

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 came from discussions with police, health professionals, carers of people with dementia and the general public. They 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.

You are invited to participate in this research project because you are a person living with dementia or have noticed problems with your memory.

What does participation involve?

If you think you want to participate after reading this information, please contact us (see contact information below). During the phone conversation we will check that you understand:

- the risks involved in participation
- what you will be expected to do
- what you need to do if you no longer want to participate, and
- what you need to do if you experience distress or discomfort during the process.

If you understand each of these points we will then set up a Zoom meeting at a time that is best for you. Unfortunately, if you are unable to show us that you understand what participation will involve you will not be able to participate in this study.

If you are eligible, you will participate in two Zoom meetings at times that suit you best.

The **first Zoom meeting** will take 10 minutes and will be used to provide support with using Zoom, answer any questions you may have about the project and record your verbal consent to participate.

The **second Zoom meeting** will take 30 minutes of your time and be scheduled at a time that suits you best.

Questions we will ask you during the second Zoom meeting will include:

- 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?

If you would like to speak to us for longer than 30-minutes, and feel up to it, the meeting time can be extended, or we could arrange to finish the discussion at another time. We will be guided by you.

It is important that we hear your ideas about this topic so the questions will be directed to you. However, you can include your care partner in the interview if you wish. Your care partner can provide support to you as well as clarify any points you raise. Their responses will also be recorded.

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 your contribution should you choose to participate, the research team is offering you a \$50 Woolworths voucher. The voucher will be sent to you via email or by registered post after the interview is completed. Note, there is no additional payment for your care partner should they also participate.

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 getting lost if you have never reflected on this possibility. It is possible you may also experience some distress if during the process of checking your understanding of the project you become aware of a decline that you hadn't been aware of. 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 without any of your personal details. The video recording will be deleted after the interview.

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.

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 any of 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 you are interested in participating and have access to an internet connected computer with a camera, please contact us (see contact information below). We will then set up a short meeting via Zoom to answer any questions you may have about the project and to ask you some questions to

check that you fully understand what is involved in you participating. Specifically, we will ask you to describe the risks associated with participation, what you will be expected to do if you participate, and what you can do if you no longer want to participate or become distressed. If you can demonstrate understanding of these points, we will then ask you to give verbal consent to participate in the interview. After verbal consent has been given, we will then set up another Zoom meeting to conduct the 30-minute interview with you.

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.