

## Improving Care for People with Dementia Taking part in research

### Information leaflet for unpaid carers

This leaflet contains information for unpaid carers of people with dementia who are being invited to take part in a research project. 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 [comparison site], and is funded by the National Institute for Health Research.

If you have any questions after reading this leaflet, please contact Kate Gridley in the research team ([kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) Tel: 01904 3212988) or speak to your ward manager.

### Our invitation to you

[Comparison site] has teamed up with the University of York to do some research about life story work. You have been contacted because the person you care for was selected to take part in the study. We are inviting you to join the study as well as. Both you and they are free to say no or yes to this invitation.

### 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 life stories research about?

In some hospitals, support to make a life story is a routine part of care. At present, [Comparison site] do not offer life story work to any patients. [Comparison site] would like to learn more about the well-being of patients who do not get support to make a life story, and about the well-being and satisfaction of the 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. Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

This study is a small preliminary study which we will use to design a bigger study. Kate and Jenni will try out a range of ways of assessing the difference between outcomes for people on wards that do and do not do life story work. The person you care for is **on a ward that does not do life story work**. If you take part in this research you would therefore be in the comparison group.

### 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.

## 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. They will also ask you about your satisfaction with the care provided at the hospital. The information you give 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.

### **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.

### **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 hospital, 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?**

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?**

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 journals. 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](mailto: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: 0207 874 7209 Email: [joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org)