



University of Manchester
School of Social Sciences
Oxford Road, Manchester, M13 9PL

Research Project:
Temporary changes to Local Authority support during Covid-19
(sometimes referred to as Care Act Easements):
understanding the impact on carers over 70
looking after partners living with dementia at home

Information Sheet

Thank you for taking the time to read about this research project. You are being invited to take part in a telephone interview lasting up to one hour. The interview is to understand the experience of carers aged 70+ who are looking after a partner living with dementia at home during the Covid-19 pandemic.

Before you decide to take part, it is important for you to understand why the research is taking place and what it will involve. Please take time to read this information carefully before deciding, and to talk to others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Who is doing the research?

The University research team are Dr. Philip Drake, Neil Allen, Professor Debora Price and Dr Jayne Astbury. Jayne is the person who will be in touch and speaking to you. The research is being done with the support of the charities TIDE, Making Space, the Alzheimer's Society and Join Dementia Research.

Why are we doing the research?

Carers over the age of 70, with spouses or partners living with dementia, and living at home, are facing many difficulties under Covid-19. On top of these, some local authorities have had to reduce services and support. We know very little about how these reductions have affected people.

Why have you been contacted?

Because you are aged 70 or over and are caring for a partner living with dementia at home.

What happens if you take part?

Jayne will get in touch with you to arrange a one-hour interview at a date and time to suit you. The interview will be by phone, but can be by Zoom if you prefer. She will audio record the discussion with your consent. However, if you prefer not to be recorded just let her know and she will take notes instead. Don't worry if you need to take a break during the interview, or would find it more convenient to do the interview in two parts – just let Jayne know.

What sorts of things will Jayne ask?

Jayne will ask you to say something about yourself, your age and general background, and also about your partner. She will also ask about your health and your care support, particularly during the pandemic. If there are any questions that you don't want to answer, just let her know and she will move on to the next one.

Do I have to take part?

Being involved in the study is completely voluntary - it is up to you to decide whether or not to take part. If you do take part, you can stop the interview at any time without give any reason. For up to two weeks after the interview you can ask for it to be removed from the study. It is important to remember that after that time, it will not be possible to do this as we will have begun to use the information and may not be able to identify which information was yours.

Possible upset

We don't expect the questions to cause you any upset. If they do, you can have a break or stop the interview completely. Jayne will talk to you about any support you might need and may call you the next day to see how you are.

What information will you collect about me?

We will need to collect two sorts of information. One sort will **identify** you:

- your name;
- your contact details, which may include your address, your telephone number, and/or your email address.

The second sort will be **non-identifiable**, for example yours and your partner's age, date of retirement etc. and the audio-recording of the interview.

How will we protect the information you give us?

The University of Manchester is responsible for making sure that your personal information is kept secure, confidential, and used only in the way you have been told it will be used. The University is legally responsible for the data we hold about you and as a result is called the data controller. All the information you give will be securely stored and the university has a data protection policy in place. Further information about how the university uses your personal data can be found by clicking on the following link: [Privacy Notice for Research](#) or can be provided by post upon request.

Who has reviewed the research project?

The project has been reviewed by the NHS Social Care Research Ethics Committee and the Association of Directors of Adult Social Services (ADASS).

Who is funding the research project?

The National Institute for Health Research (NIHR) is funding this project with the reference NIHR202259.

Will I be compensated for taking part?

Participation is voluntary but you will be offered a £20 voucher (which can be used in a wide variety of high street shops) to thank you for your time, together with £20 towards the cost of any substitute care during the meeting.

What benefit might this research be to me or others?

There is no direct benefit to you. However, the findings of this research will improve understanding of how local authorities' adjustment of care services has impacted upon carers aged 70+ of partners living with dementia at home. This will be of particular help in the event of a further wave of COVID-19 or a similar type pandemic.

To have as much impact as possible, other researchers may apply to include the anonymous data in their research. Permission to do this will be subject to ethical review and approval.

What happens next?

Jayne will be in touch with you over the next couple of days to see if you would like to participate. If you don't want to just let her know. If you do, she will arrange with you for a convenient day/time to interview you. With your

consent, we may contact you in the future to see if you might be interested to take part in other research projects.

What if you have a complaint?

If you have a complaint, please contact the Chief Investigator of the research: **DR. PHILIP DRAKE**, Philip.drake@manchester.ac.uk, 0161 275 3568.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers, then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL.

Email: research.complaints@manchester.ac.uk;

Telephone: 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, The University of Manchester, Christie Building, Oxford Road, M13 9PL.

You also have a right to complain to the [Information Commissioner's Office](https://ico.org.uk/make-a-complaint/) (<https://ico.org.uk/make-a-complaint/>) about complaints relating to your personal identifiable information: telephone 0303 123 1113.

Contact for further information

If you have any questions, please contact Jayne Astbury on telephone: 07385463137 or email her at jayne.astbury@manchester.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.