Life Story Work in Dementia Care

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Are you here to hear about life story work?
Or life story work?
Or life story work?
We reviewed the literature:

- Life story work means different things to different people

- 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:
- 4 groups
- 25 participants

Family carers:
- 3 groups
- 21 participants

Professionals:
- 3 groups
- 27 participants

73 participants in total
Virtual Advisory Group

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

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

Man with dementia (F3R4)

Sometimes you want to forget

Woman with dementia (F4R2)

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:**

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.

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

   Woman with dementia (F1R3)
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?

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 naïvety, 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**
   - People don’t want to be ‘set in stone’
     - What are they like *now*?
     - What do they want to do *next*?

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?

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References


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