

PARTICIPANT INFORMATION SHEET FOR PEOPLE LIVING WITH DEMENTIA

The LIVE-DEM study: understanding live-in care for people with dementia.

We would like to invite you to take part in our research study.

To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what participation will involve. Please take time to read the information carefully and discuss it if you wish. Ask questions if anything is not clear or if you would like more information. Your participation in this study is completely voluntary.

What is the study about?

This study is looking at live-in care for people with dementia. Live-in care is when a care worker moves into (rather than visits) a person's home to provide support. Little is known about live-in care for people with dementia in England and most of the research has been done in other countries. This study is trying to change this. If you take part, it will help us to better understand live-in care for people with dementia, what works well, and what could be improved.

This research is funded by NIHR Health Services and Delivery Research Programme (HS&DR) and the study is sponsored by the University of Southampton.

Why have you been invited to take part?

We would like you to be involved because you have a diagnosis of dementia and have a live-in carer.

What will I have to do if I take part?

A researcher will meet with you at home at a time convenient to you. At the initial visit [visit 1], the researcher will explain the study and interview you asking you about your views and experiences of live-in care. Interviews will be at your own pace and will be in a conversational style. With your permission, we will audio record the interviews. We would prefer to interview you on your own so that you can express yourself freely. However, this will be your choice, as you may wish to choose to have someone with you during their interview. After the interview, we will ask you and your live-in care worker to keep a photo diary for seven days. We will provide guidance and all the equipment you will need, including a compact digital camera. This will be used to tell us more about your care and what happens in a typical day/week (e.g. going shopping or socialising). After 7-days, the researcher will return to your home [visit 2] and interview you and your live-in care worker together, asking questions about your week and the photographs that you have taken. After a break of 3 to 4 months, the researcher will arrange a time to visit you home to interview you again [visit 3] and to ask for a second photo-diary to be kept. After seven days the researcher will return [visit 4] and interview you and your live-in care worker for a final time.

We would also like to invite your (chosen) family member, live-in care worker, and care coordinator (social worker or nurse) to be interviewed regarding their experiences of live-in care. This will be around the time of visit 1 and visit 3.

Does my (chosen) family member have to take part?

No. It's your choice whether you take part. We will describe the study and go through this information sheet. If you agree to take part, you will be asked to sign a consent form, and you will be given a copy to keep.

If you change your mind about taking part, you may withdraw from the study at any point without giving a reason. Choosing not to take part or withdrawing will have no effect on your care. If you choose to withdraw from the study, we will not keep the information you have given us. After you have read this information sheet, please contact us if you have any questions that will help you decide if you would like to take part.

What are the possible disadvantages and risks of taking part?

There are no health risks. The main disadvantage is the time that you will be giving up to take part in the study. There is a possibility that discussions linked to dementia may be upsetting to you. However, you do not have to answer every question. If the researcher observes any upset or distress, they will pause or stop the interview and seek guidance from you.

What are the possible benefits of taking part?

The research is unlikely to benefit you directly, although some people do like keeping a photo diary and talking to researchers about their lives. The information we get from this study will help to improve our understanding of live-in care for people with dementia.

What will happen to the results of the study?

We will summarise the results of the study in articles, conference presentations and reports. These will be for different audiences, including people living with dementia and family carers' organisations, policymakers, practitioners, academics and the funder. We will widely publicise the findings to relevant groups, including by using social media. Please let the researcher know if you would like to receive a copy of the end of study report.

Will details about my (chosen) family member be kept confidential?

Personal information about you will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). This means that we will treat all the data we collect as strictly confidential. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. All research documents and notes will only be identifiable by using a code number. What you say may be used in reports, articles and presentations, but your real name will not appear with these quotes; we will give you a pseudonym. Everything you say will be confidential unless you tell us, or we see, something that suggests that your situation is life-threatening, abusive or may place others at risk of harm. If this happens, we will be obliged to break confidentiality. We would discuss this with you before telling anyone else.

The interviews will be typed up by a professional transcriber. Audio recordings will be securely transferred to a transcription company; we will have a confidentiality agreement and a data-sharing agreement with that company. Otherwise, only the project team will have access to data. We will store data in locked filing cabinets, a secure remote storage platform (in line with GDPR) and use password-protected computers. We will destroy audio recordings at the end of the study. We will destroy all other data ten years after the end of the study.

Data Protection Statement

The data controller for this project will be the University of Southampton. The University will process your personal data for the purposes of the research outlined above. The legal basis for processing personal data for research purposes under GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the Participant Consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights, including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Southampton Data Protection Officer (data.protection@soton.ac.uk). If you wish to make a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Who has reviewed the study?

The research study has been reviewed and given favourable opinion by the Social Care Research Ethics Committee (Reference No.). This committee is a group of independent reviewers who protect the dignity, rights, safety and wellbeing of participants and researchers.

What if there is a problem or something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers. They will do their best to answer your questions. We do not expect any major risk associated with taking part in this study. If you have any adverse effects resulting from them participation in this study, you will be compensated through the University of Southampton Professional Indemnity Cover insurance scheme. If you believe this study has harmed you in any way, or if you wish to make a complaint about the conduct of the study, you can contact the University of Southampton using the details below for further advice and information.

Who should I contact for further information?

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

LIVE-DEM Research Associate: Anita Chonzi A.R.Chonzi@soton.ac.uk

LIVE-DEM Investigator: Dr Laura Cole Laura.cole@uwl.ac.uk

LIVE-DEM Principal Investigator: Professor Ruth Bartlett R.L.Bartlett@soton.ac.uk

University of Southampton Research Ethics and Governance Team: Ms Trudi Bartlett
(no relation to Ruth) rgoinfo@soton.ac.uk

Thank you for reading this information sheet.

You may keep this information sheet for reference and contact us with any queries.