

Participant Information Sheet

Title of Study: Eating, drinking and care for people with dementia at the end of life: How can we best support family carers?

We are inviting you to take part in this research project. Before you decide, it is important that you understand why the research is being done and what it will involve. Ask us if there is anything that is not clear. You will have a minimum of 48 hours to decide if you want to take part. Please let us know if you need longer.

1. What is the project's purpose?

People with memory problems or dementia may have problems with eating and drinking and this may get more difficult in the later stages of dementia. Families have told us that they can find it difficult to help their relative with eating, drinking and swallowing. We want to understand how family/friends caring for someone with dementia manage eating and drinking at home and what information/help they would like about eating and drinking.

Using this information and evidence from research we will develop an information resource to support people such as yourself to help manage eating and drinking for people with dementia.

2. Why have I been invited?

You have been invited to participate in this study, because you are a family/friend caring for a person with memory problems or dementia.

3. Do I have to take part?

No, participation is voluntary. If you do not wish to participate, it will not affect the treatment or care of your friend/family member in any way. You can withdraw from the study at any time without giving a reason.

4. What will happen to me if I take part?

We will interview you at University College London, or if you prefer, we can visit you in your own home.

A member of the research team will interview you for up to 90 minutes. He or she will ask you some questions about the eating patterns of the person with dementia, how you manage eating and drinking for the person with dementia, as well as what support you receive (if any) and what further support you would like. Additionally, we might describe to you some specific scenarios that

may have not been mentioned during the interview to understand how you would approach them and what elements you would take into consideration.

We may contact you in the future to ask if you would like to participate in another part of this study. With your consent you can be contacted for future research.

5. Expenses and Payments

We will pay your travel to and from the interview venue, if not your own home. Please keep your receipts. You will also receive a £20 'one4all' gift voucher.

6. Will I be recorded and how will the recorded media be used?

In order to make sure that we don't miss anything, we will record our conversation on a digital recorder and then it will be professionally transcribed by an external professional transcription service. Once the interview has been transcribed, we will ensure that everything will be pseudo-anonymised (you will be identified only as a number) so you can't be identified. After this, the recording of our interview will be destroyed.

7. What are the possible benefits of taking part?

We want to learn from you to help us devise ways to improve care and support for family/friends caring for someone with dementia. We hope that you will find being interviewed interesting and that this validates your knowledge and expertise.

8. What are the possible disadvantages and risks of taking part?

There are unlikely to be any disadvantages or risks. The research team are highly skilled in working with carers. In the unlikely event that you become upset you must let the researcher know. They will pause the interview and ask if you would like to continue. If you find this upsetting we can provide you with contact details for support services.

9. What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the research, the National Health Service (NHS) or UCL complaints mechanisms are available to you.

If you suspect that the harm is the result of the Sponsor's ([University College London](#)) or the research team's actions then you may be able to claim

compensation. Please make the claim in writing to [Dr Nathan Davies](#). His contact details are at the end of this information sheet.

You can also contact the patient advice and liaison services (PALS) if you have any concerns: Camden and Islington NHS Foundation Trust - **020 3317 7102**; feedback@candi.nhs.uk

10. Will my taking part in this project be kept confidential?

Yes. All information collected about you during the research will be kept strictly confidential. You will be assigned an ID number. This pseudo-anonymised (key-coded) information will be collected, stored, handled and processed by the research team at University College London. You will not be able to be identified in any ensuing reports, publications, lectures or presentations. If during our conversation, however, we hear anything which makes us worried that someone might be in danger of harm, we may have to inform relevant agencies and or your GP.

11. What will happen to the results of the research project?

With your consent your data may be shared with future ethically approved studies. They will also be presented at conferences and published in journals. If you wish to have a copy of the study results sent to you, please let the research team know. The results will be used to develop an information resource.

12. Data Protection Privacy Notice

University College London is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University College London will keep identifiable information (name and contact details) about you 1 year after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting UCL's Data Protection Officer is Lee Shailer at data-protection@ucl.ac.uk and visiting

<https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>

University College London will collect information from you for this research study in accordance with our instructions.

University College London will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in University College London who will have access to information that identifies you will be people who need to contact you to take part in the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

University College London will keep identifiable information about you from this study 12 months after the study.

13. Who is organising and funding the research?

The research is led by University College London (UCL) and is funded by Marie Curie.

14. Who has reviewed the study?

This study has been reviewed and given favourable opinion by a National Research Ethics Committee (REC reference [19/LO/0369](#)).

15. Contact for further information

If you would like more information, please contact: Chief Investigator **Dr Nathan Davies**, n.m.davies@ucl.ac.uk, 020 7830 2932.