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Life Story Work in Dementia Care

Everybody has a life story. These are rich and varied and can be used to communicate who we are to the people around us. People with dementia sometimes need help to communicate their histories and identities, and it has been suggested that life story work could present a way for them to do this more easily.

In 2012 the Social Policy Research Unit at the University of York launched the first study of its kind to investigate life story work from first principles. We asked:

- What is life story work?
- What is considered to be good practice in life story work in dementia care?
- How do service providers and family carers use life story work?
- Can life story work be evaluated in real world care settings?
- What are the costs of doing life story work as part of everyday care?

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What is life story work?

Life story work in dementia care involves people with dementia (and/or their families and care workers) recording aspects of their past and present lives, either for personal use, or to improve care. However, no single definition of life story work exists and there are many different approaches in practice. We looked at existing literature and grouped the ways of doing life story work like this:

1. **Chronological:** Attempts to accurately record life (from birth to now). Focuses on memories.
2. **Narrative:** A personal interpretation of life. Emphasises strengths/interests/feelings over 'facts'.
3. **Care focussed:** Focuses on using life story work in care settings (i.e. to improve care).
4. **Hybrid:** Narrative approaches applied in care settings.

We also noticed that people talking and writing about life story work are not always talking about the same thing. When some people talk about life story work they mean something that is led by the person with dementia, to reinforce a sense of identity and support pride in the life they have led. However, when service providers (like care homes and hospitals) say they are doing life story work, this is often led by a member of staff or family carer using a template and the aim is to aid communication and increase staff understanding about the person. As someone with dementia in one of our focus groups put it, there's:

> "…a division between writing the story as a matter of personal interest and writing a story… that would help other people to know us when we couldn't properly represent ourselves."

This report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

What counts as good practice in life story work?

People writing about life story work don't agree on what counts as good practice. As there was no consensus in the literature, we asked people with dementia, family carers and professionals with experience of life story work, what they thought was good practice.

We ran 10 focus groups (with a total of 73 people) on this subject and came up with the following learning points that people could keep in mind when doing life story work:

Good practice learning point 1: Whether someone wants to take part in life story work is an individual thing. It should not be assumed that a person necessarily wants to make or share a life story and no-one should be pushed into doing so.

Good practice learning point 2: A person's life story is never finished and life story work needs to reflect this. To avoid setting people 'in stone', ensure life story documents can be added to and updated.

Good practice learning point 3: Life story work can be emotional and may raise sensitive issues. Some people will value the opportunity to talk about these issues, but staff require training to handle this and should not be expected to do so without support.

Good practice learning point 4: A person with dementia may have very different views from others about what their life story is for. Respect the person's wishes about what goes into the life story and who will see it, now and in the future. If they do not have capacity to express their views, consult someone who knows them well.

Good practice learning point 5: Staff should consider making and sharing their own life stories. How does this feel? Who would they share them with?

Good practice learning point 6: Beginning the process early will enable people with dementia to take a more active role in producing their life story and communicate how they would like it to be used in the future. However, it is never too late to use life story work to improve care for a person and invoke a 'nice feeling'.

Good practice learning point 7: Outcomes for better care will only come about if care staff take (and are granted) the time to absorb life story information and the flexibility to use this to inform and improve the care they provide.

Good practice learning point 8: Short summaries might be useful for busy staff, helping them to achieve better care, but they cannot replace a life story owned, shared and added to by a person with dementia him or herself.

Good practice learning point 9: The *process* of collecting life story information enables staff to connect and build relationships with people with dementia and their families. However, in order to have wider benefits it is also important to *produce* something that can be used and enjoyed by others.

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How do service providers use life story work?

We sent a survey to a representative sample of dementia care service providers across England and received 307 responses. From these we learnt that dementia assessment wards in mental health hospitals were most likely to do life story work and community services least likely. However, the hospital wards were also most likely to use a template, whilst community services were least likely. In dementia hospital wards, making a life story was also most often seen as a one-off event, rather than something to be added to over time. It seems likely then that the type of life story work done in dementia wards is quite different from the type of life story work done in the community.

Estimated percentage of all services in England that offer life story work

Service type	Response rate (%)	% of responding services that do life story work	**Estimated % of all services in England that do life story work**
In-patient dementia assessment services	70	89	**62**
Dementia specialist care homes	61	79	**48**
Memory clinics/services	64	44	**28**
Generalist care homes	32	71	**23**
Community dementia support services	52	27	**14**

How do family carers do life story work?

We received 96 responses to our survey from family carers of people with dementia. Three-quarters (75%) had heard of life story work before, but only 41 per cent (39/96) said that the person they supported had ever done any life story work. Family carers under the age of 65 were more likely than older carers to have heard of life story work.

Most of the life story work we heard about from the survey was done in people's own homes (20/39) or in a care home (13/39). Care staff were often (but not always) involved in care home settings, but in the person's own home it was unusual for anyone other than the person with dementia and/or their family carer to be involved.

Family carers told us that the most important reason for doing life story work was to help health and social care workers to provide better care. Despite this, most family carers said that care staff and other professionals did not use the life stories often, or that they did not know how often staff and professionals used them.

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Can life story work be evaluated in real world care settings?

We collected information from three dementia assessment wards that did life story work and one that did not, as well as six care homes that were introducing life story work for the first time. We were more successful inviting people with dementia and their carers to take part through care homes than through hospital wards. In the care homes, 51 members of staff, 39 people with dementia and 31 family carers agreed to take part in the study. In the hospital wards, 12 people with dementia, 10 family carers and 82 members of staff took part.

Outcomes: Staff attitudes towards people with dementia in care homes appeared to improve significantly once they were doing life story work. However, it is hard to say whether this change was caused by doing life story work itself, or by the training that staff were given about how to do life story work.

There also appeared to be some improvement in the quality of life of the care home residents with dementia doing life story work. This is based on the answers given to us by people with dementia themselves. However, as this was only a small number of people (mainly those less severely affected by dementia) we cannot draw firm conclusions from it.

The experience of family carers of people in care homes appeared to get worse over time, while the experience of carers of people in hospital wards appeared to improve. This is perhaps not surprising given the deteriorating health of many of the care home residents.

Challenges: Care home and hospital priorities, management and culture all affected how easy it was to involve people in this study and to collect the information we needed.

The main reason we only have information from a small number of people with dementia is that some were unable to understand and/or answer the questions in the quality of life questionnaires we used (DEMQOL and QoL-AD). These questionnaires were designed specifically for use by people with dementia but still do not work for everyone.

What does it cost? Collection of resource use data in all settings was time-consuming and complicated. As part of the feasibility study, data on costs were exploratory rather than definitive. Given these caveats, the average cost of creating and using a life story product for a care home resident was £37.42 spread over 16 weeks. This was in addition to training costs of between £950 and £1581. The average cost of creating and using a life story product in the mental health hospital assessment wards was £68.21 per patient over three weeks.

Summary of study methods (for more details go to http://bit.ly/lsDem

Systematic review: 657 titles/abstracts assessed for relevance, 56 papers included in the review.

Focus groups: We spoke to 25 people with dementia, 21 family carers and 27 professionals.

Surveys: We received responses from 307 services (representative sample) and 96 family carers (drawn from an independent network of carers).

Feasibility study: To test ways of collecting information and gain a better understanding of the costs and effects of life story work in care homes and dementia wards.

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