

Life Story Work in Dementia Care

Emerging research findings

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Kate Gridley  | Social Policy
Research Unit

Joy Watkins and Val McKay

Dementia^{UK}
Improving quality of life

Nada Savitch and Chris Armitage

 Innovations
in Dementia



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The views and opinions expressed in the workshop are those of the research team and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

Definition

Life story work involves:

◆ Recording aspects of:

- past life
- present interests
- future plans and wishes



◆ Using this record to improve things/for pleasure

Different from reminiscence and life review
(some overlap)

Research questions

1. How might life story work 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 life story work feasible?

Methods

Stage 1:



You are here

Focus groups and literature review to understand:

- ◆ Outcomes/benefits
- ◆ Problems/challenges
- ◆ Key features of good practice

Stage 2:

National survey of carers and care providers

Stage 3:

Pilot study in care homes and hospital

Ten focus groups complete

People with dementia:

- ◆ 4 groups
- ◆ 25 participants

Family carers:

- ◆ 3 groups
- ◆ 21 participants

Professionals:

- ◆ 3 groups
- ◆ 27 participants



73 participants in total

Focus for today:

- a. Benefits
- b. Challenges



From the perspectives of people with dementia, family carers and staff

A large, 3D blue question mark is positioned on the left side of the image. To its right is a blue rectangular box with rounded corners, tilted at an angle. Inside the box, the text "What did people with dementia say?" is written in a white, italicized font. The background is a light blue gradient.

*What did people
with dementia
say?*

Benefits

- ◆ Good to remember (sometimes)



- ◆ Could help with communication and understanding (esp. with family)
- ◆ A creative/personal challenge

And helps put thoughts in order...

Why is it important to you
to write your story?

Kate

Person with
dementia
(F3R3)

Because I've never really
looked back at the whole of my
life at any stage, and taken
stock of what I've done and
what I aim to do...

BUT not everyone wants to make one:

Person with
dementia
(F2R5)

I don't
bother

Person with
dementia
(F4R2)

Sometimes you
want to forget

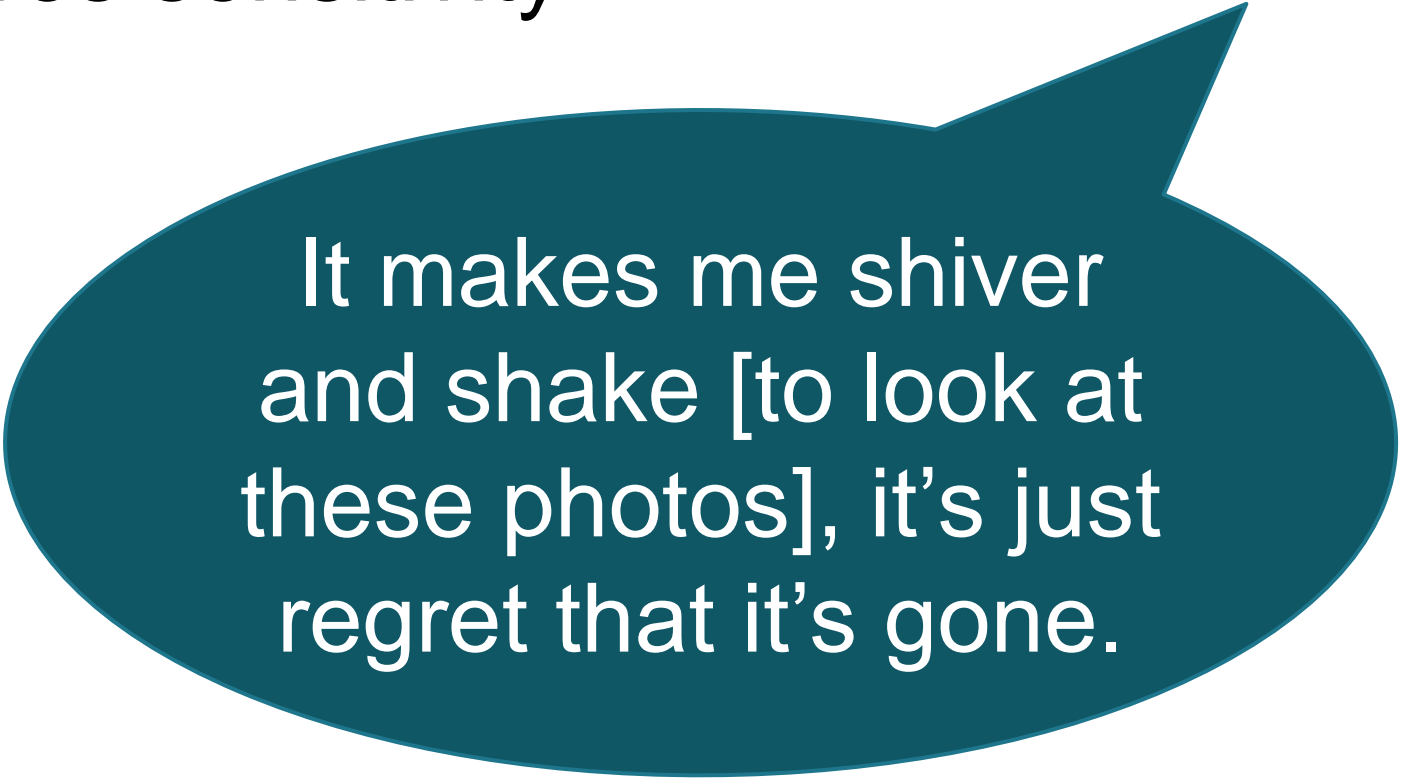
Person with
dementia
(F3R4)

I'm pretty boring!

Even for those who do:

Can be emotional:
requires sensitivity

Person with
dementia
(F1R3)



It makes me shiver
and shake [to look at
these photos], it's just
regret that it's gone.

Challenges

Privacy and control

Kate

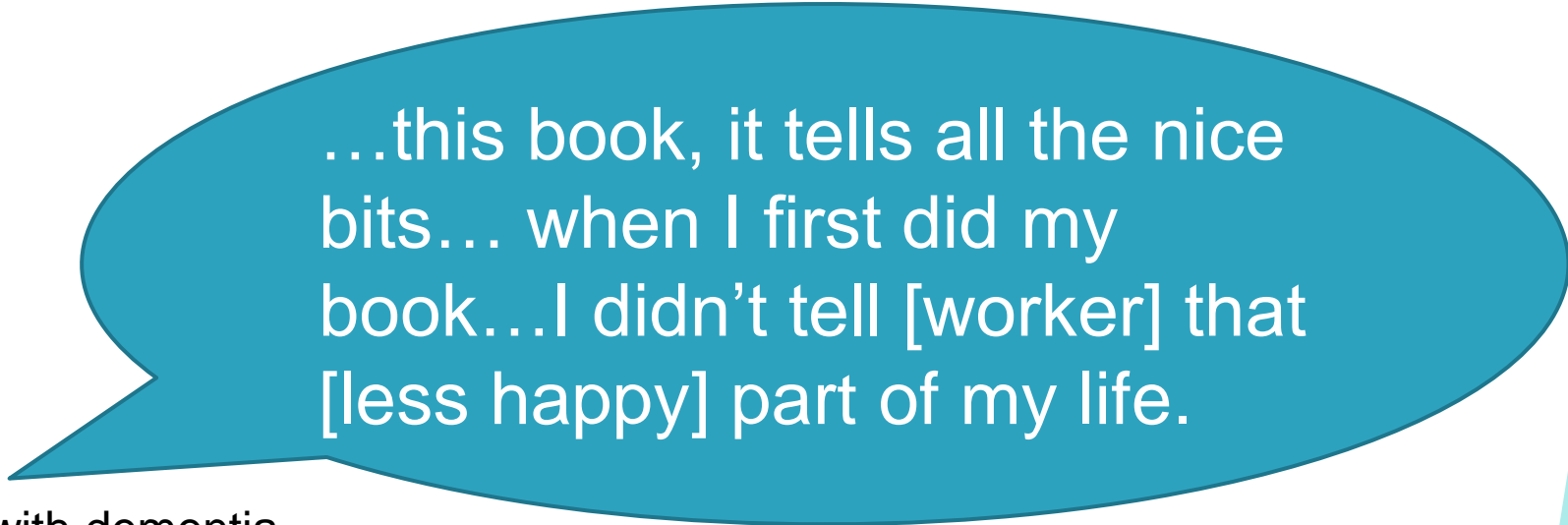
You don't want them reading about you when you're not there?

Well no, no, no. You might as well have it while you're just sitting here like we're doing now...

Person with dementia (F2R3)

Challenges

We make decisions all the time about what information to share with which people



...this book, it tells all the nice bits... when I first did my book...I didn't tell [worker] that [less happy] part of my life.

Person with dementia
(F3R6)

People with dementia don't want to lose that right to choose

Important to involve the person

Who and what is the life story being made for?

A person might choose to put different things in a document for:

- ◆ their own use/memory
- ◆ to show to family and friends
- ◆ to inform care staff

They might also want to discuss things about their lives but not have them recorded

SO – it's important that people with dementia are made aware of the possible uses of the life story and who will see it



*What did family
carers say?*

Benefit

Enjoyable shared activity:
a platform to connect



I couldn't talk to mum about what was happening today because it didn't really matter to her. And the one thing where we could sit down and be close and have a laugh and all the rest of it was actually going through [photo] albums...

F1R2 (daughter)

But it's not for everyone...

With [husband], a couple of times, people have tried to do life story work with him... but it wasn't very successful. ...he didn't want to go back. And very, very early on, he really didn't like looking at photographs, and particularly photographs of people who were dead.

F2R6 (wife)

Benefit

Learn about family history:
gain understanding



He...doesn't recognise the house and thinks that he wants to go home, you know, to his mum ... he brings these things up ...How do you validate that experience if you don't know him and any of the history?

F1R4 (son-in-law)

Challenges

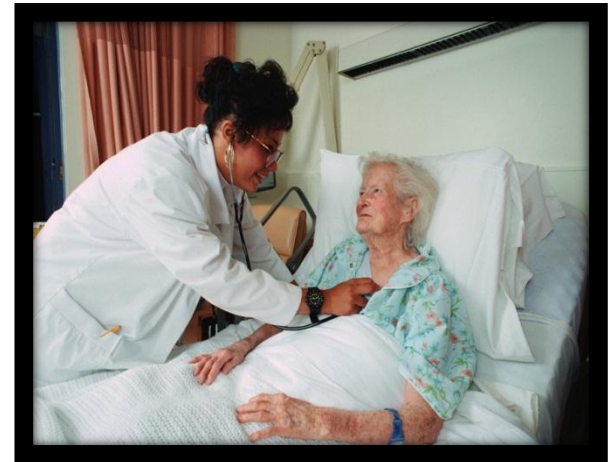
- ◆ Secrets can come out
- ◆ How to handle private/sensitive info:
 - ◆ Should it be recorded?
 - ◆ Who to share it with?
- ◆ Can be emotional
- ◆ Support should be available

Benefit

Can inform person-centred care

F2R7 (daughter)

I think it's very important for other people, third parties, to know enough background about the person themselves, because they can't express that anymore. And I think to be able to see them as a person and to respond to their individual needs, they need to know that stuff...



But – info must be used

- ◆ Staff don't have time to support people to make life stories
- ◆ Bad experiences – staff not reading or displaying life stories

**Life stories can only improve care if
staff use them**

And privacy respected

[If] it's something that's a very traumatic thing...which they've told you in confidence...you have to be very careful of how you pass that on...

F3R3

(daughter-in-law)

...once they go into a care home...it's in the lap of the gods...

F2R1
(son)

A 3D blue question mark is positioned to the left of a blue rounded rectangle. The rectangle contains the text 'What did staff say?' in white, italicized font. Both objects cast shadows on the light blue background.

*What did staff
say?*

Could be the key to person-centred care!

Life story work in itself is maybe the way to get to that person-centred care, because by ...helping people see the person as an individual, you can move forward to then working with them as an individual...

Day centre manager
(F1R3)

Benefits

- ◆ Makes person-centred care possible
- ◆ Helps staff understand behaviour
 - ◆ Presents options for management without recourse to medication
- ◆ Facilitates communication and improves relationships (with staff and loved ones)

The product:

- ◆ Valued by relatives, friends and people with dementia
- ◆ Can be enjoyable/calming to look at
- ◆ Can smooth transition between settings



Challenges

Colleagues concerned about:

- ◆ Upsetting people/handling negative emotions
- ◆ Revealing secrets

Organisational issues:

- ◆ Lack of time
- ◆ Systems not in place to record or use life story info
- ◆ Confidentiality
- ◆ Cherished items being lost/damaged



Two types of 'life story'?

...we're getting a diversion between writing the story as a matter of personal interest and writing a story in terms of things that would help other people to know us when we couldn't properly represent ourselves.

Person with
dementia
(F3R1)

Suggestion – make versions

Different versions for different purposes:

- ◆ Open ended 'living story' for the person to keep and share
- ◆ Short quick reference version to inform care

OR

Loose leaf ring-bound folder with colour coded pages/pull out sections for different uses?



Be flexible, and be led by the person with dementia – it's their life after all

Staff should make a life story too!

- ◆ People with dementia stressed the value of two way sharing
- ◆ Professionals agree that staff should share too
- ◆ E.g. of 3 days dedicated training where staff made their own life stories (supported by a specialist) then supported residents and all shared

*How can you expect them
to be proactive and interested
in other people's lives if
they're not feeling valued
themselves?*

Occupational therapist
(F1R8)

Record current activity, as well as past life

- ◆ Take pictures/keep mementos
- ◆ Involve the person and their families
- ◆ Could combine this with daily record keeping

...those photographs went in the life story book [made on the ward and passed on] to the residential home or the nursing home. So the care staff didn't just see Joe Bloggs who needs X, Y, and Z, but Joe Bloggs that actually can still do a bit of this and can still do a little bit of that...

Occupational Therapist (F2R3)

Summary

People with dementia:

- Generally positive
- More for personal use than informing care
- Strong views about what info is shared with who

Family carers:

- Can be great but doesn't work with everyone
- Onus is currently on family to ensure life stories are used respectfully to inform care

Staff:

- Life story work is key to achieving person-centred care
- Challenge is to convince colleagues and ensure it is prioritised (needs training, support and time)

More information

- ◆ For more information about research into life story work at the University of York **Social Policy Research Unit**, go to the project webpage <http://bit.ly/lsDem> or contact **Kate Gridley** on 01904 321988 kate.gridley@york.ac.uk
- ◆ To find out more about life story work in dementia care visit the **Life Story Network** <http://www.lifestorynetwork.org.uk/>

Questions/Comments?

Partners

- ◆ University of York  
- ◆ Innovations in Dementia  Innovations in Dementia
- ◆ Uniting Carers 
- ◆ Pennine Care NHS Foundation Trust 
- ◆ Anchor Trust 
- ◆ Hull University 
- ◆ Humber NHS Foundation Trust 
- ◆ Hull York Medical School 
- ◆ The Life Story Network 