



Life Stories in Dementia Care Feasibility Study

Information leaflet for unpaid carers

This leaflet contains information for unpaid carers of people with dementia 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.

You have been contacted because the person you care for was randomly selected to take part in the study. We are inviting you to join the study as well as we are interested in whether their involvement in life story work makes a difference for you. Both you and they 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.

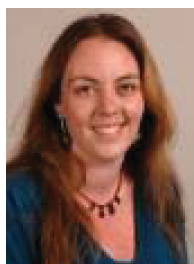
AND

- 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?

██████ want to give their residents with dementia the opportunity to make a life story. The workers in the care home have had some extra training in life story work and will soon be offering help to some of the residents with dementia to record their life stories.

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. 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 ██████ care homes, including the home the person you care for lives in. They

will use some questionnaires which measure things like quality of life and the relationships between people. They will also interview and observe some (but not all) of the people involved. Then they will write a report about what they have learnt for the National Institute for Health Research, who will use it to decide whether to do a full scale study of the effectiveness of life story work. They may also learn things about good practice that they can feed back to staff who work in and design services, as well as other people involved in the research, to help improve care.

What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete a short questionnaire about your quality of life and another one about your relationship with the person you care for. The information you provide will be kept confidential and will be stored in a safe place (see below). They will ask you to complete these questionnaires again 1 month, 2 months and 6 months after you first completed them.

Some of the people taking part in this study will also be invited to take part in an interview. This would be an informal conversation about your views on life story work and your experiences of taking part in the research. Interviews will be tape recorded and transcribed to ensure that the researchers do not forget anything that is said. No-one outside the research team (and no-one at ████████) will hear the interviews or see the notes we make of interviews. **If you do not want to take part in an interview you can still take part in the rest of the research.**

How do I consent to take part?

If you are interested in taking part, please contact Kate Gridley (see contact details below) or ask a member of staff to pass on your contact details to Kate or Jenni. They will contact you to answer any questions you have, and if you want to proceed they will ask you to sign a consent form. There is a separate box on the consent form to indicate whether you would like to take part in a tape recorded interview. If you choose not to tick this box you can still take part in the rest of the study.

Do I have to take part?

No. It is entirely up to you whether you take part in this study. The person you care for can still take part in the study even if you decide not to yourself. If you choose not to take part it will not affect the care of the person you care for in any way.

Support for you

If you require any support to take part in this study, such as help with transport to meet with the researchers at the care home, this can be arranged. Please keep all tickets and receipts to enable us to reimburse you. Similarly, if you need any help to

communicate such as an interpreter or help to fill in the questionnaires, please let us know.

What if I change my mind about taking part?

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

Will my taking part in this study 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 repeat or 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 without discussing this with you first. The information you provide, including your contact details, 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 study?

The information from the study will be used to see if life story work has made a difference for the people involved. 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.

Further information and contact details

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

Independent advice

If you would like to discuss this project with an organisation that supports carers to get involved in research please contact: **Joy Watkins** at Uniting Carers
Tel: 07967 685979 Email: watkinsjoya@yahoo.com