1.0 UNDERSTANDING THE PERSON**

- 1.1 Knowledge of life history information
- 1.2 Seeing the person behind the illness
- 1.3 Understanding behaviours
- 1.4 Improved empathy

#### **2.0 RELATIONSHIPS/COMMUNICATION**

- 2.1 Triggers to conversation
- 2.2 Improved relationships
- 2.3 Improved communication
- 2.4 Making interactions easier/more possible

#### **3.0 IMPACT ON CARE**

- 3.1 Staff attitudes
- 3.2 Helpful in transition of care settings
- 3.3 Providing cues for activities
- 3.4 Impacting on assessment/diagnosis
- 3.5 Impacting on interventions

#### **4.0 THE PROCESS**

- 4.1 Perception of process
- 4.2 Ways in which life story information is gathered
- 4.3 What helps and what hinders

#### **5.0 THE PRODUCT**

- 5.1 Displaying life story information
- 5.2 Use of life story information
- 5.3 Perceptions of the product

#### **6.0 ETHICS/DIFFICULTIES**

- 6.1 Process leading to distress / upset
- 6.2 Private v public accounts
- 6.3 Ownership and consent
- 6.4 Gathering information from person with dementia

### LSW Thematic Framework 4 – September 2009

#### **1.0 UNDERSTANDING THE PERSON**

- 1.1 Knowledge of life history information
- 1.2 Seeing the person behind the illness
- 1.3 Understanding the person in the present from the past
- 1.4 Improved empathy

#### **2.0 COMMUNICATION**

- 2.1 Providing prompts and trigger to conversation
- 2.2 Hearing the voice of the person
- 2.3 Making interactions easier/more possible

#### **3.0 RELATIONSHIPS**

- 3.1 Developing a bond
- 3.2 Finding common ground
- 3.3 Moving the person into the limelight
- 3.4 Changed / complex relationships??

#### **4.0 IMPACT ON CARE**

- 4.1 A trigger for memories
- 4.2 Providing a resource / legacy
- 4.3 Providing cues for activities
- 4.4 Helping with assessment and care planning
- 4.5 Impact on mood / behaviour

#### **5.0 THE PROCESS**

- 5.1 The need for support and guidance
- 5.2 The time factor
- 5.3 Personal values
- 5.4 Culture and continuity
- 5.5 Involvement

#### **6.0 ETHICS/DIFFICULTIES**

- 6.1 Distressing memories
- 6.2 Personal disclosures
- 6.3 Ownership and consent
- 6.4 Overuse

#### **7.0 THE EXPERIENCE OF PARTICIPATING IN LSW**

- 7.1 Feeling proud and valued
- 7.2 Emotional aspects
- 7.3 Learning something new
- 7.4 Enjoyment and pleasure
- 7.5 Suggested improvements

## **APPENDIX 20:**

**Example of page from Excel spreadsheet**



	A	B	C	D	E	F	G	H	I
37	Well from my point of view it's been very enjoyable really	3	2	3	daughter	Interview	Post	7.4	
38	really just I think it's invaluable and I hadn't thought of taking it further apart from that conversation in the general hospital just for history records but erm it was an extremely good idea	3	62	3	daughter	Interview	Post	7.4	
39	You can look through it and I think it's lovely yeah	3	6	2	worker	Interview	Post	7.4	
40	I just wish it was more comprehensive and more photographs had been used that I had put though and I suppose I could have put more into it	3	2	3	daughter	Interview	Post	7.5	
41	notice Rachel spotted spelling mistakes so shows she is reading it and taking notice	3		5	care work	Discussion	Post	7.5	
42	The text that I supplied had been re-written with poor grammar, spelling and capital letters missing. It must have been quite an effort to completely re-write it! Mother and I look at it quite often and every time she comments that things are not spell correctly etc; she and I have always been very fussy about the correct use of English. Last week when I was there I took correction fluid and corrected as much as I noticed at the time. Of course it does not matter very much but it is just an observation!	3		3	daughter	e-mail	Post	7.5	
43	And so there was that side of it as well but I think Eileen was quite pleased to have been asked and I think Eileen - well you've met her, she's a very quiet lady really very reserved but thinks an awful lot and sees an awful lot and I think she'd seen the other books and had been perhaps wondering why she hadn't got one	4	6	1	Nurse	Interview	Post	7.1	
44	Nurse manager thinks that Eileen is proud she was asked to take part in the project	4	rd2:14	1	Nurse	discussion	Post	7.1	
45	they do work their magic I've never seen anyone look at a book and not be moved	4	64	1	Nurse	Interview	pre	7.2	
46	When I first stated do Eileen's life story I was a bit nervous. I wondered whether her daughters would allow me to do the book. Also I was worried whether I would do the book to the expectation of my mentor and Eileen	4	2	2	Nurse	e-mail	Post	7.2	
47	Life story work has made me realise that there are some small things like pictures that can make a difference in some body's everyday life that people take for granted.	4	12	2	Nurse	e-mail	Post	7.3	
48	Erm I was happy to do it actually you know because for me it is the first time I've done it anyway I didn't know there was life story work for people with dementia. For me it's a learning process as well	4	2,4,6	2	Nurse	Interview	pre	7.3	
49	They talk about the challenges you know I think when they were growing up and I think she had to somehow protect them from people because people they were like stigmatized these children because of this learning disability they had so she had to fend for her children she talked about that a lot it was quite interesting	4	75	2	Nurse	Interview	pre	7.3	
50	My niece learned some new things about the family by looking at the book	4	10	3	daughter	Interview	Post	7.3	

## **APPENDIX 21:**

### **Charting a single case study across a single theme**

**Chart 1 Case Study 2**

<b>1.0 – UNDERSTANDING THE PERSON</b>					
<b>Participant</b>	<b>1.1: Knowledge of Life History Information</b>	<b>1.2 Seeing the person behind the illness</b>	<b>1.3: Understanding the person in the present</b>	<b>1.4: Improved Empathy</b>	<b>1.5: Other</b>
<b>1</b>					
<b>2</b>	Found out more depth beyond the superficial knowledge she had. 92 Appreciating not everything might be 'true'. 18	An appreciation of the person, his interests and life. 84	Could appreciate how life experiences had affected him, particularly his stroke. 92	Nurse demonstrated an appreciation of and sadness for losses in his life. 92	
<b>3</b>	Real knowledge of person, a genuine interest and enjoyed 'digging' for information. 12	Able to describe the man as a soldier and compare to the person here today. 30 Shared interests and experiences.	Could see how life, particularly as a soldier had influenced person and behaviour today. 178	Understanding of values of the person, shared experiences as a soldier led to a deep empathy.204	
<b>4</b>					
<b>5</b>	Said she knew things but gave inaccurate information. 3	Described a confused man not able to communicate. 15			

## **APPENDIX 22:**

**Charting a single theme across all case studies**

**Chart 1- Across 4 Case Studies**

<b>1.0 – UNDERSTANDING THE PERSON</b>					
<b>Case Study</b>	<b>1.1: Knowledge of Life History Information</b>	<b>1.2 Seeing the person behind the illness</b>	<b>1.3: Understanding the person in the present</b>	<b>1.4: Improved Empathy</b>	<b>1.5: Other</b>
<b>1</b>	Staff already knew things about the person but this added more depth to their knowledge and they got to know more about the person. The carers thought this was especially good for new staff and students.	Were able to get glimpses of person behind illness that had previously been difficult to see – even wife had been forgetting these	Were able to challenge their views of him an aggressive man – with new knowledge of his humour, kindness and love of family	Some evidence of empathy amongst some staff on what he had lost	
<b>2</b>	Superficial knowledge turned into in-depth knowledge and genuine interest in ‘digging for the facts’. Awareness the information may not be ‘true’. An exception was the nursing home nurse where the pen picture did not lead to increased knowledge.	Evidence of respect for the person seeing beyond illness and really appreciating him as a person. The exception was the nursing home nurse where his confusion was seen before him as a person.	Real appreciation of how circumstances in life have contributed to the person he is today regarding mood and behaviour, how his experiences in the Army and following his stroke have impacted on him. The nursing home nurse did not show this knowledge and appreciation.	Demonstration of empathy of the person and his situation,; understanding his values and expressing emotions for his circumstances. The nursing home nurse did not demonstrate this.	
<b>3</b>	There was less original knowledge known about this person and new knowledge and greater details were learned and valued. She herself was reminded of the things she had done in her life.	Some evidence of staff seeing the person behind the illness and a challenge to previously held values but not seen across all participants. Sometime the anxiety of the person may have got in the way.	No evidence of links being made.	Not explicitly described or demonstrated, although researcher believes the staff did have empathy.	
<b>4</b>	Staff already knew considerable amount about the person but LSW provided much more depth and detail. The photos were seen as powerful.	Evidence that staff could see person behind illness but daughter would still like them to have met her before illness.	Genuine appreciation how her life circumstances have made her the person she is today.	Real empathy and deep understanding shown by registered nurse.	
<b>Emerging Themes</b>					
<b>Depths of knowledge gained</b>		<b>Continuity /Discontinuity</b>			
<ul style="list-style-type: none"> <li>• Seeing person beyond the patient</li> <li>• Seeing person beyond behaviour</li> <li>• Glimpsing values / beliefs of person</li> </ul>		<ul style="list-style-type: none"> <li>• Person in context of their whole life</li> <li>• Noticing the person then and the person now</li> <li>• Sadness in what was lost</li> </ul>			

## **APPENDIX 23:**

**Transcription of excerpt from research diary demonstrating audit trail**



## Research Diary Excerpts

### Research Diary Volume 1 page 57

#### *Meeting Harry's wife re consent*

*'Visited \*\* ward... saw wife of Harry. She remembered who I was and that I had given her the [information] leaflet. She said she had thought about it and preferred not to be involved due to having lots of travelling an upheaval at home. She seemed relieved when I said that was fine. I asked her what she thought about Harry still being involved in terms of us gathering his LS information and using it with him, she seemed delighted. "Anything that might help him." Harry also seemed keen and seemed to remember what we had spoken about before although said: "If I had seen you walking down the street I would not have recognized your face but now that you mention it yes I remember you". This was affirmed by him starting to recall a story from his past.'*

### Research Diary Volume 1 page 114

#### *Meeting Rachel*

*'I introduced myself as practice development nurse, we laughed at the long title, [Rachel said] "So you're one up from being a nurse then". I spoke of LSW "I'm nothing special not got much of interest to say" but agreed " Yes if you want to"...Then I mentioned study for the University – so I will want to find out what it's like for you having people talk about your life story with you. Seemed happy and amenable to that, I said she could change her mind at any time. Asked which of her relatives she might suggest that I speak with, she said Daughter in Horsham.'*

**Research Diary Volume 1 page 76**

*Discussion with Rachel's daughter about her mother's participation  
'She listened then said "It sounds good, but you do know she has dementia don't you, perhaps it won't be relevant" I explained that it would be highly relevant. She said that whilst at the General Hospital she had written Rachel's life story, did I want a copy? She thought that Rachel would have wanted to be part of the research had she been asked before dementia ...explained process and posted necessary documentation off to her "We have no skeletons in the cupboard".'*

## **APPENDIX 24:**

### **Life story work topic prompts**



## Life Story Information Gathering Prompts

Name of person:

Date:

Name of person completing the form:

Relationship to the person who the form is about:

### **Early Childhood**

Where were you born?

Did you grow up in the same place or did you move?

What were the names of your Mother and Father?

Did you have any brothers and sisters? What were their names?

Do you have any particular memories about growing up?

### **School Years**

Where did you go to school?

What age did you leave school? (Did you go to College / University?)

Do you have any particular memories about school?

### **Working Years**

What job(s) did you do?

Where did you work?

What age were you when you retired?

Do you have any particular memories about work?

### **Family Life**

Did you get married?

What was/ is the name of your wife(s)/husband(s)

Did you have any children? What are their names?

Did you have any important friends in your life? What are/ were their names?

## **Personality**

How would people who know you well describe you?

How would you describe yourself?

## **Religious / Cultural / Spiritual Beliefs**

Do you have religious beliefs? If so what religion do you practice?

Is there anything you need to help you continue to practice?

Are there any particular festivals that you would like help to celebrate?

Is there anything that would help you to have other spiritual or cultural needs met?

Is there anything else we should know about you religious / cultural or spiritual needs?

## **Holidays / Places**

Where were the places you used to visit / go on holiday to?

Do you have any particular memories about holidays/ days out?

<b>Hobbies / Interests</b>
----------------------------

What sorts of things do / did you enjoy doing?
--

<b>Likes/ Dislikes / Preferences</b>
--------------------------------------

Food:
-------

Clothes:
----------

Activities:
-------------

Particular habits:
--------------------

Fears / Superstitions:
------------------------

Things that make you feel relaxed:
------------------------------------

Things that make you feel annoyed:
------------------------------------

## **Significant Achievements**

What things in your life are you most proud of?

Are there any things in your life that make you feel upset or that you would prefer not to talk about?

## **Anything else**

Is there anything else you want to tell us about your life that might help us to get to know you better?

This form was devised by:

Jane McKeown; Senior Nurse for Service User and Carer Involvement.

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## **APPENDIX 25:**

### **Life story work gathering roles and guidance**

## Collecting Life Story / History Information – Guidance

**Name of Client:**

<b>Sources of Information</b>	<b>Hints and Tips</b>	<b>Relevant for Client Yes/ No</b>	<b>Staff Member(s) Identified to Gather information</b>
<b>The Client</b>	<ul style="list-style-type: none"> <li>• Through everyday conversation rather than using list to ask questions</li> <li>• To fill in more details or gaps in information obtained from elsewhere</li> <li>• To get the person's own version of events</li> </ul>		
<b>Family/ Close friends who visit</b>	<ul style="list-style-type: none"> <li>• Possibly visit them in their own home to gather this so you can see where the client lived</li> <li>• Maybe work through the checklist</li> <li>• Ask about any photographs / documentation that might add to the information (offer that these can be scanned)</li> </ul>		
<b>From family that don't visit</b>	<ul style="list-style-type: none"> <li>• Check with client and with family that visit that this is OK</li> <li>• Consider a telephone conversation or sending the checklist with a letter and stamped addressed envelope</li> <li>• Allows you to fill in gaps and get another viewpoint</li> <li>• Don't do this if client or family don't agree or if relationships are strained</li> </ul>		
<b>Other staff</b>	<ul style="list-style-type: none"> <li>• Find out how much other staff know – including nursing staff, support workers, housekeepers, ward clerk, occupational therapist, psychologist, medic, GP, District Nurse, Homecare staff, social worker...</li> <li>• Either give checklist or talk to in handovers, on phone, in team meetings, make appointments to see</li> </ul>		
<b>Care Notes</b>	<ul style="list-style-type: none"> <li>• Work through care notes and medical notes</li> <li>• Check accuracy of information with client or family where possible</li> </ul>		

### **Hints and Tips for Planning and Getting the Information Gathered**

- **Appoint a co-ordinator, the person that will chase everyone up, gather information together, complete this guidance sheet and plan meetings (most likely someone involved in research but could possibly be another person)**
- **Agree who is going to do what as individuals or in pairs. Ensure that everybody for example is not asking the carer the same questions whilst no-one is looking through care notes**
- **Have a central place / box file put gathered information eg: completed checklists, photographs, snippets of information picked up in conversation**
- **Agree on a date for when all this information to be gathered (perhaps a month at the most)**
- **Agree a time, date and venue after all information is gathered to share and begin to agree how this will be used. Include carer in this and Jane please.**

## **APPENDIX 26:**

### **Summary and evaluation of LSW workshop**

# Sheffield Health and Social Care NHS Foundation Trust

## *Life Story Work Workshop Dementia Directorate*

2<sup>nd</sup> October 2008

### **Facilitators:**

Jane McKeown (Practice Development Nurse – Integrated Governance)

Amanda Clarke (Qualitative Lecturer – University of Sheffield)

Participant List removed to maintain confidentiality

### **Summary of the Day**

#### **Session 1 - What makes you YOU?**

The group spent time considering what makes them the people they are today.

The ideas included:

- Family background – close knit, influence of family, brothers, sisters
- Friends – choice, influence of
- Work – type, enjoyment (or not)
- Beliefs, politics, culture and religion
- Achievements
- Hobbies, interests, holidays
- Life experiences – travelling, moving town, schooling, death, disability, illness
- Personality – happy, miserable, bubbly, ignorant, selfish
- Likes, dislikes, choices
- Finances – what you can afford, how you were brought up
- Environment – where you live, deprived, privileged,

We watched a YouTube video about a wife talking about her husband who had severe dementia and we saw parts of his life history.

## **Session 2 - What is Life Story Work?**

We talked through a definition of life story work – the main points that came out were:

Life story work is a very broad term for many things – for example life histories, life diaries, some types of reminiscence... Life story work often involves recording information a person tells you so that it can be used in their care. What is most important is the time spent with the person listening to what they wish to tell you and considering how best to then use this with them in their care.

**It is not:**

Life review – as that is a more structured and skilled process that involves helping the person to look back at their life in terms of regrets, pride and sometimes receive counselling to help them move out of depression.

Reminiscence – where a person may just think back over their life alone, or where specific events are talked about in a group

Oral history – where stories are recorded in an archive; or used to pass on facts about social history

We watched clip from a DVD taken with Community Dementia Support Service showing how knowing a person's interests can be used in conversation and activities.

### **Session 3 – The benefits and experience of using Life Story Work**

We were joined by Lynsey (a nurse) and June and Ben (carers) from and by Amy (a nurse) – all of whom have used life story work. In two groups we discussed the benefits and experience of using life story work – here is a summary of our discussions:

- It can help the carer to re-connect with the person with dementia through shared memories – remember the things they did together – remember the person they married
- There can be sad memories for carers as well as good memories
- It helps with continuity of care if a person moves to another care environment
- The person telling the story “comes alive”
- The person has 1 to 1 time with staff or others
- It can give the person a purpose – something to focus on and talk about
- Looking through pictures can be a “key” or “trigger” to memories
- It can help to make sense of the person’s behaviour
- It connects us all as individuals
- Makes “person centred care” genuine
- Staff can feel passionate about it
- Helps staff to talk and engage with the person – a conversation piece
- It is more than a “task” – it values the person
- The person can feel proud of their life
- It belongs to the person
- It needs to focus on the “person” and may not refer to the “dementia”
- Assumptions we may have about people with dementia can be challenged
- It “legitimises” listening – it makes it OK to spend time listening to the person
- It is important to share with others

- You can learn things about the past
- It is enjoyable for everyone involved
- It can help to plan activities the person may enjoy
- You can see what has made the person that they are
- It can be used to calm a person down if they are getting upset

We watched a Youtube video of a son talking about the use of a photograph album with his Mum who went on to get dementia.

#### **Session 4 – Dilemmas Faced in Using Life Story Work**

Five small groups each looked at a scenario where there had been difficulties in using life story work. The following key points were discussed:

- Being prepared for the difficult / private subjects that might come up and having the necessary advice and supervision to deal with them with sensitivity and respect.
- Respecting the story the person presents even if it does not always seem to be accurate.
- Negotiating difficulties between what the person with dementia wants and what the family want.
- Appreciating that not everyone likes to reminisce and some people may have memories they do not wish to talk about.
- Respecting if a person changes their mind and does not want their story to be shared with others – considering consent all the time and responding to changes in consent.
- Doing your best to involve the person with dementia as much as possible in sharing their story even if this is difficult due to their communication, degree of dementia.

We watched a YouTube video helping us to think about the importance of understanding the culture of the people we care for and how we need to consider this in life story work.



## **Session 5 – Different Ways of Using Life Story Work**

We talked about ways of using life story work in everyday care and activities. Jane shared some of the important things in her life to challenge the group to think if knowing these changed their views of her in any way.

The group then rotated between 5 different activities looking at some aspect of life story work.

- 1 – Christmas Memories – we wrote our memories of Christmas onto baubles
- 2 – Credit Crunch Poster – sharing ideas on how to survive the credit crunch
- 3 – Pieces of Me – Thinking about 5 items, events, photos that are important to your life story
- 4 – Time Line – Thinking about important events – in history and personally that are significant to you
- 5 – Personal History Sheet – Completing the personal history sheet that the Rapid Response Teams use – or writing your own brief pen picture.

## **Session 5 – Summing Up and Evaluation**

You were asked to think what you might do when you got back to work to put some of the ideas from today into action. I have attached your postcard with this report to remind you. Here are your plans:

### **Plans to Use Life Story Work**

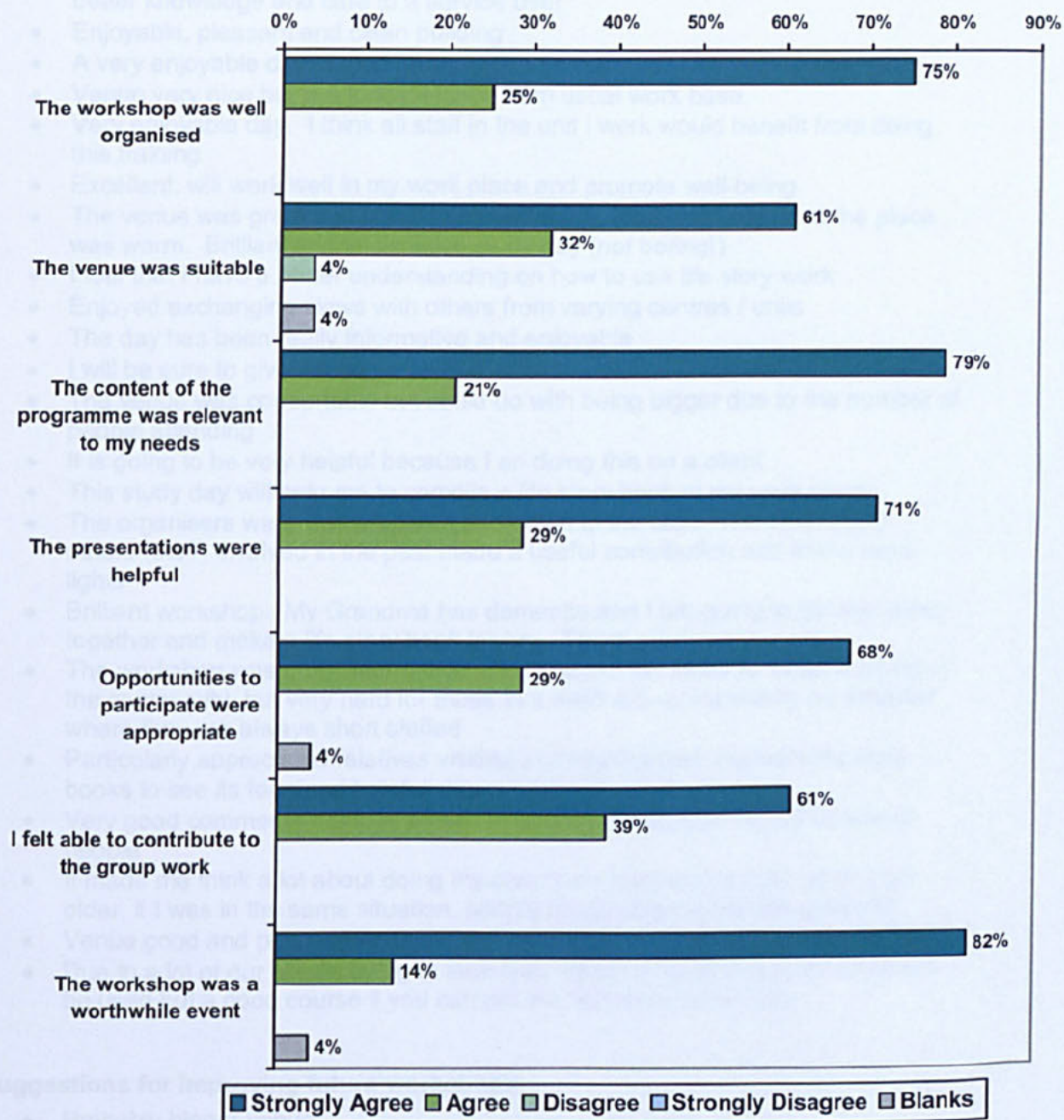
- Suggest to carers and clients making life story books. Produce a leaflet with information about this.
- Talk to relatives of a client about getting him to join in activities of maybe do a life story.
- Spend more time with the clients and relatives
- Suggest to manager and relatives about making life story books and trying to make it easier to get to know people

- To use in the group work
- To read all the life story forms of all the clients in the team to gain more information
- To use the 'life story shield' more with service users, speak to the manager and use in service users review
- Ask the carers for more information about their loved ones, their likes and dislikes
- Get to know clients history so that I understand them more: their feelings; what makes them tick; makes them happy; makes them sad.
- To use life story work. I will complete a life story book with one of the clients in my workplace
- I would involve care and family in life story to try and implement their life story book
- Put a life history sheet in patients' notes and encourage staff to record relevant information they find out about their past / present life events or history
- Maybe the personal history assessment could be extended
- Get more involved at ward level involving relatives and encouraging them to tell the stories (good and bad). Seek consent or permission to use in caring for the patient.
- Use the time with patients in the community to compile the life story information.
- To ask family and service users more about doing life story work and tell them about the benefits it can bring
- I will try and implement life story work into everyday life by providing essential information about residents either in their rooms or care plans.
- To feed back to unit manager and work with her relay this onto family.
- To put into practice asap. To compile a letter to go out to relatives and ask for input. Set a date for a discussion at carers meeting. Request files to commence work. Feedback to and involve other workers.
- To do life stories with my client getting permission from them and family and continue using pen pictures.

- Talk to a certain relative to see if I can do a life story on his wife, I think he would think it very beneficial.
- Cascade to staff and introduce life story work with clients in our care.
- Try to listen more closely to what the client wants and give them more time to choose for themselves.
- I would like to start a life story on a new client with the help of her family as I think it would be beneficial and I have never done one before.
- Share the information I have learned with other nurses and support workers and introduce the idea to relatives and service users at the next relatives meeting.
- I am going to attempt to do a life story book
- Listen to what is said and make sure it is noted and prompt more conversation when possible
- Invite Jane to carers group. Involve other staff in life story work within unit. Initiate with clients and get relatives information.

You were asked to complete and evaluation form here are the results:

## Overall Evaluation of Workshop – Results (n=28)



**Additional comments:**

- Bringing someone's life story forward and ongoing can only aid in providing better knowledge and care to a service user
- Enjoyable, pleasant and clean building
- A very enjoyable day. Good group
- Venue very nice but is a long distance from usual work base
- Very enjoyable day. I think all staff in the unit I work would benefit from doing this training
- Excellent, will work well in my work place and promote well-being
- The venue was great and should be used more, food was great and the place was warm. Brilliant and informative study day (not boring!)
- I feel that I have a better understanding on how to use life story work
- Enjoyed exchanging views with others from varying centres / units
- The day has been really informative and enjoyable
- I will be sure to give it a go
- The venue was comfortable but could do with being bigger due to the number of people attending
- It is going to be very helpful because I am doing this on a client
- This study day will help me to compile a life story book at my work place
- The organisers were well prepared and equal to the task. The carers and others (staff) involved in the past made a useful contribution and threw more lights
- Brilliant workshop. My Grandma has dementia and I am going to get the family together and make a life story book for her. Thank you
- The workshop was quite informative and / support the ideas to those working in the community, but very hard for those in a ward set-up especially on situation where they are always short staffed
- Particularly appreciated relatives visiting and sharing their partners life story books to see its form and helpfulness
- Very good comments made at times. Was lovely to look at the old photos of people
- It made me think a lot about doing my own "personal life story" so when I got older, if I was in the same situation, people would know about me properly
- Venue good and people friendly
- Due to a lot of our clients being in their later stages of dementia a lot might not be used but a good course if you can get the right carers to attend

**Suggestions for improving future workshops:**

- Probably bigger venue
- To receive updates and further workshop days on site or have someone trained to pass on knowledge to the rest of the unit. Very enjoyable and informative - thank you
- Have more of them
- Possibly the workshops could be a little longer 15mins instead of 10mins
- The venue was nice but a long way to travel
- The workshop should be part of essential training for every employee involved in dementia care
- Such workshops should be mandatory, introduced to Universities as well
- None
- The day could have been broken down to shorten the day

**APPENDIX 27:**

**Knowledge Transfer bid submission**



The  
University  
Of  
Sheffield.

Research & Innovation  
Services.

### KT Rapid Response Fund - Proposal Summary Form

Proposals should have been discussed with, and approved in principle by, the PVC (External Affairs) prior to completion of this Form.

#### 1 – Applicant Details

Primary Investigator:	Dr. Tony Ryan
Department:	School of Nursing and Midwifery
Extension:	226 9852
Email:	t.ryan@sheffield.ac.uk

#### 2 – Partner Details

Proposals will normally involve an external partner from the public, private or third sectors. In exceptional cases, proposals may not involve an external partner – if this is the case please detail the target market and how knowledge exchange will be achieved at the bottom of this section.

Organisation name:	Sheffield Health and Social Care NHS Foundation Trust
Organisation type: e.g. Commercial organisation, charity, government	NHS Mental Health and Social Care Provider
Organisation sector: e.g. semiconductor manufacturer, theatre	
Contact name:	Jane McKeown, Senior Nurse; Service User and Carer Involvement
Address:	Sheffield Health and Social Care NHS FT Practice and Professional Development Department Fulwood House Old Fulwood Road Sheffield
Postcode:	S10 3TH
Telephone:	0114 2263950
Email:	Jane.mckeown@shsc.nhs.uk
Website:	<a href="http://www.shsc.nhs.uk">http://www.shsc.nhs.uk</a>
Target market and how knowledge exchange will be achieved. (For proposals with no pre-identified partner only.)	

#### 3 – Proposal Details

Do not cross-refer to web addresses or add annexes.

Levels of information provided should be guided by the amount of funding sought.

Proposal name:	Life Story Work for People with Dementia: Wider Dissemination and Training Events
Amount requested:	
Proposed start date:	May 2010
Proposed end date:	January 2011



### *General summary of proposal*

Briefly describe the nature and scope of the initiative to be funded.

There are over 700,000 people with Dementia in the UK today with the number expected to rise to increase to nearly 950,000 by 2021 and 1,750,000 by 2051 (Alzheimer's Society 2007). The cost of caring for people with dementia is currently estimated to be £1.7 Billion per annum. Many people with a diagnosis use some form of formal care service or live in residential or nursing home care (Alzheimer's Society 2007; DH 2009). Whilst care practice has been transformed in recent years major difficulties persist. One major criticism levelled at care services is the dearth of information available to care staff to assist in making decisions that are consistent with the way in which the person with dementia has lived their life. In order to care with dignity, offer person centred care and include people with dementia and their families in decision making there is a need to understand people with dementia as individuals, this includes a sense of the person's past, their identity and biography (SCIE 2006; Kings Fund 2008; DH 2009;). Such approaches also contribute to a sense of continuity within care practices (Ryan et al 2008).

Life story work (LSW) is aimed at enabling nursing, health and social care staff and other allied health professionals who work with people with dementia, to find out about the service user's past achievements, interests, likes, dislikes, values, significant people and places in their life. LSW is based on collaborative efforts of service users, health and social care professionals and family members to produce materials that can be used as an aid for communicating the necessary information about a person with dementia. Evidence suggests that LSW can promote:

- Person centred care (McKeown et al 2010)
- Improved collaborative planning around future care (Hansebo and Kihlgren 2000; Keady et al 2005)
- Closer relationships with families (Kellett et al 2010)
- Enriched activities (Bruce and Schweitzer 2009)
- Health and social care staff satisfaction with their practice (Bakken et al 2009; McKeown et al 2006).

The applicants (principally McKeown) have been involved in the research and development of LSW for a number of years within a University of Sheffield Doctoral study (cite). An important component of the diffusion of LSW practice into care settings is the training and education required to ensure life story work is implemented in a sustainable, safe and ethical way (Clarke et al 2003, McKeown et al 2010) and a method of implementation consistent with current approaches to practice development (Manley et al 2008).

In order to both disseminate findings from the research and to promote use in a sustainable manner we are seeking to:

1. Organise and facilitate a series of participatory workshops aimed at a range of audiences.
2. Produce a laminated 'flyer' summarising the research, findings and practical applications.



The planning and delivery of the workshops and the co-design of the information flyer will be undertaken with the collaboration of a reference group that supported the primary research and that now intends to support the implementation of the findings into practice. This group comprises care staff, managers and family carers of people with dementia.

In addition to the Principal Investigator (Ryan) and named partner (McKeown) the work will be assisted and supported by Prof. Christine Ingleton. Professor Ingleton's time will be cost neutral.

#### Workshops

We are planning six workshops in all:

- Three workshops aimed at care staff working in NHS health and social care settings and in residential/nursing home settings from the independent sector.
- One workshop aimed at family carers of people with dementia in South Yorkshire
- One workshop aimed at a mixed audience including people with dementia and family carers (the applicants have considerable experience of facilitating such events)
- One workshop aimed at Black and Minority Ethnic communities in South Yorkshire, and will be developed in collaboration with Community Development Workers.

The workshops will have three primary aims:

1. To disseminate findings and to inform practitioners and others of specific methodologies involved in LSW;
2. To seek further validation/ adjustment to existing methods and practices in LSW;
3. To build and extend relationships with the practice community, in particular with those representing significant providers within the industry in order to facilitate further (self-funded) dissemination and those from more difficult to reach communities.

Each workshop will be facilitated by at least two of the applicants (McKeown, Ryan or Ingleton). Each workshop will be fully evaluated and a report will be produced.

SHSC will provide match funding in kind for this initiative in the form of staff time, appreciation costs will be paid to carers who contribute to the workshops, resources to aid workshop facilitation and administrative costs in organising the workshops, sending out letters, telephone calls.

#### Laminated Information 'flyer'

The laminated information 'flyer' will be con-designed with the help of the small steering group. Although it will provide some information about the research, its emphasis will be on the practical applications of LSW, ethical issues and potential outcomes. It is estimated that 250 laminated information 'flyers' will be produced and mailed directly to care providers in South Yorkshire with a request that they are displayed in a prominent position. SHSC Trust and University of Sheffield logos will be included in the design.

### Impact

What outcomes do you expect to achieve from the above? What impact will the initiative have and how will this be measured. Impact should be considered in terms of:

- Economic benefit
- Informing public policy
- Improving quality of life
- Social impact
- Cultural impact

The impact of the initiative is detailed below:

It is hypothesized that life story can provide economic benefits also in: reducing costly complex needs; maintaining independence when used in primary care settings and enhancing staff satisfaction with work, contributing to reduced absence and turnover. The intervention is primarily aimed at facilitating an 'enriched' care environment, changing cultures and promoting diverse activities for recipients of services. In public policy life story work is being increasingly advocated as a means of promoting dignity and person-centred care with people with dementia, both of these synonymous with quality of life and care.

The development of the workshops through the reference group will model an approach that promotes the involvement of family carers and people with dementia in service development; this will provide learning for the Care Trust and the University. The considerations of people from BME backgrounds will be explored leading to an improved understanding of the needs of older people with dementia and their carers from BME groups. LSW has been found to be helpful in engaging with BME groups to seek advice and access mental health services (Kaiser et al 2009).

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### Benefits

How will the University and Partner organisation benefit, both in the immediate and longer term?

#### Benefits to partner organisation

- To be able to implement the findings from research into clinical practice
- Being able to access an educational resource to support the implementation of life story work which will enhance quality of care and person centred outcomes; this will support the organisations commitment to evidence-based practice.
- To learn from the experience of people with dementia and family carers from a range of communities and for them to be able to influence education and service provision
- The initiative will also provide evidence to the statutory bodies of the organisations commitment to working in partnership with carers and persons with dementia. There will be enhanced links with the University.

#### Benefits to the University

- Meeting the expectations of implementing research into practice
- Developing the skills of the University and the Practice Leads
- The possibility of income generation through the potential to disseminate the resource more widely.
- Building links with practice that could facilitate future joint funding bids.
- Academic paper reporting on translation of research into practice.

### Proposal delivery

Briefly outline the proposed programme of work over the timescale stated.

The initiative will take place over nine months commencing in January 2011 through to September 2011. Workshops will take place once per month beginning in March 2011.

January-February: Identification of partner organisations; identification of venues and other resources

January-March: Co-design and production of laminated 'flyer'

March-August: Providing workshops 1-6

July: Dissemination of laminated 'flyer'

September: Production of evaluation report

### 4 – Financial Details

uBASE Person Responsible (the account cannot be set up without this information)

Total amount requested: £9094

*Staff costs (N.B. it is recommended that URMS is used as a costing tool for calculating the value of staff time. However, it is not necessary to formally submit an URMS costing.)*

Name	Role	Hours	Cost (£)
Dr. Tony Ryan		0.5 days a month for 9 months	£4294
Jane McKeown		1 day a month for 9 months	£2200
<b>TOTAL</b>			

### Travel & subsistence

Destination	Purpose	Method	Cost (£)
From carers homes within Sheffield to central venue	Taxis for carers/people with dementia to workshops: 30 @ £20 each	Taxi (sharing where possible)	£600
<b>TOTAL</b>			

### Consumables & equipment

Consumable / equipment	Purpose	Amount	Cost (£)
Workshop materials	To support creative approaches to learning		£100
Laminated 'Flyer'	Dissemination	250	£100
<b>TOTAL</b>			

### Other costs

Costs of venue and refreshments: 6 @ £300 = £1800

### 5 – Signatures

I confirm that I wish to apply for funding from the KT Rapid Response Fund. I confirm that the information presented in the application is accurate to the best of my knowledge.

Signature of principal investigator:	
Date:	
<b>6 – Return</b>	
One hard-copy signed application form to:	Liz Bell Impact Manager Research & Innovation Services Academic Division New Spring House 231 Glossop Road Sheffield S10 2GW
One electronic copy to:	<a href="mailto:e.bell@sheffield.ac.uk">e.bell@sheffield.ac.uk</a>

Confirmation of funding will normally be confirmed within 10 working days.

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