

Survey Participant Information Sheet: Crossing the Line

Study title: Crossing the Line: Providing personal care in the context of families affected by dementia.

The University of Worcester engages in a wide range of research which seeks to provide greater understanding of the world around us, to contribute to improved human health and to wellbeing and to provide answers to social, economic and environmental problems.

This study is being led by Dr Shirley Evans and Professor Tracey Williamson. Dr Evans is a researcher based in the School for Allied Health and Community at the University of Worcester, and Professor Tracey Williamson is Professor and Consultant Nurse for dementia at Betsi Cadwaladr University Health Board.

We would like to invite you to take part in our research project. The following information explains what the research study is about and what it would mean for you if you decide to be involved. Please take time to read it and discuss the information with other people before you decide about taking part.

What is the purpose of the study?

This study will look at the experiences of family carers who provide personal care to a family member who is living with dementia. Personal care includes such things as helping them with going to the toilet, dealing with any continence problems, washing, having a shower or bath, getting dressed and undressed, cleaning their teeth, shaving, washing and brushing their hair, keeping their feet clean and looking after their fingernails and toenails.

Many family carers of people with dementia have said that personal care is one of the most important parts of their caring role. Providing personal care is not easy, and it can be even more difficult when the person you are looking after has dementia. With so many more people being diagnosed with dementia and being cared for at home, it is important that we learn more about how family carers are affected by their experiences of providing care and what training and guidance would help to support them.

Why am I being asked to take part?

We are asking you to take part in the study as you have direct experience of caring for a family member. We want to ask you as a family carer about your own experiences of providing care, what the main challenges are for you and how you deal with them, and what could help you to feel more supported.

We are looking for a wide range of participants who:

Are an existing or previous family carer of a person who has dementia.

Have direct experience of personal/intimate care and bathing with a cared for person who has dementia.

Are adult carers.

We cannot include carers who:

Have no experience of the topic under investigation in the last ten years.

Are less than 18 years old.

Do I have to take part?

No, you do not have to take part in the study if you do not want to. If you do decide to get involved, you can change your mind at any time and without giving a reason. However once you have submitted your survey responses, we would be unable to identify you as the survey is anonymous, so we will still include your responses in our analysis.

If you decide after reading this information sheet that you would like to take part, you will be asked at the start of the survey to agree to a number of statements to indicate that you are 18 years old or over, have read and understood this information and agree to take part in the survey. By completing and submitting the survey, you are providing consent for the data you have given to be used in the study.

What will happen if I wish to take part?

If you get involved in the study you will be asked to complete a survey about your experiences as a family carer. This should take about 20-25 minutes. You can also complete the survey in a telephone call or online meeting on Zoom or Teams with a member of the research team. To arrange a phone call or online meeting, please use the contact information at the end of this Information Sheet. The survey is also available in Welsh. Please use the contact information at the end of this Information Sheet to request a Welsh version.

You may also want to be considered for an interview as part of the study. You can do an interview as well as or instead of this survey. You can request an Interview Information Pack using the contact information at the end of this Information Sheet.

Will my involvement be kept confidential?

The information you provide in your survey responses will be kept completely confidential. You will not need to include your name so all surveys will therefore be anonymous. When we write up our findings, we may use quotes from survey responses, but these will not identify you.

What are the possible disadvantages to taking part?

There are no obvious disadvantages to you taking part in the research. However, discussing your experiences may be upsetting, and we have provided useful contacts for support should you need it at the bottom of this information sheet.

What are the possible benefits of taking part?

By taking part in this study you will be providing valuable information that we can learn from, to help us develop resources that give guidance and advice for family carers. We know that each family's situation is different, so information about your own experiences will help us to develop resources that can support carers in a wide range of situations.

What will happen to the results of the study?

The results will give us the information to develop resources that provide training and guidance on personal care for family carers. The results of the study will be written up in a final report and shared with the National Institute for Health Research, School for Social Care Research, who are funding the study. The results will also be used to write articles, reports and include in presentations and training of family carers and health and social care staff and students. We will widely publicise our survey findings once the study is

complete including on our project web page.

What will you do with my data?

The data you submit will be treated confidentially at all times. No personal identifiable data will be obtained during or as part of the study. Your answers will be completely anonymous.

During the project, all data will be kept securely on password protected computers and servers in line with the University's policy on Effective Management of Research Data and its Information Security Policy. The data will be accessible to members of the project team.

At the completion of this project, we will retain your data in the anonymised form that it was collected for a maximum of 3 months. The anonymised data will be archived and shared in line with our policy for the Effective Management of Research Data.

Who has reviewed the study?

The study has been reviewed and approved by the Research Ethics Panel for the College of Health, Life and Environmental Sciences in line with the University's Research Ethics Policy. The National Institute for Health Research has also reviewed the study prior to award funding to undertake it.

To request a **Welsh version** of the survey, to arrange a **phone call** or **online meeting**, or if you have any **questions** or would like **more information**, please contact:

Pauline Finlay, Research Associate
Association for Dementia Studies
University of Worcester
Henwick Grove, Worcester, WR2 6AJ
Email: p.finlay@worc.ac.uk Telephone: 01905 542309

Please also use these contact details if you would like to be sent an **Interview Information Pack**.

If you would like to speak to an independent person who is not a member of the research team, please contact:

Michelle Jellis, Secretary to Health, Life & Environmental Sciences Research Ethics Panel
University of Worcester
Henwick Grove, Worcester, WR2 6AJ
Email: ethics@worc.ac.uk Telephone: 01905 542767

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

Useful contacts for support

Samaritans

Telephone 116123 (24 hours a day, 365 days a year)

Email: jo@samaritans.org

Freepost: SAMARITANS LETTERS

Help pages: <https://www.samaritans.org/how-we-can-help/contact-samaritan>

Carers UK

Telephone 0808 808 7777 (Monday to Friday, 9am – 6pm)

Help pages: <https://www.carersuk.org/help-and-advice>

Email: advice@carersuk.org

Dementia UK/ Admiral Nurse Dementia Helpline

Telephone 0800 888 678

Email: helpline@dementiauk.org

Helpline Enquiry Form: <https://www.dementiauk.org/get-support/helpline-form/>

Dementia Carers Count

Telephone 0800 652 1102. Mon-Fri 9am to 5pm

info@dementiacarers.uk.org

Online resources for carers: <https://dementiacarers.org.uk/vcc/>