



Life Stories in Dementia Care

Feasibility Research

Information leaflet for staff

This leaflet contains information for staff in [REDACTED] care homes who are being invited to take part in research about life story work. Please read it all before deciding whether to take part.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with [REDACTED] and is funded by the National Institute for Health Research.

Our invitation to you

[REDACTED] has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured.

Ten people with dementia in your care home will be randomly selected to take part in the research. We are inviting you to join the research as well, as we are interested in learning how life story work might affect the staff supporting people with dementia. You are free to say no or yes to this invitation.

If you have any questions after reading this leaflet, please contact Kate Gridley in the research team on 01904 3212988 kate.gridley@york.ac.uk or speak to your care home manager.

When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



What is the research about?

We want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them, including paid staff. There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this.

This study is a pilot study which will inform future evaluations of life story work. Kate and Jenni will try out a range of ways of assessing the impact of life story work in six [REDACTED] care homes, including the home you work in.

What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete three short questionnaires: one about personhood and dementia; one about your approaches

to working with people with dementia and one about whether you are experiencing 'burnout'. The information you provide will be kept confidential and will be stored in a safe place (see below) – no-one else at the care home will see it, and we will not share the findings with your manager. You will be asked to complete these questionnaires again 1 month, 2 months and 6 months after you first completed them.

Towards the end of the research we will also invite you to come to a focus group discussion about the research, and about your views on life story work. This will be an opportunity to feed back to the research team about your experiences of taking part in the project, and to tell us your views on life story work. The focus group session will be tape recorded but all tapes and transcripts will be kept secure and confidential. **If you do not want to take part in a focus group you can still take part in the research.**

How do I consent to take part?

If you would like to take part, please tick all the boxes on the consent form and sign it. There is a separate box on the consent form to indicate whether you would like to take part in a tape recorded focus. If you choose not to tick this box you can still take part in the rest of the research.

Do I have to take part?

No. It is entirely up to you whether you take part in this research. If you choose not to take part it will not affect your job or the work that you do in any way.

What if I change my mind about taking part?

You can withdraw from the research at any time without giving a reason. However, if you withdraw after the research has started, the information you have already given may still be used.

Will my taking part in this research be kept confidential?

Yes, we will keep the information you provide safe and secure and it will not be shared with anyone without your permission. We may refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you. The information you provide will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

What will happen to the results of the research?

The information from the research will be used to see if life story work has made a difference for the people involved, including staff. We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

Scientific and ethical review

This research has been scientifically reviewed as part of the National Institute for Health Research funding process and the methods and materials have been approved by the Social Care Research Ethics Committee for England (REC reference 13/IEC08/0046).

Further information and contact details

If you would like further information or have questions about this research please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD Tel: 01904 321988 Email: kate.gridley@york.ac.uk

If you would like to speak to someone at [REDACTED] about the organisation's involvement in this study, please contact: [REDACTED]
[REDACTED]