

Participant Information Sheet

Study title: What are the experiences of informal carers of people living with dementia during an acute hospital stay?

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage:

<http://www.lancaster.ac.uk/research/data-protection>

My name is Kerri Rance, and I am conducting this research as a student for a PhD in Dementia Studies programme at Lancaster University, Lancaster, United Kingdom.

Please take time to read the information and discuss it with others if you wish. Please contact me if you find anything is not clear or you would like more information.

What is the study about?

The purpose of this study is to explore the experiences of informal family or friend carers for people living with dementia during an acute hospital stay. I am interested to find out about:

- The positives and challenges of the time the person you cared for was in hospital
- How you found visiting the hospital and the time you were there
- How you found the layout of the hospital ward helped or hindered you and your family member or friend
- The extent to which you felt your family member or friend was treated as an individual by the healthcare teams caring for them
- To what extent your advice was listened to

Why have I been approached?

I would like to recruit family or friend informal (unpaid) carers for people living with dementia who have had an acute hospital stay of more than 24 hours in the last two years. You will need to be over 18 years of age and the person you care for will be living within their own home and not currently in hospital.

Do I have to take part?

No. It's completely up to you to decide whether you take part in the study. If you decide to take part, you are welcome to withdraw at any point during the interview or ask for your data to be removed up to 14 days after you have completed the interview. If you decide you do not wish to participate in the study this will have no negative impact on you.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to complete a consent form and to undertake an interview with the researcher to discuss your experiences when your family

member or friend who you care for was admitted to the hospital. It is anticipated that the interview will take up to one hour. The interview can be undertaken online (via Microsoft Teams) or by telephone, or if you prefer a face-to-face interview at a place of your choice within Oxfordshire. To allow for the analysis of the data, the interview will be recorded with your permission.

Will my data be Identifiable?

The data collected for this study will be stored securely using University approved secure cloud storage, and only the researchers conducting this study, and the PhD supervisors will have access to this data.

- Audio/video recordings will be deleted once the project has been submitted for publication/examined.
- The files on the computer will be encrypted (that is no-one other than the researchers will be able to access them) and the computer itself password protected. Data will be securely kept for 10 years.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. The researchers will use a pseudonym; you are free to choose your own pseudonym for use. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisors about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The anonymised results will be summarised and reported in a dissertation/thesis and may be submitted for publication in an academic or professional journal and presented at conferences. The results will be shared with qualified and unqualified healthcare professionals to develop learning and enhance the care provided to people living with dementia and their informal carers. A summary of the results will be shared with participants who are interested in receiving this. The results may also be presented in Dementia groups from which people may have been recruited.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, by sharing these findings with healthcare professionals the hope is to enhance the experiences of informal carers of people living with dementia when their family member or friend is admitted to hospital.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Kerri Rance – PhD researcher k.rance@lancaster.ac.uk Telephone: 01865 534143

PhD supervisors:

Dr Caroline Swarbrick – c.swarbrick2@lancaster.ac.uk

Dr Andrew Harding – a.harding5@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact the Director of Research:

Professor Jane Simpson
J.simpson2@lancaster.ac.uk
Division of Health Research
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT

If you wish to speak to someone outside of the Dementia Doctorate Programme, you may also contact:

Professor Stephen Jones
Chair of FHM REC Email: s.jones@lancaster.ac.uk
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YG

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

Resources in the event of distress

Should you feel distressed either as a result of taking part or in the future, the following resources may be of assistance.

If you need information, advice and support with any aspect of dementia contact **Dementia Oxfordshire Service support line** 01865 410210. Lines are open Monday to Friday 9am to 5pm. Or **Admiral Nurse Dementia Helpline** 0800 888 6678. Lines are open Monday to Friday 9am to 9pm, Saturdays, Sundays or bank holidays (except Christmas Day) 9am to 5pm. Or you can contact for support via email: helpline@dementiauk.org

Northamptonshire Carers support 01933 677907 lines are open Monday to Friday 9am to 4pm

Dementia Connect in Warwickshire 0333 150 3456 lines are open Monday to Friday 9am to 5pm

Dementia Support Service Buckinghamshire 0333 150 3456 lines are open Monday to Friday 9am to 5pm

Dementia Care Adviser Service Berkshire 0118 959 6482 lines are open Monday to Friday 9am to 5pm

Alzheimer's support Wiltshire 01225 776481 (opening hours not listed)

Dementia Adviser Gloucestershire 01452 525222 lines open Monday to Friday 9am to 5pm

Mind is a mental health charity which offers advice and information to people experiencing mental health concerns and their family and friends. www.mind.org.uk Information Line: 0300 123 3393 Lines are open Monday to Friday (except bank holidays) 9am to 6pm

If you would like to find out more or express your interest in participating in the study, please email: k.rance@lancaster.ac.uk

or

telephone: 01865 534143

or

Please click this link to complete an expression of interest form

<https://forms.office.com/e/DHJR8DxyXb>

or scan the QR code on a smartphone or tablet

