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INFORMATION SHEET for 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 you want 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. We hope to understand more about how hearing loss may be affecting people living with Parkinson's Dementia and Dementia with Lewy bodies every day 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 indicated you are interested in this study and are living with either Parkinson's Dementia or Dementia with Lewy bodies and have hearing loss.

3. Do I have to take part?

No, you do not have to participate. Taking part 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 ability to participate in other research. You may also agree to take part, but then chose not to answer certain questions.

4. What will happen if I take part?

This research will involve taking part in a short interview where we will ask you to share your experiences of hearing loss related to your dementia. The interview will last up to 45 minutes and with your permission will be audio-recorded and auto-transcribed.

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 you participate in this study. 1) live audio captions will be presented on the screen during your 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/> .

Your interview will occur virtually (via the internet). So, we ask that you only sign up if you have ability to join an online Microsoft Teams call. You can join a Microsoft Teams call from a PC, Laptop, internet enabled tablet or a smart phone. If you choose to participate 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. But, as the researcher will not be with you in person there is a limit to the amount of IT support the researcher can provide. So, 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 store 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. Things to know about the study

- Everything that you tell us will be kept in strict confidence, except where we feel that someone is at risk of serious harm. In this case, we have a duty to pass this information onto the relevant service.
- 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.
- 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. You will not be identifiable in any publication or data file.

- 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.

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

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| 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 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 details below and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, 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.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

7. What do I do next?

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

8. 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

9. 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>