

Life Story Work in Dementia Care

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Kate Gridley, SPRU, University of York, kate.gridley@york.ac.uk

Nada Savitch, Innovations in Dementia nada@innovationsindementia.org.uk

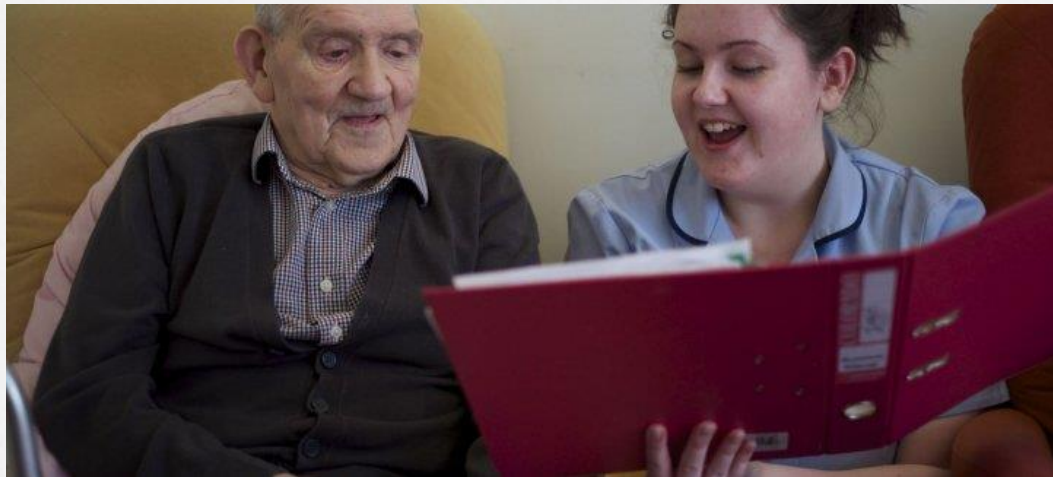
Are you here to hear about life story work?



Or life story work?



Or life story work?



We reviewed the literature:

- o Life story work means different things to different people
- o Not as simple as asking 'does it work'?
 - ❖ For who?
 - ❖ In which settings?
 - ❖ What are you actually doing when you say you're doing 'life story work'?
 - ❖ What do you actually want to achieve??

There is no consensus on good practice in the literature...



So, what next??



Ten focus groups

People with dementia:

- o 4 groups
- o 25 participants

Family carers:

- o 3 groups
- o 21 participants

Professionals:

- o 3 groups
- o 27 participants

*73 participants in
total*



Virtual Advisory Group

- o Equal voices
- o Involvement on their terms
- o Specific questions
- o Links with advisory group of professionals
- o Relaxed
- o Good communication
- o Appropriate documents

9 good practice messages

o Things that were agreed upon by all three types of participant:

- ❖ People with dementia
- ❖ Family carers
- ❖ Care staff and other professionals

Views about good practice

1. Not everyone wants to make a life story...

Woman with
dementia
(F2R5)

I don't bother

Woman with
dementia
(F4R2)

Sometimes you want to forget

Man with
dementia
(F3R4)

I'm pretty boring!

Is it the right approach for *this* person?

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.

Wife [F2R6]

2. The person whose life it is may have different views from you about what their life story is for...

Researcher

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)

How would *you* feel?

3. Beginning the process early will enable people with dementia to take a more active role

Researcher:

Is it important to be able to do it on your own?

Woman with dementia:
F3R7

Yes...because I like a challenge, but at the moment the challenges are getting harder and harder [laughs], needless to say.

4. Life story work can be emotional and may raise sensitive issues.

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

Woman with dementia
(F1R3)

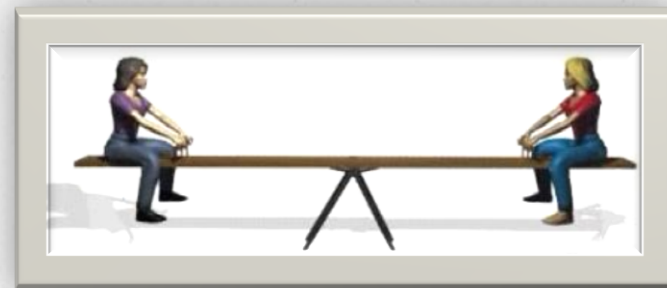
- ❖ It could provide the opportunity to have feelings acknowledged and validated
- ❖ Staff need training and to be supported

5. Staff should consider making and sharing their own life stories

- How does it feel?
- What would you share?
- What wouldn't you share?



- Shifting the power balance?



6. Process or product?

Hospital
occupational
therapist
[PF1R1]

Obviously, you're always trying to get to know somebody... [but] so much of that information is lost... the [health care assistants] for example, have very little opportunity to feed into things like ward rounds, but they're the people that know the patients the best

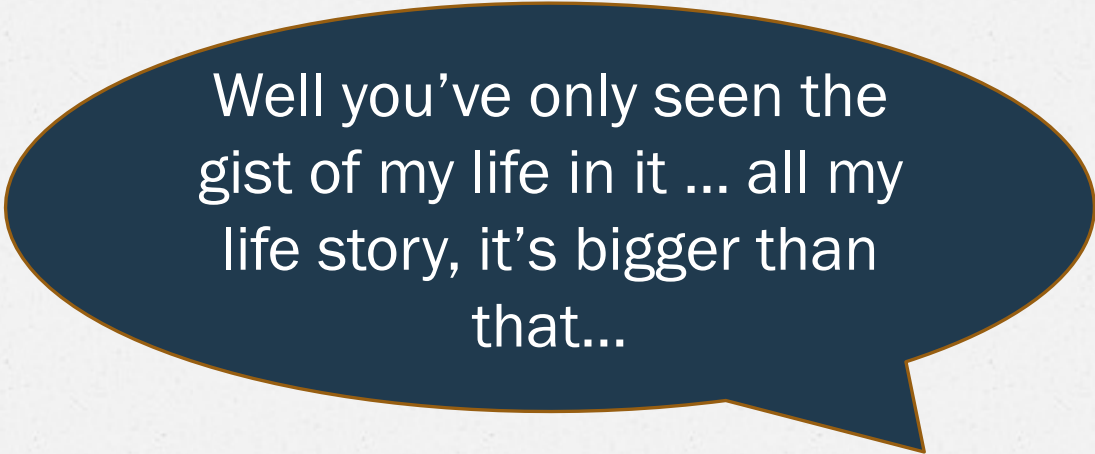
It's both!

7. Outcomes for better care will only come if care staff *use* the life story

... I put it in her bedroom, and I just, in my naivety, thought that they would share it... She was given dreadful antipsychotic drugs to keep her sedated ...and they ignored what I'd put together... They didn't use it at all.

Daughter [F3R7]

8. Short summaries might be useful for busy staff, but cannot replace a full life story



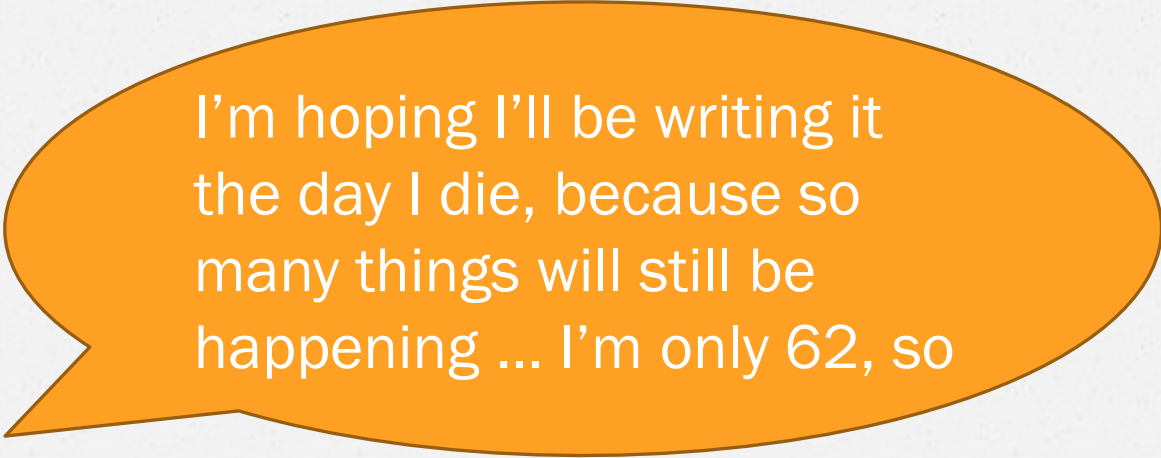
Well you've only seen the
gist of my life in it ... all my
life story, it's bigger than
that...

Man with
dementia
[IH2P04]

9. A person's life story is never finished

- o People don't want to be 'set in stone'
 - o What are they like *now*?
 - o What do they want to do *next*?

Man with
dementia
[F3R5]



I'm hoping I'll be writing it
the day I die, because so
many things will still be
happening ... I'm only 62, so

Questions?

For more information contact:

Kate Gridley, SPRU, University of York

kate.gridley@york.ac.uk

References

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