

**PARTICIPANT INFORMATION SHEET FOR CARERS
OF PEOPLE LIVING WITH DEMENTIA**

SORTED study:

Improving social care practice in integrating mouth and teeth care in personal care for people living with Dementia

Principal Investigator: Dr Dia Soilemezi

You are invited to take part in a study about teeth and mouth care. Please take time to read the following information to understand more about it. Talk to your family and friends about the study if you wish.

What is the purpose of the study?

We want to interview family carers (including friends) of people living with dementia about their experiences of helping the person living with dementia after their teeth and mouth. We are interested in what you do to help and what you find helpful. In particular, we would also like to know if you have talked about your relative's mouth and teeth care with anyone from the local council and with a home care worker.

Why have I been invited to take part?

You are being asked to take part because you support (or have supported in the last 6 months) someone in your family or a friend who lives with dementia at home, and they receive home care from a paid worker. The researcher will talk with you and discuss your views on the help your relative receives with their mouth and teeth care. This is a research study, so your experience will be helpful in learning about the support people living with dementia receive from

homecare workers with their mouth and teeth care and about making arrangements with home care workers.

Do I have to take part?

No, it is up to you to decide whether to take part. If you take part and later change your mind, you are still free to stop at any time without giving a reason. If you decide to withdraw, any data collected will be deleted. No questions will be asked if you stop. If, during the interview, there is a question you prefer not to answer, that question can be left out.

What will happen if I take part?

If you agree to take part, please contact the researcher via email or telephone (details at the end). After that, the researcher will get back to you to arrange a convenient time to conduct an interview. This interview will be recorded on a digital audio recording device.

The researcher will ask if you prefer to talk with her online, over the phone or arrange a convenient place to meet in person (if we are allowed to do so). You can then decide a convenient day and time for the interview. If you would like, you can ask a friend or a family member to be there for support.

What will happen on the day?

At the start of the interview the researcher will ask you to sign a Consent Form to show that you understand the study and agree to take part. The interview will last about 20-30 minutes, depending on what you want to say. Some time will be spent getting to know you at the beginning and end. You can take a break part way through if you like. As a gesture of thanks, we will give you a £20 gift voucher and meet reasonable travel expenses and costs in arranging alternative care for your relative or friend.

What will we talk about?

We will ask some questions about ways you look after your relative's teeth and mouth and in particular any help they get with this from their home care worker. We hope you will give us your honest views on the topics that are important to you. There are no right or wrong answers; we are interested in everything you have to say about home care support in this area. If you wish, the researcher will send you the questions before the interview so you can have plenty of time to think about them.

What will happen after the interview?

The interview recording will be labelled with a code number and given to a typist who will type out everything you said in the interview. The typist signs an agreement to keep everything you say in the interview confidential. We will remove any names or details, which would identify you or any other individuals and then delete the recording.

The typed-up record (transcript), identified only by the code number, will be kept for up to 10 years on a securely encrypted, password-protected university computer, in case we need to check the recordings.

How will the researcher use the interview recording and transcript?

The researchers will listen to the conversations carefully and work out what people thought were the most important topics. These will be compared with other interviews. An article will be written based on these topics. The findings may also be presented in reports and conferences. Some selected sections from your interview may be used in these publications and presentations, but your name and any identifiable information will never be mentioned.

What if I decide to withdraw after the interview has taken place?

You are free to decide to withdraw even after the interview. Your interview and transcripts would then be destroyed, except data which has already been published.

Will what I say be kept Confidential?

In our reports and presentations, names will be taken out, so that those reading it will not know who was there or who said what. If you talk about things that have happened to you or others, the researchers will not pass this information on to anyone else.

The researcher will need to keep your contact details to be able to get in touch with you. These details will not be shared with anyone else and will be kept in a password protected file. Details kept on the computer will be protected so that only the researchers working on the project can see them. None of the records will be kept longer than 10 years after the study finishes and will be disposed of securely.

However, if the researcher learns during the conversation that anyone is being harmed or exploited, then it is her obligation to pass on this information to the local safeguarding service with your agreement if possible.

What are the Benefits of taking part?

The aim of this project is to understand how people living with dementia and their carers get help from home care workers with teeth and mouth care. This study is not aiming to help people with problems they face here and now. We hope this will help other carers, social care practitioners and policy makers understand more about people's mouth and teeth care needs and the best ways home care workers can help.

Are there any Disadvantages to Taking part?

You will be able to choose the topics you want to discuss. Occasionally, you may find parts of the discussion upsetting. The researcher will do all she can to make sure you feel at ease and have a break if needed.

What if there is a problem?

If you wish to complain or have any concerns about any aspect of this study, please contact the Head of Department, Dr Lucy Akehurst, on 02392 846337.

You may also contact the Research Integrity and Governance manager at the University of Portsmouth (email: Denise.Teasdale@port.ac.uk or telephone 02392 846196)

Who is organising and funding the research?

This research is organised by researchers at the Universities of Portsmouth, King's College London and Queen Mary University of London. It is funded by the National Institute for Health Research (NIHR) School for Social Care Research. The study Sponsor is the University of Portsmouth.

Who has reviewed the study?

Research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the Social Care Research Ethics Committee (REC ref: 21/IEC08/0032).

Further questions

If you have any further questions, please contact the researcher (Dia), who will try to answer them for you.

Contact: Dr Dia Soilemezi
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Thank you for your time in reading this invitation; we hope to see you in our study soon.

