Enhancing the use of Life Story Work in Health and Social Care Practice

Jane McKeown: Senior Nurse Sheffield
Health and Social Care

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Introduction

The use of Life Story Work (LSW) with people living with dementia is increasingly referred to and promoted in health and social care policy. In Sheffield, a small group of practitioners, academics, people living with dementia and family carers meet with the aim of promoting the use of life story work in South Yorkshire. Named Told in South Yorkshire, the group evolved from a research reference group supporting the Doctoral work of one of the group members (Dr Jane McKeown) and has become an established advisory group for LSW in Sheffield. Aware of some of the challenges in getting LSW used in health and social care practice the group supported a programme of implementation work aimed at getting current research on the use of LSW embedded into practice. This work was supported by the Foundation of Nursing Studies and General Nursing Council for England and Wales Trust practice based development and research programme with associated match funding from Collaborations in Leadership for Applied Health Research and Care (CLAHRC) South Yorkshire (now CLAHRC – Yorkshire and Humber).

Background

LSW is a way of gathering biographical information about a person and using it to inform their care and the evidence base supporting its use is growing. LSW has been found to be an enjoyable and beneficial activity from the perspectives of care staff, people with dementia and their family carers in a range of health and social care settings (Batson et al. 2002; McKeown et al. 2006, 2010; Bakken et al. 2009; Thompson 2011). It has been shown to: facilitate relationships (Bakken et al. 2009; McKeown et al. 2010); help staff to see the person behind the patient (Batson et al. 2002; Gibson and Carson 2010; McKeown et al. 2010); improve communication between the people with dementia, care staff and other residents (Murphy 2000; Batson et al. 2002; Kellett et al. 2010; McKeown et al. 2010); and help the person to feel proud about them-self and their life (McKeown et al. 2010).

The importance of biographical knowledge in caring for people with dementia is reflected in recent policy and guidance, for example: Dignity in Care (SCIE 2006); NICE / SCIE Guidance on Dementia (National Collaborating Centre for Mental Health 2006); Dementia Strategy (DH 2009); Common Core Principles for Dementia Care (Skills for Care 2011).

However despite the reported positive outcomes of using LSW and the support from policy and guidance, challenges remain in the consistent implementation of LSW into dementia care practice (Thompson 2010; Gibson and Carson 2010; McKeown et al. 2010). Additional challenges persist in nurses applying theory in relation to listening to narratives of people with dementia into practice (Russell
and Timmons 2009), whilst Bakken et al. (2009) point out the careful planning, education and support are needed to implement LSW into nursing home care.

In addition to the research and the policy understandings of LSW, this project also drew upon the practice experience of the Told in South Yorkshire group; their experience being that there were sometime challenges in getting LSW used in practice.

The project aimed to integrate three work packages to support health and social care staff to use LSW in practice; these were:

1: The development of a resource pack to support the use of LSW informed by the identified needs of and in collaboration with stakeholders.
2: The organisation of a dissemination event to showcase good practice and launch the resource pack.
3: The implementation and evaluation of LSW into the care of people with dementia who have enhanced needs in a SHSC nursing home.

This report begins by locating the project within a model of Knowledge Translation. Next the outcomes from the project will be reported under each of the work packages. Finally conclusions will be drawn and key outputs and future steps identified.

Knowledge Translation

The Knowledge to Action Framework Graham et al. (2006) provides a helpful framework within which to locate this project (see Figure 1).

The framework offers understanding of the Knowledge Creation process depicted by the upside triangle or funnel and the Action Cycle which encircles the funnel. Graham et al. (2006) note that knowledge includes empirical knowledge as well as other forms of knowing.

The project was relevant to two parts of the Knowledge to Action Framework. The first was the development of tools relevant to the Knowledge Creation Funnel (the proposed LSW information resource). The dissemination event was designed to share this learning with a broader health and social care audience. The second was to explore more clearly through the Action Cycle, the challenges in implementing LSW in a care home.

Project Management

The project was led by Jane McKeown and the Told in South Yorkshire advisory group participated and helped guide the project. The group acted as a ‘critical friend’, asking relevant questions through the process and challenging actions
and assumptions where necessary. The group were instrumental in developing the resource pack through undertaking focus groups, assisting in analysis of the data and contributing to content and design decisions. The group were also central to the planning and delivery of the showcasing event.

**Figure 1 Knowledge to Action Framework**

![Knowledge to Action Framework](image-url)

Graham *et al.* (2006)

**Knowledge Creation: Developing and Disseminating a Life Story Work Resource Pack**

**Development of a Life Story Work Resource Pack**

Previous research had identified that health and social care staff sometimes found it difficult to know how to get started with LSW (Bakken *et al.* 2009; McKeown 2011) but there were few resources to guide staff through the LSW process that are not costly to purchase. The expertise within the Told in South Yorkshire group was drawn upon to develop a resource pack through a planned process of engagement with people with dementia, family carers and care staff.

A series of 6 focus groups were undertaken with a range of people with dementia (n=5), family carers (n=4), health and social care staff and voluntary / charity organisation staff (n=31) in a variety of settings. The purpose of these was to find out what people who had used LSW had found helpful in terms of knowledge, information and resources to get them started and what they felt
would have been useful. For people who had not used LSW we were interested in what they felt they needed in order to get started.

Members of Told in South Yorkshire planning group facilitated the focus groups using a topic guide (see Appendix 1). One person made notes during the focus groups and these were typed up immediately following the group. This process enabled some people to gain experience in facilitating a focus group, supported by a more experienced group member.

The focus groups notes were read and analysed through the identification of similar themes / topics by JM. Each of these tentative themes were written onto A4 sheets of paper and presented to the Told in South Yorkshire group members, each of whom had read the focus group notes. Some minor adjustments were made to the themes and these formed the proposed ‘pages’ within the resource pack. The group made notes under each of the theme headings and started to place them in a logical order. Discussions took place about what the resource pack might look like and contact was made with a designer at this stage. JM used the notes to begin to provide information to address the topic headings and questions raised. This draft was shared with the group and a number of amendments were made based on group feedback. At this point when a fairly comprehensive draft was available, this was shared with 3 staff members, external to the group, but with some knowledge of life story work, to see if the pack was understandable and helpful. Positive feedback was received along with some suggested improvements (mainly around formatting and presentation rather than content).

A small event was organised for people with dementia and family carers from Darnall Dementia Group who were in agreement to having their photographs taken for the pack. This involved a buffet lunch and social gathering, to help the group to relax and to inform them what was happening. The designer also attended the lunch so that people were familiar with him and he could meet the group informally. After lunch a number of tables were set up and people shared their life story books and other methods of recording life story work. The designer took the photographs which eventually appeared in the pack.

The draft pack from the designer was shared with Told in South Yorkshire Advisory group and two group members took responsibility for the final proof reading and editing. The final pack was produced in printed form (200 copies) and also in electronic form. It can be found on the FoNS website at:


Six months after the packs were produced and disseminated a survey was sent out to all known recipients. This involved an email with the survey link to all
people who attended the life story work showcasing event; a paper copy to nursing home staff who may not have access to emails and a link went via the Told in South Yorkshire website and the FoNS newsletter.

Over 100 surveys were sent out, 16 responses were received (10 online and 6 paper), 9 from NHS staff, 6 from care home staff and one from a former carer. 13 people had seen the printed copy and 3 people had viewed both the printed and online versions.

The key things people valued from the pack were:

- The ideas, suggestions and tips on how to get started
- The look of the pack, how it was laid out and the visual information
- As a useful resource for training
- The ideas for activities to get to know the person with dementia

Following use of the pack 6 people went on to undertake life story work and 4 did not, 6 were already using life story work (see Figure 2).

**Figure 2: Whether staff went on to use LSW after seeing the pack**

![Figure 2](image)

The LSW pack helped people as it provided ‘helpful advice to begin and maintain’ LSW and showed them they were ‘going in the right direction’; they liked the prompts and examples as it enabled them to give their client choice.

The reasons people gave for not going on to undertake LSW were that their family member was no longer alive and the ‘lack of opportunity and having a suitable client’.

Suggested improvements to the pack included:

- Advice on how to get families involved
- Prompts regarding what faith people have and its value in their lives
- More visuals regarding staff using life story work
- More written information and less pictures
- More ideas for activities including the prompt for life story work on DVD

One person through the pack would be useful for staff inductions.
These suggestions will be considered in any future re-developments of the pack. The information will also help to inform the planned development of an online learning package on using LSW. The pack has since been evaluated against other resources in a review by Kindell et al. (2014) and their findings will help inform any future developments. Of particular interest in this review was the absence of guidance on how to evaluate the effectiveness of LSW.

**Life Story Work Showcasing Event**

The showcasing event was planned towards the end of the project, the aims were to:

- Share good practice taking place regarding the use of LSW
- Provide opportunities to participate in LSW activities to stimulate interest and creativity
- Launch the LSW resource pack

The event was held in a city centre location with the aim of attracting health and social care staff, academics, family carers and people with dementia. Care staff were invited to bring along people with dementia they were working with. The event ran for half a day in the morning and then was then repeated in the afternoon, participants chose the morning or the afternoon session. All participants were invited to lunch and over the lunch period live music was performed by local care staff and service user musicians.

On arrival participants registered and were given a LSW resource pack. A short opening talk provided a brief background to the event, information on the resource pack and then an orientation and invitation for participants to participate in activities, visit stalls and enjoy themselves.

Stall holders included: local services who had been using LSW, with leaflets and information; the Alzheimer’s Society; Darnall Dementia Group; Sheffield Museums with reminiscence artefacts; University of Sheffield researchers on an oral history project, IT and reminiscence and use of iPads; an interactive Paroseal used for communicating with people with dementia; life history cushions made by a local care home activities co-ordinator.

Activities included: a ‘Soundscape’ room where sounds that stimulated reminiscence were played; a timeline of historical and personal events that participants were invited to contribute to; Christmas Memories through making baubles and writing down special memories which were then hung on a Christmas Tree; celebration bunting which people decorated with favourite memories and hung up; a range of life story work records (story books, images, memory boxes) that people could look at; creative thoughts, memories and
stories; maps which people wrote on their favourite places in the UK and around the world; suitcase of life which contained objects that people had donated with a luggage tag recording the associated memory.

There was also a showing of the film of the life stories of a group of older men from the Yemen living in Sheffield, which had been made by members of the Told in South Yorkshire advisory group and a local film maker.

Evaluation was undertaken by people being asked to write on post it notes and post in: ‘BIN’ (what they thought could have been improved); ‘BAG’ (what they would take away with them) and ‘HEART’ (what moved them). Some comments regarding improvements included:

- More orientation / explanation of stalls and activities
- Just too much to see and take part in
- More information on what LSW is – more presentations

Many people reported enjoying the active aspect to the event, being able to participate and try things rather than being talked at. People also commented on the ‘buzz’ and positive energy generated. The responses were typed up and turned into a word cloud (see Figure 3).

Figure 3 Evaluation Word Cloud
Knowledge to Action: Implementing and Evaluating Life Story Work in a Care Home.

The second aspect of the project focused on the implementation and evaluation of LSW in a care home. We anticipated being able to support the implementation of LSW whilst also being able to explore the facilitators and the challenges throughout the process. Unfortunately, it was not possible to make significant progress with this aspect of the project. A brief outline of this work is provided below using Graham et al.’s (2006) Action Cycle to inform the reporting process.

Identify problem – Identify, review and select knowledge

The use of life story work with people with dementia specifically in care homes has been reported (Bakken et al. 2009; Russell and Timmons 2009; Kellett et al. 2010, Hansebo and Kihlgren, 2000).

Specific challenges in implementing LSW in nursing and residential care settings are rarely reported although it could be speculated that similar challenges exist as reported in other care settings.

The nursing home identified to work with was an NHS 60 bedded unit offering care for people with dementia with enhanced care needs; that is dementia related needs that non-specialist nursing homes were unable to meet.

The home was organised into 4 cottages each with 15 residents and a fixed staff group working with one Registered Nurse and two or three support workers on each shift. There was a central management team of a service manager, a nurse manager and two deputy managers but each cottage operated fairly independently with limited collaboration between one another. The home had previously been owned by a housing association and staffed by NHS staff but had recently come under the organisation and management of the local mental health and social care Foundation Trust. Some residents had been at the home for many years and had advanced dementia, requiring end of life care nursing. Other residents had arrived more recently and sometimes presented with behaviours that were challenging to staff, such as difficulty communicating, shouting and restless or aggressive behaviour.

The home had a reputation for providing good physical care, but there were development needs for staff to support them in offering an improved standard of psychological care to residents. It was for this reason that Senior Clinical Managers within the mental health and social care Foundation Trust identified the home as a relevant location to implement and evaluate LSW, as a means to enhance person-centred care. It was anticipated that development work would be welcomed within the home, but also that challenges may be present and a deeper understanding of these would be helpful.
Although a Senior Nurse within the organisation the project lead did not have a specific clinical or management role within the nursing home and as such was working as an external facilitator. In order to be able to influence practice the aim was to work with internal facilitators within the nursing home.

The original project plan had identified the implementation of LSW directly with care staff in the home, however there were concerns from the managers of the home and the project team that might create a ‘task-focus’ i.e. the creation of books and not result in person-centred practice i.e. the knowledge about the person gained from creating the life story books being used to inform care/practice. Consequently an Appreciative Inquiry approach was used with the aim of identifying good practice in relation to ‘knowing’ the residents and explore how this good practice could be enabled to happen more often.

Adapt knowledge to local context

A staff nurse was identified as an internal facilitator for the project lead to liaise with. An initial meeting with him identified that a leaflet would be helpful to explain the initiative to care staff and relatives. This was developed in collaboration with the staff nurse and a number of ‘Appreciative’ questions were included in the leaflet (see Appendix 2). The leaflets were displayed and distributed within the home and the questions formed the basis for conversations between myself or the staff nurse and care staff and family carers.

The responses from the initial ‘Appreciative’ questions were collated and displayed in poster format (see Appendix 3). A poster was displayed in each cottage and in the entrance to the home, with an invitation for people to make further comments and post these in a sealed box. The rationale for this was that it provided an opportunity to contribute for family carers or care staff who wanted to respond more privately, or who had not had the opportunity to speak with the project lead or the staff nurse.

A small group of staff and a relative interested in the project had emerged and a meeting had been held to review the responses to the posters. Unfortunately no further responses were received. Shortly after that the relative who had been involved was unwell, and staff changes meant the interested staff were no longer able to attend. The identified staff nurse moved cottages and then left the home.

In view of the changes and limited engagement with the ‘Appreciative’ questions and alternative approach was adopted. Two student nurses had started their placement at the home and were interested in life story work. A short information session on LSW was organised and the 2 student nurses and a number of staff attended. The student nurses were supported by the project lead to develop a life story book that had been started by the staff nurse before he left.
The students valued the opportunity to get to know the resident and her family. A life story book was produced which provided the resident and her family with a life story record and the care staff in the home with an example of a life story book.

A new manager was appointed and suggested a lunch time event about LSW for family members. Two families attended; the daughter of a resident subsequently made a life story book for her Mum, a resident in the home. The wife of a resident purchased an iPad and with help from her son uploaded some photographs on it which she shared with her husband (a resident) on one occasion.

A conversation with a staff nurse at the home identified two support workers and an activity worker who were enthusiastic about LSW. A small interest group was formed and this helped to plan a small LSW showcasing event at the home. Some residents, relatives and staff attended the event and participated in life story work activities. Following on from this the manager has supported one of the support workers to develop some LSW profiles for residents. The support worker has joined the Told in South Yorkshire Advisory group where she is able to share her progress and seek support for her work.

Assess barriers to knowledge use

Reflecting upon the difficulty in implementing LSW within the home a number of challenges are evident. These can be reported in relation the Promoting Action on Research Implementation in Health Services (PARIHS) Framework (Rycroft-Malone et al. 2002) which identifies three key elements that impact on evidence being successfully transferred into practice.

Evidence

- Challenges emerged in engaging staff in sharing of evidence around knowing the person and links with person-centred care
- LSW was not seen as a priority by many staff – or staff were not dissatisfied with current approach to care therefore they lacked the commitment to developing a new way of working
- Loss of relative participant

Context

- Changes in management structure, sickness in deputy managers
- Staff workload practically made it difficult for staff to get involved and prioritise LSW; when some staff did get involved they either moved cottages or left the home
Facilitation

- Challenges in impacting on the prevailing culture as an ‘outside’ facilitator and challenges in recruiting and keeping internal facilitator
- Whilst management supported the work, often this support was passive rather than active, thereby having limited influence on the participation of staff – supporting in principle rather than practice

Monitor knowledge use

As previously reported the nursing home had been identified by senior managers as a relevant environment to implement and evaluate this work, however the result has been pockets of interest and activity, rather than a genuine commitment to developing a more person-centred approach to care informed by LSW.

Evaluate outcomes

Upon reflection it is uncertain whether an Appreciative Inquiry approach was helpful to the particular nursing home context and to the project. Although at the time it was seen as relevant, particularly as the home was used to being criticised and not praised, some staff may have found the approach overly positive and not genuine or were perhaps suspicious of the intentions. In a draft discussion paper Gallagher and Heyne (2012) reflect on how an emphasis on appreciation may sometimes deny people to openly discuss negative or critical feelings even though they may be present. In previous practice development work the project lead has found it sometimes important for staff to tell their work situation stories, even if negative, before they can consider working in a different way. It was also difficult to assess whether the identified issue, i.e. the need to better understand residents’ life history was perceived as significant to care staff.

The subsequent approaches to implement LSW were significant to the individuals concerned but were not able to dovetail with any organisational framework to support the development of a person-centred culture of care.

Whilst skilled facilitation is acknowledged as a key factor in the successful implementation of evidence into practice (Rycroft-Malone et al. 2002) and the development of workplace cultures that are person-centred (Manley et al. 2011), in this project, the project leader in her role as external facilitator was not able to influence the overall culture of the home.

Summary

The overall practice based development project resulted in some significant achievements. The most obvious outcome was the development of the LSW
resource pack which offers guidance in getting started with LSW. The pack is available electronically on the FoNS website and also on the CLAHRC Yorkshire and Humber e-repository of tools to support the use of evidence in health and social care practice. The evaluation of the pack was based on a small number of responses and although it was pleasing to see that some people had gone on to implement LSW after receiving the pack, it is unclear if these efforts were sustained.

The dissemination event was well attended, well evaluated and created a sense of energy and enthusiasm on the day; however we were not able to follow up on whether it resulted in LSW being used more widely.

The challenges in progressing the work within the nursing home reflect the evidence in what helps and hinders getting evidence into practice. What remains unclear is whether it is prudent to not attempt implementing initiatives where culture is not conducive. This question was put to the Told in South Yorkshire Advisory group and there was an overwhelming response that it had been important to continue to try and introduce the work. There were some small achievements, albeit at a much slower pace than anticipated and a subsequent review of the home and planned changes to leadership, training, supervision and activities should mean that LSW has a future in the more positive culture being created.

References


Assist Patients from a Long Stay Psychiatric Hospital in their Move to Community Care Situations. (Unpublished work)


APPENDIX 1

Topic Guide for Life Story Work Resource Pack Focus Groups

Question 1:
If you have already been involved in life story work what information or resources were helpful to you in getting started?
(Prompts if group don't speak – specifically what did you use, what was most helpful and why, what would you have liked that wasn’t there?)

Question 2:
For people who have not used life story work what information or resources do you think would help you get started?
(Prompts if group don’t answer – for example what information would you like about what life story work is, how you get started? What information about how you record a person’s life story...?)

Question 3:
In what formats / ways would you like this information available?
(Prompts – written, web based, newsletters, videos)

Question 4:
Is there anything else you want to say about your information / resource needs to enable you to undertake Life Story Work
APPENDIX 2

Copy of Information Pamphlet with Appreciative Questions

Getting involved
We want to get the views and opinions of as many residents, family carers, staff and students as possible at ***** and hope you will chat with Derrick and with Jane when she visits.

We want people to take an interest in the project and help us to learn from what people have told us and make plans to get new ideas into practice.

We want your ideas on the best ways to keep everyone updated and include people who want to get involved.

For more information and to get involved speak with Jane on: ***** or email: *****

Or:
Derrick on ***** Cottage: *****

About the project
A project is taking place to find out what works well in getting to know and understand residents at *****.

***** has been chosen to take part in this project because of the close relationships that exist between staff, residents and family carers.

An "Appreciative" approach to the project will build on what already works well on knowing and understanding residents.

Jane ***** is a Senior Nurse in SHSC, is being supported by an advisory group of staff, carers and people with dementia to lead the project.

Derrick ***** is a staff nurse at ******, who is working with Jane on the project.

What will happen?
We want to find out from staff, residents and family carers:

What works well at ****** about getting to know the residents?

What good examples are there of how knowing the person is shared within the team?

In what ways is knowledge of the resident used successfully in their everyday care and activities?

What do relatives think ***** do well in finding out about the residents?

In what ways does the environment of ******* encourage an interest in finding out more about the residents?
Knowing and Understanding Residents at

We Asked ... And You Said ...

What works well at ***** about getting to know the residents?

Staff hold a lot of information about residents and seem to know them really well, such as things about their life or how they are feeling.

What good examples are there of how knowing the person is shared within the team?

If someone finds something out about a resident it is shared - not always in a formal way but through conversations when they visit.

We took some residents to an Irish Tea Dance. At the end they played an anthem and a resident stood up and sang alone - we had not known he was Irish.

The new care plan have a space to ask about a resident's past personality and interests and then this can be shared.

Staff tend to find out information about residents through talking to any relatives - not in any formal way but through general conversations when they visit.

In what ways is knowledge of the resident used successfully in their everyday care and activities?

A support worker knows that Mum likes nature and animals and he sits with her looking at books and magazines. If there is a television programme on nature he asks if she would like to watch it.

What do relatives think ***** do well in finding out about the residents?

The television programme about re-designing the garden at ***** helped us to find out more about some of the residents.

We found out that a female resident was reluctant to eat at the table but would eat when her meal is put on a tray in her room. This was shared amongst staff and now she eats well.

In what ways does the environment of ***** encourage an interest in finding out more about the residents?

The staff at ***** love the residents. It's like they see them as part of their family which is nice. You can 'feel the love'.

Some visitors to the home commented on the renaissance boards on the corridor walls between the bungalows. They said they were great for sparking off conversations and sharing memories.

Tell us what you think by adding your comments to the blank speech bubbles and posting them in the box. To find out more about the project speak with Derrick on *** or Jane at ****.