

Participant Information Sheet

1. Background and aims of the study

This research aims to explore the lived experiences of parental carers of adult children with a learning disability. We are aiming to cover topics such as how much help you receive, how you feel about your role, your thoughts about the future and the past. We hope that hearing from you will help us understand your experiences and may have an impact on future service delivery.

2. Why have I been invited to take part?

You have been invited to take part in this study because you are the main carer for your adult child who has a learning disability.

The inclusion criteria are:

- You must be fluent in English.
- You must be over the age of 65
- Be the main carer of your child who is over the age of 18
- Your child must have a learning disability

3. Do I have to take part?

No. You can ask questions about the study before deciding whether or not to participate. If you do agree to participate, you may withdraw yourself and your data from the study, without giving a reason and without penalty, by advising the researchers of this decision. The deadline to withdraw will be 2 weeks after your interview. After this point, your data will have been collated and anonymised with the data from other participants and will no longer be recognisable.

4. What will happen in the study?

- If you do decide to participate you will be asked to sign a consent form.
- You will be asked to answer a demographic questionnaire consisting of questions about your age, gender, etc.
- You will then take part in an interview with the researcher at a location that is convenient for you. This should take approximately one hour.
- The interview questions will be around your personal experiences of being the main carer of your adult child.
- The interview will be recorded on a Dictaphone. This will only be accessed by the researchers. The only exception to this will be in the event a safeguarding risk is identified.
- There will not be any follow-up visits.

5. Are there any potential risks in taking part?

There are no known risks to taking part in this research. If you feel uncomfortable at any point during the interview you can stop. The researchers are trained professionals who are under supervision and have developed skills in managing and supporting people in emotional distress.

6. Are there any benefits from taking part?

Any information you provide about your experience, positive or negative, will help us to gain an insight into your role as a carer.

7. What happens to the data provided?

The research data and personal/sensitive data will be stored using an encrypted Universal Serial Bus (USB). All audio recordings and information gathered during this research study will be locked in NHS premises and/or on the password protected NHS computer system; in accordance with the Data Protection Act of 1998, and will be destroyed after ten years.

Your responses will be anonymised. Pseudonyms will be used and any identifying information will be changed or removed. Information disclosed about other people, e.g. relatives and friends, will be treated in the same way, with information anonymised if included in the write up. All research data and records will be stored for a minimum retention period of 3 years after public release.

If you share information during the interview which leads the interviewer to be concerned about your safety or the safety of others, they will discuss these concerns with the research leads. If a safeguarding risk is identified, we are required to follow Berkshire NHS Foundation Trust Safeguarding Adults Policy and Procedures. This may require us to break confidentiality and discuss issues with the local safeguarding team and other relevant agencies. This would be discussed with you.

8. Who has reviewed this study?

This study has been reviewed by, and is registered with the Berkshire NHS Foundation Trust Research Department. It has also received ethical approval from the NHS and the University of Reading ethics department (UREC).

9. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please speak Dr Olivia Hewitt, Clinical Psychologist, who will do her best to answer your query.

10. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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Dr Olivia Hewitt

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