

Version Number: 2

Date of this version: 03/08/2023

INFORMATION SHEET for unpaid carers of people living with Parkinson's Dementia or Lewy Body Dementia

Study Title: Understanding the experience of hearing loss in people with Parkinson's Dementia and Dementia with Lewy Bodies.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

1. What is the study about?

In this study we aim to understand more about the experiences of hearing loss for people living with Parkinson's Disease Dementia and Dementia with Lewy bodies and their carers. Specifically, we aim to understand more about how hearing loss may affect someone living with Parkinson's Disease Dementia and Dementia with Lewy bodies daily and whether services aimed at improving hearing are accessible to people living with Parkinson's Disease Dementia and Dementia with Lewy bodies.

2. Why have I been chosen to take part?

You have been chosen to take part because you expressed interest in this study and the person you care for is living with either Parkinson's Dementia or Dementia with Lewy bodies and hearing loss.

3. Do I have to take part?

No, you do not have to participate. Participation in this research is completely voluntary and you can withdraw at any time without having to give a reason. Not taking part will not affect your, or the person you care for's ability to participate in other research. You may also agree to take part, but then chose not to answer certain questions.

4. What does the study involve?

This research will involve taking part in a short virtual interview where we will ask you to share your experiences of hearing loss related to the person you care for's dementia.

You do not have to have hearing loss to take part. However, we do ask that you only take part if the person you care for has hearing loss and Parkinson's Disease Dementia or Dementia with Lewy bodies. The virtual interview will last up to 45 minutes and with your permission will be audio-recorded and auto transcribed.

As previously explained, you do not have to have hearing loss to take part. However, if you do have hearing loss, we ask that you only sign up to take part if you feel you will be able to hear the researcher well enough to engage in a conversation. The researchers have taken several steps to help those who have hearing loss during this study. 1) live audio captions will be on screen during your video interview, 2) the researcher will write the questions on the screen as well as asking you them verbally and 3) if you have a Bluetooth connected hearing device (e.g. Bluetooth connected hearing aid) it is possible to sync your hearing aid with the online call. More information on how to ensure you can hear the researcher well during your online interview will be emailed to you closer to the time, or can be found on the RNID:

<https://rnid.org.uk/information-and-support/technology-and-products/video-conferencing-accessibility-meetings/video-conferencing-accessibility-meetings-microsoft-teams/> .

As the interview will occur virtually, we ask that you only sign up to this study if you have ability to join an online Microsoft Teams. You can join a Microsoft Teams call from a PC, Laptop, internet enabled tablet or a smart phone. If you choose to participate in this interview the researcher will email you a guidance document that will help you join the Microsoft Teams call. The researcher will also be able to help you with any small IT problems over the phone or on the call. However, please note that as the interview is virtual there is a limit to the amount of IT support the researcher can provide. Therefore, please do feel free to ask family and friends for assistance before the interview if needed and please only sign up to the interview if you feel you have the ability to join the online call.

We will hold your email contact details for the duration of the study and for 3 weeks after your interview. We will do this to enable us to: 1) contact you if before the interview to discuss any questions you may have, 2) contact you if you have any technical difficulties during the interview, 3) contact you if you have questions after the interview or wish to discuss your data and withdrawing your data from the study.

5. Will the information I provide be kept confidential and how will my data be stored?

Yes. Everything that people tell us will be kept in strict confidence, except in extreme circumstances where we feel that someone is at risk of serious harm. In this case, the researcher will have a duty to pass this information onto the relevant service. All information obtained from the study will be stored securely on the University of Liverpool M drive, accessed via password protected computers. Hard copies will be stored in a locked filing cabinet at the University of Liverpool.

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. Megan Readman acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to m.readman@liverpool.ac.uk.

Further information on how your data will be used can be found in the table below:

How will my data be stored?	Your data will be stored in a password protected electronic data file on a password protected folder on OneDrive.
How long will my data be stored for?	Your data will be stored 10 years.
What measures are in place to protect the security and confidentiality of my data?	The files will be stored securely on the University’s OneDrive and will be password-protected.
Will my data be anonymised?	Yes. Your data will be assigned a “participant ID” and you will not be personally identifiable
How will my data be used?	This study will only analyse anonymised data and present the findings in a collective manner. Anonymised data will be also stored indefinitely and made available for other researchers via an online repository.
Who will have access to my data?	Research and project staff only.
Will my data be archived for use in other research projects in the future?	The research team will place the anonymised data on an online repository in case any other researchers want to use it for future research purposes.
How will my data be destroyed?	After 10 years it will be disposed of via confidential waste disposal and will be deleted electronically.

6. What are the benefits of taking part in the study?

There are no direct benefits for you to taking part, but by telling us about your experiences we hope this will help us to understand the impact of hearing loss in Parkinson's Dementia and Dementia with Lewy Bodies and their carers. You will be given the opportunity to be entered into a prize draw with the chance of winning either a £50, £30 or £20 shopping voucher. The winners of the prize draw will be selected once recruitment for the study is completed.

7. Are there any disadvantages to taking part?

You may experience some of the questions we ask you to be upsetting or uncomfortable to answer. Specifically, we will ask you about the effects of hearing loss on the person you care for's mood, ability to engage in social activities and ability to complete daily tasks. You may find it difficult or uncomfortable to answer some of these questions. However, you do not have to answer any question if you did not want to or provide a reason for not wanting to answer particular questions.

8. What will happen to the results of the study?

The results from this study will be published in a scientific journal. The anonymised information you provide may be provided to the journal and made publicly available online for use by other researchers. The data will be completely anonymised (with a random participant ID) and you will not be identifiable in any publication or data file. If you are interested in the results of the study, please let us know and we will share the results of the study with you when we publish it.

9. What will happen if I want to stop taking part?

You are under no obligation to take part in this study; it is completely your choice. If you decide to take part, you are free to withdraw at any time during participation and without giving any reason or explanation. You are also free to withdraw your data from the study for up to 3 weeks following participation, after this time we will be unable to withdraw your data from the study as we will have started to analyse your data.

10. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting us on the below details. If you have a complaint which you feel you cannot come to us with then you can contact the Research Governance Officer on 0151 794 8290 (ethics@liv.ac.uk). Please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

11. What do I do next?

If you are interested in taking part please email Megan Readman to arrange a suitable date and time to engage in a virtual call and complete the interview.

12. Who can I contact if I have further questions?

Dr Megan Readman

Postdoctoral Research Fellow
m.readman@liverpool.ac.uk
Telephone: 07784364808

Dr Clarissa Giebel

Senior Research Fellow & Older Adult
Subtheme Lead ARC NWC

13. Support services

The Samaritans

Telephone: 116 123(24hours a day):
Email (response time: 24 hours): jo@samaritans.org
<https://www.samaritans.org/>

Parkinson's UK

Telephone helpline: 0808 800 0303 (Monday to Friday: 9am to 6pm
Saturday: 10am to 2pm)
<https://www.parkinsons.org.uk>

Lewy Body Society

Telephone helpline: 0800 888 6678 (Monday-Friday 9am-9pm Saturday and Sunday
9am-5pm)
<https://www.lewybody.org>

Alzheimer's Society

Telephone helpline: 0333 150 3456 (Mon to Weds: 9am – 8pm, Thurs and Fri: 9am –
5pm, Sat and Sun: 10am – 4pm)
<https://www.alzheimers.org.uk>