

Exploring the impact of coronavirus related closures of social care services on the lives of people with dementia and family carers.

INTERVIEW INFORMATION SHEET FOR PEOPLE WITH DEMENTIA

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Why is the interview being conducted?

The aim of this interview study is to explore the effects of coronavirus related closures of social care services on the lives of people with dementia and family carers. We are also interested in whether there might be any barriers to accessing substitute care depending on where you live and your background. We will be asking questions about your experiences with available services, how these changed during the COVID-19 pandemic, how did you feel about self-isolation.

What does the interview involve?

The study involves you being interviewed on the telephone by one of the researchers listed above, at a date and time that suits you. The telephone interview will last a maximum of 45 minutes, and it will be audio-recorded. This is so the researchers can listen to and analyse the interview.

Who can participate in this interview?

This project is open to people who are living with dementia in Australia and can communicate in English. During the phone interview, the researcher will make sure that you feel comfortable i.e. they will repeat questions and answers as many times as you need to help you to understand so that you can choose the most appropriate one; you can also skip a question you do not want to answer.

The expected benefits of the research

By taking part in the interview, you can share your experiences of social care service closures, helping raise awareness of the effects that the coronavirus might have on the daily lives of those living with dementia and those caring for a person with dementia.

Risks to you

There are no direct risks to you. You will be asked to give up some of your time to participate in the interview, which will last up to 45 minutes. The nature of the questions should not cause you any distress. However, if you feel distressed throughout the interview, you can stop the interview and speak to the researcher who would refer you to support organisations like Lifeline on 13 11 14 or National Dementia Helpline on 1800 100 500 for free and confidential counselling.

Your consent

You are required to provide formal consent over the phone prior to the interview, and this includes consent to participate in the interview, consent for the interview to be digitally audio-recorded. It also permits your responses, including any written comments, to be reported and/or published in a non-identifiable way in research outputs.

How will we use any personal information?**What is Personal Information?**

Personal information is defined as information or an opinion, including information or an opinion forming part of a database, whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion. Personal Information can be almost any information that is associated with an identifiable living individual. It can include a name, address, date of birth, gender, correspondence, audio recordings, images, alpha-numerical identifiers and combinations of these.

How are we going to use your Personal Information?

The interview will be digitally audio-recorded and, after the audio file has been transcribed verbatim, will be destroyed. The transcribed interview data will then be stored in a re-identifiable way, meaning that your personal information will be removed and replaced by a code. Your name or other directly identifiable data will never be reported in any research publication or output arising from the study, and only the code and non-identifiable information will be used in interview quotations (i.e., #1, carer). Data will be presented in a de-identified format and will be used to produce reports, research publications or conference presentations.

Who are we going to give this Personal Information to?

Your interview will be professionally transcribed by a reputable and trusted transcription service. The transcribed data will be available to the named research team from Griffith University. Researchers from the University of Liverpool (the UK), Wroclaw Medical University (Poland) and the University of Bologna (Italy) may be granted an access to the research analysis to enable comparison between countries.

How will this Personal Information be stored?

Transcribed interview data will be stored electronically in a secure Griffith University research drive, and any hard copies will be stored in a locked cabinet within a restricted access area at Griffith University (Nathan campus). All data will be retained for five-years from the end of the project or, if later, the date of the last publication. It will then be

shredded and disposed of using a secure confidential document disposal service.

Storage of all electronic data is within the cloud (i.e., sometimes outside of Australia) and, as a result, this information may be stored overseas. Griffith University has entered into arrangements that protect the privacy of this data; however, any data stored outside of Australia may be subject to compulsory access through process of law, under the relevant jurisdiction in which it is stored.

Your participation is voluntary

Participation in this interview is entirely voluntary. You do not need to answer every question unless you wish to do so, and you are free to stop or withdraw at any time, without penalty.

Feedback to you

You will receive a one-page summary of the final findings after the project has finished.

Questions / further information

For further information, or if you have any questions, please contact:

Dr Katarzyna Lion, Chief Investigator
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The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project, please contact: The Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (Tel: 07 3735 4375 or research-ethics@griffith.edu.au).

Privacy Statement

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. As outlined elsewhere in this information sheet, your identified personal information may be transmitted, stored or appear in the publications/reports arising from this research that may be available to overseas recipients. This is occurring with your consent. Any additional personal information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes, including publishing openly (e.g., in an open access repository). However, your anonymity will at all times be safeguarded, except where you have consented otherwise. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone 07 3735 4375.