

THE UNIVERSITY *of York*

Life Stories in Dementia Care

Taking part in research



Innovations
in Dementia



Social Policy
Research Unit

We Are Doing Some Research About Life Story Work - Can You Help?

Our invitation to you

We would like to invite you to take part in a focus group discussion about life story work with other people with dementia. This is part of a larger research project that will run from July 2012 – December 2014.

This leaflet

This leaflet contains information about the research. Please read it all before agreeing to take part.

The research

The research is being conducted by the Social Policy Research Unit, in partnership with Innovations in Dementia, and is funded by the National Institute for Health Research.

More information

If you have any questions please contact Nada Savitch at Innovations in Dementia on 07549 921901 or email nada@myid.org.uk

What is Life Story work?

Life story work involves recording aspects of people'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 wants – for example, with music.

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



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.

We also want to learn when, how and with whom it is best to do life story work.

Getting Involved

We want to hear what you and other people in your group think about life story work



A group discussion will take place on:

Date _____

Time _____

Venue _____

Please bring:

An object or picture that you would be happy to discuss with the group or your life story book/record, if you have one.

Please note - you do not have to take part: It is entirely up to you whether you take part in this study. Please discuss with Nada any questions or concerns you have. If you agree to take part, we will then ask you to sign a consent form.

Tape recording: We will tape record the discussion so that we can remember exactly what everybody said. The recording will be kept safe and confidential. **If you do not want to be tape recorded you will not be able to take part.**

Changing your mind about taking part

You can change your mind about taking part at any time before or during the discussion. You do not have to give a reason.

If you change your mind once the discussion has started we will still keep a record of the things you said up till that point.

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 said in a safe place.



If you tell us that you or someone else is being hurt, we might have to tell someone, but we would try to talk to you first.

Support to take part

If you would like someone, like a friend, support worker or family member, to be with you during the discussion, that's fine – please discuss this with Nada or the person who runs your group. If you need help to hear or speak, or any other support to take part, please let us know.

If you need help to travel to the discussion or home again we could help with this, please let us know.

Expenses

We will reimburse your expenses for coming to the discussion. Please keep your travel tickets and receipts.



Thank you

If you take part in the focus group, we will give you a gift of £20 to say thank you.



Deciding whether to take part

Remember, you do not have to take part in the focus group.

When deciding whether or not to take part, it might help to talk to someone at home, or a friend,


Alternatively, you could speak to a member of staff at your group or someone else you trust.

If you do not want to take part

You can still come to your group as usual - there will be other things for you to do

After the focus group

The tape recording of the discussion will be typed up and analysed by researchers. Once this is done, Nada and a researcher will come back to the group to discuss what they have learnt and ask you what you think.



The project is due to be completed in January 2015, after which we will send a short summary of all the research findings to your group.

This study is being conducted by the Social Policy Research Unit (University of York) and Innovations in Dementia. It has been approved by the Social Care Research Ethics Committee for England

Further information

If you would like further information about the focus group, please contact **Nada Savitch**: 07549 921901 nada@myid.org.uk PO Box 616, Exeter EX1 9JB

If you would like to speak to the researcher on this project, please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York, YO10 5DD 01904 321988 kate.gridley@york.ac.uk

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
Tel: 01904 321957 or email spru-director@york.ac.uk