



# Life Stories in Dementia Care

## Taking part in research



# **We are doing some research about life story work – Can You Help?**

## **Would you like to take part in some research?**

You are invited to take part in some research about life story work

## **What is life story work?**

Life story work involves recording aspects of a person's:

- past life
- present interests
- future wishes, hopes and dreams.



This could be in a book, box or in any other way that the person prefers – for example, on a computer.

The life story is owned by the person who made it and is a living document that can be added to as life goes on.

## **Research into life story work**

We want to find out how life story work affects people's lives. Does it make things better or worse? Or do they stay the same?

Please read this leaflet if you are interested in taking part.

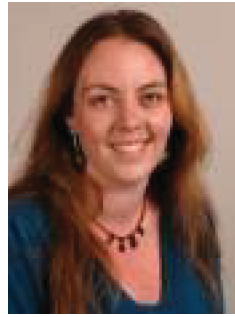
## Who we are

The research is being carried out by two researchers from the University of York Social Policy Research Unit:



Kate Gridley

and



Jenni Brooks

## What is the research about?

██████ want to give their residents the opportunity to make a life story. The workers in your care home will soon be offering help to some people to record their life stories.



Kate and Jenni are doing some research to see whether making a life story makes a difference to people's lives. They would like to gather some information from people who make life stories and the people who support them.

## Why have I been given this leaflet?

You have been randomly selected to take part in this study.

## What will happen if I take part?

**SOME QUESTIONS:** Kate or Jenni will visit you before you start making your life story and three times after to ask you some questions. The questionnaires they will use are about how you feel ('quality of life') and your relationships with others. They will keep all your answers confidential.



### AN INTERVIEW

Kate and Jenni will interview some of the people who take part in this research. The interviews will be informal conversations about making a life story. These will be tape recorded and written up. If you do not want to take part in a tape recorded interview that is fine, you can still take part in the rest of the research.

## What other information will they collect?

Jenni and Kate would also like to collect information about what medication you are on, how often you use different services and whether you had any falls or other problems before and after making the life story. If you agree to take part in the research they will collect this information from your care records (they may use your NHS number for this).

## Deciding whether to take part

You do not have to take part in this research. It is entirely up to you. Please discuss any questions or concerns you have with Kate or Jenni. You can also talk to someone else about it – like a family member or friend.

## What if I do not want to take part?

That's fine - nothing will change.

## Support to take part

If you would like someone, like a friend, care worker or family member to be with you when we visit you, that's fine – please discuss this with a member of staff.



If you need help to hear or speak, or any other support to take part, please let us know.

## Agreeing to take part

If you would like to take part, we will ask you to sign a consent form. Someone else can sign this form for you if you prefer.

## Changing your mind about taking part

You can change your mind about taking part in the study at any time. You do not have to give a reason.

If you change your mind halfway through, we will still keep a record of the things we've learnt up to that point, but we will not ask you anything else.

## Confidentiality

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you say in a safe place for 5 years.



The only time we might have to speak to someone else is if you tell us that you or someone else is being hurt, but we would always try to speak to you about this first.

## How will the research be used?



We want to find out if life story work could make things better for people with dementia. The findings of this small study will be used to help plan a larger study about this. We will write a report for the National Institute of Health Research and talk about the research

at conferences and in articles, but we will not use your name.

When the research is finished we will come back to the care home to talk to you about what we have learnt.

**This study is being conducted by the Social Policy Research Unit (University of York) and [REDACTED].** It was funded by the National Institute for Health Research and has been approved by the Social Care Research Ethics Committee for England

## Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

**Nada Savitch** at Innovations in Dementia

Telephone: 07549 921901

Email: [nada@myid.org.uk](mailto:nada@myid.org.uk)

## Further information

If you would like more information about this research please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321988

Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

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



## Complaints

If you are concerned or would like to complain about this study, please contact: **Gillian Parker**, Director, Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321957

Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)