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Life story work with people with dementia

Kate Gridley, Prof Gillian Parker, Nada Savitch, Joy Watkins, Victoria Metcalfe, Polly Kaiser, Professor Yvonne Birks, Jean Tottie, Dr Victoria Allgar, Dr Kate Baxter, Prof Esme Moniz-Cook

Evaluating life story work: development and initial feasibility study, July 2012 - Dec 2014

Life story work involves:
Recording aspects of:
- past life
- present interests
- future plans and wishes

Using this record to improve things for pleasure

Outcomes: why do people do life story work?
- For themselves - for memory, identity, as a personal project
- To share – to make/reaffirm connections and relationships, to support communication
- To improve care – to inform staff, to improve understanding, to challenge assumptions

Good practice learning:
Workers who help people with life story work should:
- Discuss how the person would like their life story to be used (including who will see it) – this might affect what they choose to put in
- Get to know the person well – and share their own life experiences
- Continue to support people with their life story work as life goes on

Outcomes:

- 10 focus groups held spring 2013 (73 participants):
  - Four focus groups with 25 people with dementia
  - Three focus groups with 21 family carers
  - Three focus groups with 27 professionals with experience of life story work

Good practice learning:

- Workers who help people with life story work should:
  - Discuss how the person would like their life story to be used (including who will see it) – this might affect what they choose to put in
  - Get to know the person well – and share their own life experiences
  - Continue to support people with their life story work as life goes on

Remember: not everyone likes to look back and not all memories are happy

Next steps for 2014:

- National survey of dementia services and family carers
- Feasibility study to test ways of measuring costs and outcomes in care homes and hospitals

Rationale

With current moves towards embedding life story work in dementia care, robust evaluation of the technique, its outcomes and costs, is urgently needed.

As a complex intervention, however, this must be preceded by a development and feasibility stage to improve our understanding of good practice and explore what outcomes might be achieved through life story work. We will then test the feasibility of different approaches to measuring these outcomes and the associated costs of doing life story work.

Contact details
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

Telephone: 01904 321988
Email: kate.gridley@york.ac.uk
Web: www.york.ac.uk/spru

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