



'STAND BY ME' - RESEARCH STUDY

Research project, exploring sustainability of relationships and support among people with a learning disability and dementia.

Why is this study needed?

The idea for this study came from a married man with a learning disability who has dementia and shared his concern about how the diagnosis may impact on his relationship. To date, no studies have been conducted with couples who have a learning disability where one partner has a diagnosis of dementia. This new research will inform health and social care practice in learning disability and dementia services.

What will happen?

We will meet with couples with a learning disability together or separately; the relationship may be current or previous. We will also interview support staff and family members to find out about the experience of couples with a learning disability where one partner has dementia, and those that support them. Interviews will take place either online or within offices at the university or participating organisations.

Who will be involved?

- To be included in the study, **people with a learning disability** will have capacity to agree to take part. The relationship should be (or have previously been) for a minimum of six months. If one partner has died, then the death must be more than twelve months before the participant is approached to take part in the study.
- **Social care staff** will be recruited based on having current or previous experience of providing support to one or more people in a relationship affected by dementia.
- **Family members** will be invited to join the study if they have, or had, a relative in a relationship where one partner has/had a diagnosis of dementia.
- An **advisory group** including three adults with a learning disability are guiding the research which is funded by the Dunhill Medical Trust. The study is led by Dr Karen Watchman, University of Stirling and Professor Heather Wilkinson, University of Edinburgh. Dr Paula Jacobs is the Research Fellow and will conduct most of the data collection.

Ethical considerations

Approval for the study was given by the UK IRAS social care research ethics committee. Whilst face to face data collection will be considered, interviews and data collection may also be conducted online or by telephone if preferred.

Would you like to take part?

If you would be interested in taking part or if someone you know may like to be involved, please contact Paula Jacobs for more information including an accessible format: paula.jacobs@stir.ac.uk. You can also read more about the study on the project website: www.learningdisabilityanddementia.org/relationships-study