

## Survey of Support for Carers

This leaflet contains important information for family carers of people with dementia considering taking part in the University of York survey about support for carers. Please read it before completing the questionnaire.

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

If you have any questions after reading this information sheet please contact Kate Gridley at the Social Policy Research Unit who will be happy to discuss the project further. Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) Telephone: 01904 321988

### Am I eligible to take part?

For this study, we would like to hear from people who are currently caring for someone with dementia **who is living at home** (so not in a residential care or a nursing home). They could live with you or separately in their own home.

### Purpose of the survey

We are interested in hearing about any support you receive, or have received in the past, to help you in your caring role. We are also interested in hearing from you if you have not had any support. This is part of a larger study looking at the outcomes of different types of support for carers of people with dementia. For more information visit the project web page at <https://www.york.ac.uk/spru/projects/admiral-nursing/>

### Do I have to take part?

No. It is entirely up to you whether you take part in this survey. If you do not want to take part, please ignore this email and the follow-up email that you will receive.

## What would taking part involve?

If you would like to take part in the survey, please click on the link in the email which will take you to an online survey.

If you would prefer to complete the survey on paper, please contact Kate Gridley at the Social Policy Research Unit on 01904 321988 or by email [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) and she will send you a paper copy with a pre-paid return envelope.

The survey should take no more than 30 minutes to complete, and may be shorter depending on the answers you give. You do not have to complete the survey all in one go as your computer will save your answers and when you click on the link again you will be taken to the page you were last on.

The questions you will be asked in the survey cover:

- Some background information about you and the person you care for
- *Your* quality of life as a carer
- *Your* health
- How confident you feel in your ability to handle various aspects of caring
- The type of support you provide to the person you care for
- How much time you spend on caring tasks
- What services you and the person you care for have used.

We will offer you a £10 gift to say thank you for completing the questionnaire, but this can only be posted out to you if you choose to give a postal address at the end of the questionnaire. If we send you this gift we will ask you to complete and return a receipt so that we know that you have received it.

**The deadline for completing the survey is 10<sup>th</sup> April 2017.**

## What if there are questions I don't want to answer?

The survey logs your answers as you go along, but if there are any questions you do not want to answer you can just leave them blank. The survey also allows you to go back and change answers before you press the 'submit' button.

## Will my taking part in this study be kept confidential?

You do not have to give your name and we will not tell anyone you have taken part in this study. We may repeat or refer to the answers you give in reports, articles or presentations, but you will not be named and no details will be given that could identify you. In keeping with University of York policy, we will keep the information you provide for five years.



National Institute for  
Health Research

*The Evaluating support for carers of people with dementia project is funded by the National Institute for Health Research HS&DR*

This will be kept safe and confidential on a password-protected computer drive and/or in a locked cabinet, and will only be seen by the research team.

### **What will happen to the results of the study?**

The information from all the completed questionnaires will help us to understand more about the support available to people caring for someone with dementia. We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. This should be available by the end of 2017. We will send a summary of the report to NHS and government decision-makers in England and circulate an online version to organisations working with family carers. No names will be used in the report.

### **Scientific and ethical review**

This study has been reviewed and funded by the National Institute for Health Research and received ethical approval from the Health Research Authority (Chelsea Research Ethics Committee).

### **Further information and contact details**

If you would like further information about the survey or would like to discuss any aspect of this research 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)

If you are concerned or would like to complain about any aspect of this study, please contact the Co-director of the Social Policy Research Unit: **Yvonne Birks**, Social Policy Research Unit, University of York, Heslington, York, YO10 5DD Tel: 01904 321951 Email: [yvonne.birks@york.ac.uk](mailto:yvonne.birks@york.ac.uk)

### **Need to talk?**

If you have any concerns about the issues raised in the survey and would like further support please contact **Louise Langham** at TIDE (Together in Dementia Every Day, part of the Life Story Network) on **07960 503 783** or email [Louise@tide.uk.net](mailto:Louise@tide.uk.net)  
Alternatively, you could access specialist advice by calling the following helplines:

- **Admiral Nursing (Dementia UK) Helpline 0800 888 6678**
- **Carers Direct Helpline (NHS) 0300 123 1053**

**Thank you for taking the time to read this information sheet**