

# Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care

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**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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## Scientific summary

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# Scientific summary

## Background

Dementia is a growing health problem internationally. With an imminent cure unlikely, providing good-quality and cost-effective care, over a long period of need, will remain a major challenge for health and other care providers. Improving the quality of care in general hospitals, living well with dementia in care homes, reducing the use of antipsychotic medication and improving health outcomes through improving care outcomes are priority policy objectives for dementia.

Listening to people with dementia and understanding their rich and varied histories is seen as essential to good care. 'Life story work' (LSW) is used increasingly for this, which involves gathering information and artefacts about the person, their history and interests, and producing a picture book or other tangible output: the 'life story'. LSW has been used in health and social care settings for nearly three decades. Since the 1990s, there has been growing interest in its potential to deliver person-centred care for people with dementia.

Despite LSW's increased use in the NHS and elsewhere, its outcomes for people with dementia, family carers and staff, its costs and its impact on care quality remain unevaluated.

## Objectives

The aim of the project was:

- to carry out the development and initial feasibility stages of evaluation of a complex intervention – LSW – for people with dementia.

The research questions were:

1. How might LSW improve outcomes for people with dementia, carers, staff and wider health and social care systems?
2. How cost-effective could this be?
3. Is formal evaluation of LSW feasible?

## Methods

We used a mixed-methods design in two stages to explore the feasibility of formal evaluation of LSW in health and social care settings.

### ***Stage 1a: a systematic review of the existing literature to produce a narrative synthesis of good practice and of theories of change***

Searches were designed to identify any type of study about LSW published in or after 1984. Algorithms guided the selection of publications for relevance and for review by three team members. One team member was responsible for data extraction and analysis but discussed progress with other team members and the project advisory groups throughout. Narrative synthesis and mind-mapping were the predominant approaches to analysis.

### **Stage 1b: qualitative focus groups and individual interviews with people with dementia**

These elucidated the outcomes people wished to see from LSW and the routes through which they felt those outcomes might be reached. A framework approach was used to analyse the material.

### **Stages 2a and b: two national surveys carried out via electronic survey software**

One survey was of a representative sample of health and social care settings, and the other was of family carers of people with dementia, drawn from a third-sector support organisation for carers. Both surveys drew on findings from stage 1 and discussion with our advisory groups. The national survey of health and social care settings was also used to estimate the spread of LSW.

Analysis was largely descriptive and bivariate.

### **Stage 2c: feasibility study**

We carried out two small feasibility studies to test data-gathering processes and instruments. One study used a stepped-wedge design to introduce LSW in six care homes and the other study used a pre-test post-test design in three NHS assessment units that already used LSW and one that did not. In both settings, we also aimed to examine the potential size of outcomes from and costs of using LSW to inform the design of a full evaluation.

Measures mapped onto outcomes identified in stage 1 (where these were available) covering:

- quality of life (QoL) for the person with dementia (assessed by the person him- or herself, where possible, and by a family carer or other proxy)
- the quality of relationships between people with dementia and family carers (assessed by the person with dementia him- or herself, where possible, and the carer)
- the experiences of family carers
- staff attitudes towards dementia care and staff burnout.

We tested different ways of identifying, collecting and measuring relevant resource inputs. We then valued these using local or national unit costs to establish the costs of LSW.

### **Public and patient involvement**

The project was informed throughout by the involvement of people with dementia, family carers and staff working in dementia care. This was done through an advisory group, supported by virtual advisory groups of people with dementia and family carers. These groups met throughout the project and advised on the contents of the survey, the findings of the review and the qualitative work, and the choice of outcome measures for the feasibility study. They also commented on the findings.

## **Results**

### **Stages 1a and b**

We identified 657 studies from our reviews, of which 55 were included in the review; 47 were used in the good practice review and 18 were used in the theories of change review.

Twenty-five people with dementia, 21 family carers and 27 professionals and care staff participated in a total of 10 focus groups or interviews.

Material from the review and from the qualitative work was used to produce good practice 'learning points' and to elucidate the routes through which LSW was felt to achieve given outcomes. The good

practice learning points are an outcome of the project in their own right but they also informed questionnaire development for the surveys in stage 2.

The qualitative work identified QoL, both for the person with dementia and for family members/carers, and relationships between them, as outcomes.

The review identified outcomes that might eventually *lead* to improved QoL. These included an increased sense of self-worth for the person with dementia, improved psychological well-being, reduction in behaviour that challenges and improved 'coping' for the family carer. Improvements in the care environment were also important in the review, reflecting the professional orientation of the publications included. There was sufficient commonality in the outcomes and the hypothesised routes between LSW and achievement of these to inform stage 2.

### **Stage 2: surveys**

Response rates varied across the health and social care settings, from 32% from generalist care homes to 70% in NHS specialist assessment units. Overall, we had a return of 58% (307 responses).

Life story work has spread relatively widely, particularly in hospital assessment settings, although to a lesser extent in care homes.

Services varied widely in the type of LSW they did, the overall objectives of LSW (including the involvement of the person with dementia), whether LSW was past or forward looking and how LSW was used. These differences probably reflect the different places in which services were located on the dementia care pathway.

The day-to-day use of the life story product was not as high as might be hoped. Doing LSW is one thing; using it to inform and improve care is clearly another.

The service survey emphasised the role of carers in LSW, and the carers' survey confirmed this. Carers reported heavy involvement, and, in some cases, had led the LSW. However, although they played an important part in services' LSW, carers were unlikely to be offered training to do it. Again, the reported *actual* use of the life story by care staff, and even by the person with dementia and carers, was lower than might be expected.

### **Stage 2: feasibility study process**

Recruitment and retention was challenging, being most difficult for people with dementia in the NHS assessment settings, and most difficult for staff in care homes. The recruitment and retention of family carers was somewhat more successful. Staff turnover, differing priorities and continuity of management in the care settings all influenced the success of recruitment of people with dementia, over and above any issues of their capacity to consent. Fifty-one staff, 39 people with dementia and 31 carers were recruited in care homes. Twelve people with dementia, 10 carers and varying numbers of staff participated in the NHS settings.

### **Stage 2: feasibility study outcomes**

Even after successful recruitment, gathering data was difficult. Completion rates for outcome measures were best overall for family carers in care homes (up to 61% at final follow-up) and worst for people with dementia in hospital wards (none at final follow-up). Completion of measures by staff in care homes was disappointing, given the commitment of the care home provider to the study.

However, there was useful learning for future research. We observed fatigue effects in the completion of outcome measures over time, the competing demands of the routines in care settings and the inability of conventional outcome measures to capture 'in-the-moment' benefits for people with dementia. The measures also missed how LSW was used, in particular for the de-escalation of behaviour that challenges in hospital settings.

We observed some changes in our outcome measures from baseline to follow-up and these were significant for staff attitudes towards dementia in care homes, for self-reported QoL (DEMQOL) between baseline and final follow-up for 12 people with dementia in care homes who were able to complete the measure, and for the experiences of carers.

The first change may be an effect of LSW, as we saw evidence of it in both measures of staff attitudes. Whether the change was due to the training associated with implementing LSW or to LSW itself is not clear.

The people with dementia able to complete DEMQOL might have been less cognitively impaired than others in the study, meaning that we cannot extrapolate this finding to everyone.

Carers' experience scores worsened in the care homes but improved in the hospital setting. We are not sure that LSW caused either effect. People with dementia in the care homes were often approaching the end of their lives; for carers of people in hospital it was often the case that the person with dementia had been admitted in a crisis, but, during his or her stay, was stabilised and assessed and had his or her future care planned (in some cases meaning admission to long-term care).

### **Stage 2: collecting resource-use data**

The collection of resource-use data in all settings was time-consuming and complicated. In all cases, data collection was better when assisted by the presence of a researcher.

### **Stage 2: resource use outcomes**

The cost of delivering the LSW training in care homes ranged from £950 to £1581 and the average cost of creating and using LSW products for a resident in the care homes was £37.42 spread over 16 weeks. If all costs were additional, resource implications would be relatively small at an individual resident level but could be substantial if extrapolated to all residents.

Life story work was a part of routine care in the hospital intervention wards, so there were no initial training costs. The average cost of creating and using LSW products was £68.21 per patient over 3 weeks. The more intensive activity may be attributable to staff attempting to complete life story products before patients are discharged, or to staff having dedicated time for this activity.

The most frequently used services in care homes were visits to the care home by the general practitioner (GP) and the district nurse. Care home staff accompanied residents to these consultations on at least 25% of occasions, which potentially adds to overall costs. Visits by the GP showed some reduction at follow-up compared with baseline, but visits by the district nurse did not.

The resources with the highest monetary values per use were an inpatient stay on a general medical ward, an accident and emergency attendance by ambulance, an outpatient appointment and a GP visit to a care home. Because of their relatively high cost, these events are more likely than other types of input to affect total costs. Over a larger number of residents in a full evaluation, differences in the costs of this type of activity might be substantial.

Care home use by participants of prescribed medication for anxiety and depression was low. Only two homes provided home-wide data on antipsychotic prescribing. In one, prescribing was low; in the other (the specialist dementia care home), 12 residents were prescribed antipsychotics, all but one on a continuous basis. Overall, however, for study participants in care homes, the use of antipsychotic or other drugs was not a big driver of costs. The small numbers of participants in the hospital settings make it impossible to judge from individual patient data how extensively antipsychotic drugs were used. Ward-level data suggest antipsychotic prescribing cost up to £1350 per ward over 6 months.

Although never intended to be robust enough to demonstrate change, this feasibility work does suggest a possible reduction in service use and adverse events and indicates the main drivers of costs.

### ***Stage 2: participants' experiences of life story work as part of the research project***

Carers in particular were unsure of the benefits of LSW, particularly for people in whom the dementia had progressed, which sometimes led to reluctance to get involved, feeling that LSW would have no effect. People with dementia in the study enjoyed looking at their life story books, and staff were more certain of a positive effect, particularly in facilitating interactions and encouraging staff to get to know the person.

Staff were positive about collecting life story information but had some scepticism about the need for a physical life story product, particularly as this was considered time-consuming to make. LSW was easier when one person or a small team took the lead; when this was the case, all staff members were encouraged to collect information, but only the core team or lead person had responsibility for making a product.

Although some aspects of LSW can be beneficial for people with dementia, it is unclear whether this is attributable to the presence of a physical life story product, or to the act of spending time with someone, learning about their life. Although the latter may occur without LSW, LSW can be a mechanism for this learning, and a physical life story product may facilitate interactions and enhance relationships with family members and staff.

## **Conclusions**

### ***Implications for health care***

Stage 1 of our work was based on in-depth qualitative research and a systematic review of the literature. This found consistent messages about good practice in doing LSW. The survey of health and social care services showed that not all services follow these practices. We have drawn together good practice learning points and will disseminate these widely to health and social care audiences.

Stage 2 was intentionally exploratory. Although we did observe effects in this stage of the work, particularly in relation to staff attitudes in care homes, it is clearly not right at this stage to draw out implications for health and social care providers.

### ***Recommendations for research***

Our work means that we now have a clear idea of the challenges and benefits of attempting to establish evaluation of this complex intervention in care settings that are themselves complex and often complicated. In order of priority, there is a need for:

1. Formal evaluation of LSW as a method of changing staff attitudes about dementia, and particularly in care homes. This should compare LSW against more general training input about dementia.
2. Qualitative research that explores the motivation and 'emotional intelligence' of care staff, recognising that delivering person-centred care for people with dementia requires particular qualities of both.
3. Methodological development in assessing QoL for people with dementia 'in the moment'.

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