

Life story work can help care workers and relatives connect with people with dementia



An NIHR-funded feasibility study about life story work with people with dementia showed how the approach could improve outcomes by supporting identity expression, fostering understanding and facilitating person-centred care.

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Positive interventions to improve wellbeing

People with dementia experience a progressive decline in their cognitive and communication skills, making it increasingly difficult for them to express themselves and their identities over time. Sharing stories can help people connect with others. However, when communication becomes difficult for a person with dementia, paid carers and professionals involved in their care may know little about the person behind the condition.

Interventions that help people share their history and identity can play an important role in tailoring care. Life story work is one such intervention that has been used in dementia care for many years. It focuses on recording key elements of a person's life story - including past experiences, current interests and future wishes - and sharing these with others.

With support from family, friends or professionals, the person with dementia gathers information such as photographs, letters and objects from their life to create a life story book, box or other product (this could be wall art, music playlists or even a film). By sharing this with others, the life story provides prompts to support communication and improve understanding.

Life story work has been increasingly valued as a means of facilitating person-centred dementia care within the NHS and other settings. However, no standard approach or robust research evidence existed to support its perceived benefits or to evaluate its costs.

In the first study of its kind, the [NIHR Health and Social Care Delivery Research \(HSDR\) Programme](#) awarded Kate Gridley and her team at the University of York £418,000 [to investigate what is currently known about life story work and the feasibility of assessing its effectiveness in a future trial](#). Their project included a survey of settings in which life story work was already being used with people with dementia, as well as a study of features considered to be good practice (published in the journal [Health Services and Delivery Research](#)).

“Through our research we aimed to provide care providers, service planners and policy makers with robust evidence of the costs and potential outcomes of life story work to help improve decision making about the use of this approach.”

Ms Kate Gridley, lead researcher for the Life Stories Work study

This pioneering study was one of 21 research projects to receive a share of £22 million funding from NIHR. This was part of a drive to improve dementia diagnosis and trial ground-breaking treatments, aiming to help the 700,000 people with dementia in the UK live well with the condition.

Person-centred care and research

Working alongside study partners including the University of Hull, Dementia UK, Innovations in Dementia and the Life Story Network, the research team at York began by collecting evidence on life story work in dementia care through a review of published literature (published in the [*Journal of Health Services Research & Policy*](#)).

This was followed by focus groups and interviews with people with dementia, family carers and professionals involved in life story work. In their report published in [*Social Research Practice*](#), the team outlined their experiences of involving people with dementia in their research, both as advisers to shape the project and as participants.

A family carer who became an advisor for the study commented on why she chose to take part, saying: “Life stories with photos and words can be shared together and act as a reminder and gives others insight into the person with dementia. This is why I became involved in the project and am pleased that family carers and people with dementia have been involved in the project from the very start.”

Focus groups and interviews provided key opportunities for professionals, staff, carers and people with dementia to share their experiences and opinions of life story work. Published in the journal [*Dementia*](#), analysis of their comments showed that family carers and professionals had different motives for engaging with life story work from people with dementia. They also found that the person with dementia should lead the work where possible, ideally before they move into permanent care, so they are comfortable with how the content is created and used.

Their research also showed that some people were not keen to engage in life story work at all. Alongside other feedback from family carers and people with dementia directly, this fed into the creation of nine key features of good practice for all those involved in life story work to consider (available from [the study's University of York website](#)).



low-cost intervention to improve quality of life

The team's next step was to explore the feasibility of introducing life story work more widely. They measured costs and possible outcomes in six care homes that were introducing life story work to their residents for the first time, and three hospital wards that already used it routinely. As a feasibility study it was not designed to provide conclusive evidence of effectiveness, but the results were promising.

Although practice varied between settings, and good practice was not always followed, the study recorded positive changes in care home staff attitudes towards dementia and some improvements in residents' quality of life. Full results were published in the journal [*Health Services and Delivery Research*](#).

“Life story work is a low-cost intervention which brings multiple opportunities to improve outcomes for people with dementia.”

Ms Kate Gridley

The cost of introducing life story work in care settings was found to be fairly low, with staff training being the greatest cost at between £950 and £1,600. The average cost per resident over a 16-week period was approximately £37. Overall, the outcomes suggested that life story work could help people with dementia and that a larger trial to evaluate the approach was possible.

With the help of a study participant with dementia and based on the study's findings, a short film was produced about good practice in life story work. It has been downloaded for staff training and education by a range of organisations including NHS trusts, memory assessment services, dementia nursing homes, care homes and care home providers, community activities services and universities. The film is freely available on [the study's University of York website](#).

Following involvement in the project or receipt of study outputs, community and health service organisations commented on their value, with the Quality and Research Lead for Older People at one mental health trust saying:

Participating in the study was positive and it has allowed us the opportunity to

think about the potential of life story work, particularly its use in supporting transitions between care environments/settings”.

Research around the theme of living well with dementia is an ongoing priority for NIHR. Ms Gridley’s study on life story work, including the team’s reflections and suggestions to improve research in care homes published in the journal [Social Research Practice \(.PDF\)](#), was highlighted as an example of good practice in NIHR’s [Advancing Care: Research with care homes themed review](#). Such investigations are particularly timely as care home research is relatively new and complex, and good examples support other researchers in the challenges they face.

The study’s promising outcomes also helped the team secure £49,000 funding from the Joseph Rowntree Foundation to explore the experiences of women who are affected by dementia. Published in their report (available from the [Joseph Rowntree Foundation website](#)), the team highlighted how person-centred services, such as life story work, and policies could be more supportive of women who are diagnosed with dementia, or who care for or work with people with dementia.

Learning from their feasibility study has fed into a vibrant literature on different ways of capturing outcome measures for people with dementia, and was cited in Keady and colleagues’ study investigating ‘in the moment’ outcomes (published in the journal [Ageing & Society](#)). It has also helped shape further research into the experiences of people with dementia [taking part in research](#).

Reflecting on their research, Ms Gridley said: “Our findings contribute to a body of literature about good practice in dementia care and add to our understanding of ways to meaningfully involve people with dementia in research.

Methodological learning from the study also prompts us to think differently about approaches to measuring outcomes with this group and appreciate the challenges of undertaking research in real world care settings”.



The study was funded by the NIHR [Health and Social Care Delivery Research Programme](#).

More information about the study is available on the [NIHR's Funding & Awards website](#).

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