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**‘Caregiver experiences: visual hallucinations in Lewy body disorders’**

**Researchers:**

Jake Hutchinson (Student Researcher, Teesside University)

Dr Angela Prout (Chief Investigator, Teesside University)

Dr Alan Bowman (Academic Supervisor, Teesside University),

Mr Daniel Collerton (Academic Supervisor, Newcastle University)

**I want to understand your experience further. What is it like looking after somebody who has visual hallucinations?**

*I am carrying out a study on the experiences of caregivers of people who have visual hallucinations in the context of Lewy body disorder. I am recruiting people who are willing to talk for a maximum of ninety minutes about their experience. This will contribute towards my doctoral thesis being completed at Teesside University.*

If you are interested, please contact me on the details below to discuss further, thank you very much.



Email Jake Hutchinson: **T7126601@live.tees.ac.uk**



**Fill out the reply slip** (at the end of this pack) and post it to the address provided

**Before you make your decision, please read the information provided below and discuss it with others if you wish. You may wish to read the information sheet more than once and should take time to decide whether or not you wish to take part. Please contact me if you have any questions, or if you would like me to make something clearer.**

**Participant information sheet**

‘A study understanding the experiences of informal caregivers of people who have visual hallucinations in the context of Lewy body disorders’

**Why am I being invited to take part?**

I am (Jake Hutchinson, Student Researcher, Teesside University) contacting those who provide the primary, unpaid, day-to-day help and support (informal caregiver), to those with a Lewy body disorder (Parkinson’s disease, Parkinson’s disease dementia, or dementia with Lewy bodies). In order for me to meet the purpose of this study, the person being cared for also has to have experienced visual hallucinations (seeing something that is not actually there) for at least four weeks. If you think you meet these criteria and are able to hold a conversation in English without the use of a translator and/or interpreter, then I would like to hear from you.

Unfortunately, if you do not meet these criteria then you cannot take part in the study.

* You also cannot take part in this study if you are below aged 18.

**What is the purpose of the study?**

This study is being completed in part fulfilment for the Doctorate in Clinical Psychology award, which is being completed at Teesside University.

While I know that it is a very important role to provide mostly unpaid help and support to people with physical and/or psychological difficulties, there is a lack of research focused on what the actual experiences are in terms of caring for those experiencing visual hallucinations in the context of Lewy body disorder. It is important to understand this experience further, not only to better understand what it is like, but to identify specific needs that caregivers may also have in relation to this role.

**Do I have to take part?**

No. It is your choice entirely whether or not to take part. If you decided to take part, I would ask you to sign a consent form and proceed with the study interview as mentioned below. If before or during the interview, you decided that you no longer wanted to take part, you can have your participation in the study stopped. You would just have to let me know.

**What will happen to me if I take part?**

I would contact you to arrange a time to meet at a suitable venue in which there is a quiet and private place to talk. Before starting any research activities, I would discuss this information sheet with you, check that you still want to take part and ask you to read and sign a written consent sheet.

If you do decide to take part in the study, I will record whether you are male or female. I will also collect other demographic information; this will include your age. This information will help me to describe the overall sample of participants and help me with interpretation of the data collected. Your name will not be used, and you will not be identified in any publication arising from the study.

I would then ask you some questions about your experience of caregiving for somebody experiencing visual hallucinations in the context of Lewy body disorder. This interview would be audio recorded and a transcript of the conversation made so that I can listen again to what has been said. This should last no more than 90 minutes. It is important during this time that you do not name any specific people nor give any information that could render anyone or any location identifiable and if you did, I would destroy that part of the data and would not include it in the analysis.

Once the interview is complete, you will be welcome to ask and have answered any questions that you may have about the research and you will be able to keep this information sheet which contains contact details should you wish to discuss the research further. You might be contacted after your interview once more, via telephone or email (whichever you prefer) by myself, so I can share with you what I found out and find out what you think. This is to ensure that I accurately capture your experience; it also helps to maintain accuracy, credibility and validity within the research. This should last no longer than 20 minutes, although you will not have to do this if you do not wish, although you can still take part in the interview mentioned above.

You can request that information about the findings from the research is sent to you once it is completed, although this is optional; the relevant clause on the consent form would need to be signed to reflect your consent where appropriate.

**How will we use information about you?**

We will need to use information from you for this research project. The information used for the research follows:

* your name;
* whether you are male or female;
* your age group;
* contact details where appropriate.

People will use this information to do the research or to check your records to make sure the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a participant identification number instead. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What will happen to the information collected about me?**

Interviews will be audio recorded using a Teesside University encrypted portable audio recording device and a transcript of each interview made. Only I and Dr Angela Prout (Chief Investigator) will have access to this recording. Once the recording has been transcribed by myself, I will confidentially delete the audio recording. Transcripts will then be stored as an electronic ‘Microsoft Word’ encrypted document and stored securely within a password protected Teesside University server. All transcripts will be created in non-person identifiable format and will not have any of your person-identifiable information on. Your consent form which contains person-identifiable information will be stored securely at Teesside University in a locked filing cabinet. A single hard copy sheet (link document) will exist which will detail which set of person-identifiable information is linked to a participant identification number’. Again, only I and Dr Angela Prout (Chief Investigator) will have access to both of these pieces of information. After I have had contact with participants for the last research contact whereby I may feedback what I have captured (or 4 weeks after your first interview if you do not provide consent to take part in this second research activity) I will destroy this link sheet so that the ‘participant identification number’ can no longer be linked to you personally and the data will become fully anonymised (non-identifiable).

During the data analysis stage of the current research, both Dr Angela Prout (Chief Investigator) and Mr Daniel Collerton (Academic Supervisor), will have access to the non-identifiable transcripts for the purpose of triangulation (gaining more than one perspective when undergoing analysis of the data) in order to cross-validate the information captured. Excerpts from these transcripts will also be included within my doctoral thesis to support my data analysis, although again these will be anonymised; so, while you may recognise your own words, nobody else will. When writing up the doctoral thesis and any publications I will also thank Northumberland, Tyne and Wear NHS Foundation Trust, The Lewy Body Society and Parkinson’s UK for their involvement, which you may be involved with, however I will never name you personally.

When the research has been examined in part fulfilment for the qualification of Doctor of Clinical Psychology, consent forms will then be retained indefinitely in a sealed envelope and stored in a locked filing cabinet at Teesside University by Dr Angela Prout (Chief Investigator). When the study is complete, I would also like to publish the results in a scientific journal and may also deliver presentations at scientific conferences. You will not be identified in any publication or presentation as your name and other personal details will have been removed, as mentioned above. The non-identifiable research data will be stored indefinitely on a secure password protected server at Teesside University. This is in case other scientists wish to raise questions about the results that need checking against the dataset. If the study is published in a scientific journal, the non-person identifiable research dataset may be made publicly available (for example, as a supplement to the journal article, or stored on an on-line scientific data repository). This non-identifiable data may also be used for future studies (this is called secondary analysis) but only in research projects that have received ethical approval from an appropriate committee. I would be very happy to provide you with a copy of the study results via postal mail if you would like. If you are interested, you can indicate this on the Consent Form. If you indicate you would be interested in the results, your details will be kept on a Password Protected Teesside University Server, in a password protected document. These details will be destroyed as soon as the results have been sent out.

**Is this study confidential?**

This study strictly adheres to confidentiality. However, should any abusive or unprofessional behaviours or actions be disclosed and/or discovered then confidentiality will be breached, and I will contact Dr Angela Prout (Chief Investigator), in the first instance, and if deemed appropriate further actions may be taken. I will make every effort to explain to you why we need to share this information before doing so.

Personal data including special category data obtained for the purposes of this research project is processed lawfully in the necessary performance of scientific or historical research or for statistical purposes carried out in the public interest. Processing of personal data including special category data is proportionate to the aims pursued, respects the essence of data protection and provides suitable and specific measures to safeguard the rights and interests of the data subject in full compliance with the General Data Protection Regulation and the Data Protection Act 2018.

**What are your choices about how information is used?**

You can stop being part of the study at any time, without giving a reason, although I would ask for your permission to use the data collected from you up to that point, or you can decide that any data collected already is to be removed from the study and confidentially destroyed. Due to the qualitative nature of the study, you will only be able to have your data withdrawn up-to four weeks after your interview. Participants can do this by contacting me and giving their anonymous ‘participant identification number’ which you will receive during interview. We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**Where can I find out more about how information is used?**

You can find out more about how we use your information:

* Att [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
* By sending an email to T7126601@live.tees.ac.uk
* Or asking one of the research team members listed at the top of this document

**What would happen if I lost capacity to consent during the study?**

If you provided informed consent and then lost capacity to consent during the study, I would withdraw you from the study. No further data would be collected, and no other research activities would be carried out. Should any objections be raised if this occurred, these can be discussed with Dr Angela Prout (Chief Investigator) on the details below.

**What are the advantages and disadvantages of taking part?**

There are no direct benefits to taking part. However, by taking part you are aiding research which helps me understand people’s experiences of caring for those with Lewy body disorder experiencing visual hallucinations. This may result in a greater understanding of this area and could result in the development of potential strategies to help people with their experiences in the future.

Some of the questions will cover sensitive topics relating to your experience of providing care, which you may find upsetting. You will have the opportunity to discuss any concerns you have with me before deciding to take part and you are free to stop the interview at any point without giving a reason.

**Expenses and payments**

Unfortunately, it is not possible to offer payment for your participation in the project. It is not expected that this study will incur any expenses for you.

**What happens if something goes wrong?**

This study involves talking about peoples’ experiences, so I do not expect anything to go wrong. However, talking about personal experiences could be a sensitive topic for some. So, at the beginning and at the end of your meeting with me, or at any other time, you would be welcome to voice any questions or concerns that you may have about the study. As mentioned above, you are also free to stop your interview at any time and withdraw from the study if you wish.

**Should you feel you need more support at any time, the following contacts may be useful:**

* **The Samaritans: “Talk to us any time you like, in your own way and off the record, about whatever’s getting to you.” Tel: 08457 90 90 90 / www.samaritans.org**
* **Parkinson’s UK: “Because we’re here, no one has to face Parkinson’s alone.” Tel: 0808 800 0303 / parkinsons.org.uk**
* **The Lewy Body Society: “Shining a light on Lewy body dementia.” Tel: 0800 888 6678 / info@lewybody.org**

If you remain unhappy or have a complaint which you do not wish to talk to me about, you can contact the below person at Teesside University, who knows about but is not involved in the research:

Dr Alasdair MacSween

Chair of School of Health and Social Care Research Governance and Ethics Committee

C1.10 Constantine Building

Teesside University

Middlesbrough

TS1 3BX

Tel no: 01642 342 965

Email: a.macsween@tees.ac.uk

Or you may also wish to contact your local PALS service (Patient advice and Liaison service) on:

North of Tyne PALS
FREEPOST RLTC-SGHH-EGXJ
The Old Stables
Greys Yard
Morpeth
NE61 1QD

**Email:** northoftynepals@nhct.nhs.uk
**Tel:** 0800 032 0202

**Who can I contact for more information?**

If you have any questions, or you would like more information, please contact:

Jake Hutchinson (Student Researcher, Teesside University)

Email: T7126601@live.tees.ac.uk

Address: School of Social Sciences, Humanities and Law, Centuria Building, Southfield Road, Middlesbrough, TS1 3BX.

Or,

Dr Angela Prout (Chief Investigator, Teesside University)

Email: A.Prout@tees.ac.uk

Address: School of Social Sciences, Humanities and Law, Centuria Building, Southfield Road, Middlesbrough, TS1 3BX.

If you would like to have a meeting with someone to discuss participation in this study and ask any questions that you might have about it before you make a decision, please contact Jake Hutchinson on the details above or below.

**I am interested in taking part, what should I do next?**

If you are interested in taking part, please get in touch using one of the methods below. You will then be contacted to discuss the next steps:

**Email Jake Hutchinson: T7126601@live.tees.ac.uk**

**Fill out the reply slip (below) and post it to the address provided**

***Thank you***

**Caregiver experiences: visual hallucinations in Lewy body disorders – REPLY SLIP**

**If you are interested in taking part, please:**

Write your name here:

**How would you like to be contacted?**

Phone number:

Email:

Contact address:

**Do you have a preferred time(s)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_or day(s)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_to be contacted?**

You can post this slip to:

Jake Hutchinson (Student Researcher)

Doctorate in Clinical Psychology

School of Social Sciences,

Humanities and Law,

Centuria Building,

Southfield Road,

Middlesbrough,

TS1 3BX.

Or you can:

* Email Jake Hutchinson on: **T7126601@live.tees.ac.uk**