

Life Stories in Dementia Care

Focus Groups

Information Sheet - Family Carers

This sheet contains information for family carers of people with dementia considering taking part in a focus group about life story work in dementia care. Please read it all before consenting to take part in a focus group.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with Uniting Carers (part of Dementia UK), and is funded by the National Institute for Health Research.

Our invitation to you

You have been contacted because you have experience of life story work and we would like to invite you to take part in a focus group discussion about this.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part in a focus group would involve. If you have any questions after reading this information sheet please contact Joy Watkins at Uniting Carers (joy.watkins@dementiauk.org 0207 874 7209) who will be happy to discuss the project with you. If you do decide to take part in a focus group, there will be further opportunity to ask questions on the day.

What do we mean by 'life story work'?

Life story work involves:

1. Recording aspects of people's:
 - past life
 - present interests
 - future wishes, hopes and dreams

This could be in a book, box, collage, or in any other way that the person wants.

2. Using the life story to improve things (care, relationships, etc.) for the person with dementia and others.

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.

There have been no large-scale, rigorous studies of life story work in dementia care so little is known about its effectiveness. It is not even clear, at this stage, what outcomes could or should be measured to assess its effectiveness.

The first step towards formal evaluation of life story work is to learn more about its potential outcomes and what the core elements of good practice are. We plan to do this by running focus groups with people with dementia, family carers and professionals with experience of life story work as well as bringing together all the research evidence already available on the subject and reviewing it in a systematic way.

Purpose of the focus groups

The purpose of the focus groups will be to hear what outcomes you have experienced or would expect from life story work, for whom, under what circumstances, and the reasons for this. We also want to hear what you think are core elements of good practice in life story work, what challenges it might present and how these can be overcome.

What would taking part involve?

If you would like to take part, please reply by email to Joy Watkins at joy.watkins@dementiauk.org . If you would like more information or have any questions please ring Joy Watkins on 0207 874 7209. Joy will give you further details of the focus groups, including dates and venues. Three focus group sessions for family carers have been planned in total, and where possible you will be given a choice of which one to attend.

Each focus group session will have no more than ten participants and will last about two hours, with fifteen minutes at the start and finish for questions. The discussion will be facilitated by Kate Gridley, a researcher at the Social Policy Research Unit,

with support from Joy Watkins, and will cover an agreed list of topics. Please let Joy know if you would like to see a list of the topics in advance.

Focus group discussions will be audio-taped (with your consent) and transcribed so that we have a full record of everything said. All recordings and transcripts will be kept on a secure drive and/or in a locked cabinet, and will only be seen/ listened to by the project team and transcribers.

We would like to give you a gift of £20 to say thank you for taking part in the focus group.

Support to take part

We will cover your travel expenses to enable you to take part in the focus group. If you need to arrange for someone to support the person you care for in order for you to attend the focus group, please discuss this with Joy. Similarly, if you require any other support to attend a focus group, such as help with transport, this can be arranged. Please keep all tickets and receipts to enable us to reimburse you.

Do I have to take part?

No. It is entirely up to you whether you take part in a focus group. We will talk through the study with you and discuss any concerns you have in advance. If you agree to take part, we will then ask you to sign a consent form.

What if I change my mind about taking part?

You can withdraw from the study at any time before or during the focus group discussion without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained so as not to undermine the contributions of others.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study 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.

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 before passing on any information.

What will happen to the results of the study?

After the focus group we will send you a summary of key points from the discussion. At this point you still have the opportunity to clarify specific issues by ringing us or sending an email. The data from all the focus groups will then be analysed thematically and considered together with the findings from the literature review to produce an account of what works, for whom, and in what circumstances, from the perspectives of people with dementia, carers and professionals. The next stage of the research will be a national survey of family carers and care providers, followed by a pilot study of costs and outcomes in care home and hospital settings.

The project is due to end in January 2015, after which time we will send you a short summary of all findings. If your contact details change in the meantime and you would still like a copy of the findings please do let us know so that we can update our records.

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the focus group methods have been approved by the Social Care Research Ethics Committee for England.

Further information and contact details

If you would like to take part in a focus group, or would like further information about the carer focus groups, please contact:

Joy Watkins

Tel: 0207 874 7209

Email joy.watkins@dementiauk.org

If you would like to speak to a researcher at the Social Policy Research Unit about any aspect of the study, please contact:

Kate Gridley

Tel: 01904 321988

Email: kate.gridley@york.ac.uk

If you are concerned or would like to complain about any aspect of this study, please contact the director of the Social Policy Research Unit:

Professor Gillian Parker

Tel: 01904 321951

Email: spru-director@york.ac.uk