

Getting home safely with dementia: Through the eyes of people with memory problems or early stage dementia

QUT Ethics Approval Number 2021000114

Research team

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Research Assistant:	Ms Katy Wyles Queensland University of Technology (QUT)

Why is the study being conducted?

The purpose of this project is to get the opinions of people living with memory problems or early stage dementia about suggested recommendations to improve their safety should they ever get lost. The recommendations will relate to strategies that optimise safety and autonomy for the person with memory problems or dementia, and policy and procedures for both reporting a missing person with dementia and emergency service response. These strategies were recommended following discussions with police, health professionals, carers of people with dementia and the general public.

What does participation involve?

Your participation will involve supporting the person living with memory problems or dementia that you care for and is the participant in this study. It is not essential that you are involved, the person with memory problems or early-stage dementia is able to participate by themselves if they prefer.

Your participation would involve sitting in on two Zoom meetings organised for the person with memory problems or dementia. Access to an internet connected device with a camera is needed. The first meeting will take approximately 10 minutes and will be used to provide support with using Zoom, answer any questions you both may have about the project and record your verbal consent to participate. The second Zoom meeting will take approximately 30 minutes and will be scheduled at a time convenient to you both.

During this meeting we will ask the person with memory problems or dementia questions including:

- Informing people in your community that you have memory problems or dementia and therefore could get lost is a way of helping to keep people safe.
 - Would you want your community to know that you have memory problems or dementia and could be at risk of getting lost?
 - What are the benefits of informing your community?
 - What are the problems with informing your community?
- Maintaining the safety of people with memory problems or dementia is an important issue. Some strategies include asking the person to wear a device that allows tracking.
 - Would you find these acceptable? Why or why not?

The questions will be directed to the person with memory problems or dementia. You may be able to help them express themselves if needed and clarify some of the points they raise. Your role would also be to notify us if you think the person is becoming fatigued or needs a break and hasn't been able to communicate this to us. Your responses will also be recorded.

If the person with memory problems or dementia would like to speak to us for longer than 30-minutes, and feels up to it, the meeting time can be extended, or we could arrange to meet with you both again to finish the discussion at another time. We will be guided by you both.

Your participation in this research project is entirely voluntary. If you do agree to participate you can withdraw from the research project without comment or penalty. You can withdraw anytime during the interview. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT.

What are the possible benefits for me if I take part?

It is expected that this research project will benefit you directly. You will learn about the potential risks of a person with memory problems or dementia going missing and some possible strategies to prevent this happening. You will also contribute to recommendations that may improve the outcomes of people with dementia who go missing in the future.

To recognise the contribution of the person with memory problems or dementia they will be offered a \$50 Woolworths voucher, however, there is not additional voucher if you are also involved.

What are the possible risks for me if I take part?

There are potential risks associated with your participation in this research project. It is possible that some of the questions may bring up personal memories related to a getting lost event. You may also find it confronting to learn of the risks of the person you care for getting lost if you have never reflected on this possibility. It is possible you may also experience some distress if during the process of determining capacity you become aware of a decline in the person's capacity that you had not previously realised. We can stop the interview at any time.

QUT provides for limited free psychology, family therapy or counselling services (in-person or by telehealth services) for research participants of QUT research projects who may experience discomfort or distress as a result of their participation in the research. Should you wish to access this service please call the Clinic Receptionist on **07 3138 0999** (Monday–Friday only 9am–5pm), QUT Psychology and Counselling Clinic, 44 Musk Avenue, Kelvin Grove, and indicate that you are a research participant.

Alternatively, you can call the National Dementia Helpline on 1800 100 500 or Lifeline who provide access to online, phone or face-to-face support, call **13 11 14** for 24-hour telephone crisis support.

You may also experience fatigue from attending the online interview. To minimise this risk, the interview will go for approximately 30 minutes and there will be opportunity to take breaks if needed.

What about privacy and confidentiality?

The Zoom meeting will be recorded (as both video and audio). After the discussion, the audio recordings will be written word for word and checked for accuracy. All identifying features in the written script of the interview (your name and location) will be removed. The video recording will be deleted after the interview. Notes made during the interview by the interviewer will not contain any information that could identify you, for example, they will record "a male carer stated".

As the research project involves analysing recordings of the online interview:

- It is not possible to participate in the research project without being recorded.
- The audio recording will be retained for the minimum retention period of 7 years after the last research activity. The video recording will be deleted after the interview.
- Only the named researchers will have access to the recording.

Every effort will be made to ensure that the data you provide cannot be traced back to you in reports, publications and other forms of presentation. For example, we will only include the relevant part of a quote, we will not use any names, or names will be changed, and/or details such as dates and specific circumstances will be excluded. Nevertheless, while unlikely, it is possible that if you are quoted directly your identity may become known.

Any data collected as part of this research project will be stored securely as per QUT's Management of Research Data Policy. Data will be stored for a minimum of 7 years, and can be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

Information collected during the interview may be used as comparative data in future research related to this project. Only de-identified data will be used in the comparative analysis. You will also be provided with a link to a summary of the research findings as the conclusion of the data analysis.

The research project is funded by the QUT Centre for Healthcare Transformations and no-one outside the research team, including the Queensland Police Service will have access to the data obtained during the project. At the conclusion of the study, we will give you a summary of our findings.

How do I give my consent to participate?

If the person with memory problems or dementia you care for is interested in participating and wants you to be involved in the interviews please contact us (see contact information below). We will then call you to answer any questions you may have about the project and to ask you some questions about your opinion of whether the person you care for would be able to participate. If you feel they are capable we would call them to assess understanding and then organise a Zoom meeting, when convenient, to record your verbal consent

What if I have questions about the research project?

If you have any questions or require further information please contact one of the listed researchers:

Margaret MacAndrew	margaret.macandrew@qut.edu.au	07 3138 5956
Katy Wyles	catherine.wyles@qut.edu.au	07 3138 3852

What if I have a concern or complaint regarding the conduct of the research project?

QUT is committed to research integrity and the ethical conduct of research projects. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on 07 3138 5123 or email humanethics@qut.edu.au.

Thank you for helping with this research project. Please keep this sheet for your information.