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## **PARTICIPANT INFORMATION SHEET**

### **Study Title: Help-seeking among family caregivers to people showing early signs of dementia – a preliminary qualitative study.**

We are inviting you to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and if you have any queries, discuss it with friends or relatives if you wish. Please take time to decide whether or not you want to take part. We will be very happy to explain anything that is not clear.

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

The purpose of the study is to better understand the views, decisions and experiences of seeking help by people who suspect a loved one is showing early signs of dementia, their support needs at this time, and what factors may have impacted on their seeking help. We are interested in learning about your family's experiences during this time, the support you received and how you think the process could be improved.

There is currently little knowledge about help-seeking behaviour among family caregivers prior to their loved one receiving a diagnosis and this knowledge will help inform planning and policy to equip healthcare professionals and others to better support people at this time and respond to their emotional and practical needs.

#### **Who is running the study?**

This study is being carried out by a researcher in the Centre for Health and Social Care Improvement (CHSCI) at the University of Wolverhampton Trust. The project is funded through the University of Wolverhampton's Early Research Award Scheme 2018-19.

#### **Why have I been chosen for this study?**

You have been chosen to take part in this study because your family member or friend has been diagnosed with dementia in the previous twelve months and you provide informal care to that person.

#### **Do I have to take part?**

No, it is your choice whether you would like to take part. You are under no obligation to do so. If you agree to take part you can withdraw at any time without giving a reason and without your care or legal rights, or those of your family member or friend, being affected. Following the interview you may still choose to withdraw your data from the study for up to 2 weeks following the interview, however after this date it may not be possible to isolate your data from the analysis. If you would like to withdraw your data please contact the researcher.

#### **What would happen to me if I take part?**

We are asking you to share your experiences and perspectives through an interview with a researcher. The interview would be carried out at a time and place to be agreed by you and the researcher, for example in a private room at the University or community centre. It may be possible to

conduct the interview at your home if you prefer. If you would like to bring a family member or friend with you for support you are more than welcome to do so.

The researcher would explain the study before starting the interview and you would have the opportunity to ask questions. We would then ask you to sign a Participant Consent Form to confirm that you have agreed to take part in the study. You would be given a copy of the signed Participant Consent Form to keep.

The interview would be audio-recorded to provide an accurate record of the experiences you share with us. The interview is expected to last between 60 and 90 minutes. However if you wish to take a break or to finish the interview at any point, you only need to tell the researcher and do not need to give a reason for stopping the interview.

#### **What are the benefits of me taking part?**

There is no anticipated direct benefit to you of taking part in this study. However, we hope that the information you provide will have wider benefits to others in a similar situation in the future through contributing to improvements to service provision.

#### **What are the risks and disadvantages of me taking part?**

There are no major risks anticipated for you taking part in this study. However, interviews can be emotionally tiring and you may like to have someone whom you can talk to afterwards. The researcher will be able to discuss with you possible routes to support, if you think this would be helpful. However please note that the researcher herself is not a trained counsellor and would not be able to offer direct support.

The period of time in question would likely have been a very difficult one for you and your family. Please be assured that we understand this and the complexities of seeking help. It is not our intention to challenge your experiences but only to understand how we can better provide for those who require more support.

#### **Would my taking part in this study be kept confidential?**

All information collected would be kept in the strictest confidence. Your name will not be recorded anywhere within the study and no individual would be identifiable from the published results.

In very exceptional circumstances, such as if something you say indicates that you or others may be at significant risk of immediate and serious harm, the researcher may need to report this to the appropriate authorities. The researcher will normally discuss their intended actions and the reasons for this with you first.

#### **Who has reviewed this study?**

This study has been independently reviewed by the Faculty of Education, Health and Wellbeing ethics committee at the University of Wolverhampton. It has also received a review by members of the University of Wolverhampton's service user involvement group, RESULT.

#### **After the interview**

After the interview the audio-recording will be listened to and the information on it transcribed by a service with whom we have a data sharing agreement. Please be assured that this agreement ensures your confidentiality. The transcription of the interview will then be analysed by the researcher.

The University of Wolverhampton is committed to responsible and ethical research. All data will be collected and processed according to the General Data Protection Regulation (GDPR) and the UK's Data Protection Act 2018; the University's Data Protection Officer can be contacted for more information at [dataprotection@wlv.ac.uk](mailto:dataprotection@wlv.ac.uk). Your personal information will be destroyed within 6 months of the end of the study; your transcript may be held securely by the researchers for up to 10 years, after which it will be destroyed.

You will receive a thank you letter from the Research Team, which will include a short questionnaire in which we will ask you to give us some feedback about your experience of being involved in the interview. Please let us know if you *do not* wish to receive this. We will be happy to provide you with a

summary of the research when the study is completed (estimated Autumn 2019). If you would like to receive this please let the researcher know.

**What if something goes wrong?**

If you have a concern about any aspect of this study, you can ask to speak to a member of the research team who will do their best to answer your questions. If you wish to complain about the way you have been approached or treated during the course of this study, please contact:

Prof Silke Machold  
University of Wolverhampton  
The Research Hub, Ambika Paul Building  
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Telephone: 01902 323970  
Email: [S.Machold@wlv.ac.uk](mailto:S.Machold@wlv.ac.uk)

**Contact for further information about the study**

If you would like to discuss anything or have further questions at any time, please contact Dr Angela Clifford, who is the lead researcher for this project.

You can also find out more about the study and the funding arrangements at:  
<https://www.wlv.ac.uk/research/the-doctoral-college/early-researcher-award-scheme-eras/>

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**Thank you for taking the time to read this information.  
This Information Sheet is for you to keep.**