

Participant Information Sheet

Improving continence management for people with dementia in the community

Invitation

We would like to invite you **and** your supporter(s) to take part in a research study. Using the toilet is one of the most important activities of daily living that adults want to do independently.

Sometimes dementia and the progressive decline in memory can interfere with getting to and using the toilet or can contribute to incontinence. If you have dementia or memory problems, and this is something that you are experiencing, we would like you to help us understand how you and your supporter(s) deal with these challenges.

We want to identify promising strategies for promoting continence and managing incontinence. We want to co-develop culturally appropriate guidelines and support materials to help others with these challenges.

This research is being conducted in Northland, Auckland and Hawkes Bay and other regions so that we can have views from a range of older people.

Before you decide whether you would like to take part, we would like you to understand why the research is being done and what it would involve for you.

- Section 1 of this booklet tells you the purpose of this study and what will happen if you take part.
- Section 2 gives you more detailed information about the study.

You might like to talk with family or friends about taking part in this study. If anything is not clear or you have any questions, please ask us.

Contact Details Principal Investigator

Professor Vanessa Burholt

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University of Auckland

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Section 1



What is involved?

Why are we doing this study?

Using the toilet is one of the most important activities of daily living that adults want to do independently. Sometimes dementia and the progressive decline in memory can interfere with getting to and using the toilet, or can contribute to incontinence of urine (pee) or faeces (poo).

We would like to know more about how people living with dementia and their supporters deal with these challenges. We want to identify promising strategies for promoting continence and managing incontinence and develop culturally appropriate resources to help others with these challenges.

What will I do if I take part?

If you would like to take part, you will meet with a researcher from the University of Auckland who is part of the research team. The researcher will contact you by telephone or email to arrange a convenient time to visit you to interview you about your experiences.

You can make an appointment to be interviewed in your own home, or at a local venue – anywhere you feel comfortable. We will also arrange to talk with your supporter. This can be at the same time if you agree.

The interview will take between 30 min – 1 hour, but you may decide that you would like to have half of the interview on one day, and the other half on another day.

The researcher will talk to you about your experiences of getting to and using the toilet or managing incontinence. These interviews will be audio recorded. You may request a copy of the recording of the interview if you wish.



The researcher will talk to you about the study. You can ask them any questions. If you are happy to take part they will ask you to sign a consent form.

You will be sent the transcript, that is a typed up copy of the interview. If you need to edit this, you can do so and return it to us within a week.

At the end of the interview the researcher will provide you with another information sheet like this, with some more information about future interviews that we will be conducting. You will be able to take some time to consider whether you would like to participate in these.

Do I have to take part?



You or your supporter do not have to take part in this study. If you would rather not take part, that is fine. It will not affect your health care in the future.

If you would like to take part, we would appreciate your help. Thank you! You can change your mind at any time and stop the session. You don't have to give a reason.

Can my support person stay with me?



We are only inviting people to take part who have a supporter who is also willing to take part in the study. Your support person is welcome to be present while we talk about the study. We would also like to ask your support person some questions about any support they provide that helps you with toileting or incontinence issues.

If you or they request, we can interview your support person at a different time and place.

What are the risks and benefits of taking part?



There is no foreseeable risk to your participation in this project, but it is possible you may find some of the topics upsetting.



If you do not want to talk about any of the topics, you do not have to – just tell the researcher that you prefer not to talk about that issue.

If you do become upset, you should make this known to the researcher immediately. They will be able to provide you with advice on free counselling services that are available. The researcher will stop the interview and ask if you would like to resume the interview at a later time or date, or withdraw from the study.

We take very seriously and make every effort to protect your privacy through coding and removing any information that could identify you. The risk of people accessing and misusing your information is currently very small. However, this risk may increase in the future as people find new ways of tracing information.

Our researchers will reduce the risks of COVID-19 transmission in the following ways:

- We will only arrange face-to-face interviews during orange and green settings under the COVID-19 Protection Framework (or when the COVID-19 Protection Framework is no longer necessary)
- All researchers are double vaccinated
- Researchers will maintain at least 1 metre distance from participants and will wear masks during interviews
- Interviews will only be undertaken if you and the researcher(s) are able to answer 'No' to the questions:
 1. Are you feeling unwell with flu-like symptoms such as fever, cough, shortness of breath or sore throat?
 2. Do you, or has someone that you have had contact with have a confirmed case of COVID-19?

We cannot promise that the study will help you, but the information we get from the study will help to us to identify challenges associated with toileting and incontinence so that support can be strengthened in New Zealand in the future.

Section 2



More information

Who will take part?

We would like 30 people and their supporter/s to take part in the study, some of whom we hope will be happy to have on-going contact.

We are seeking people who are over the age of 65 years who have dementia and have experienced some challenges in getting to and using the toilet or incontinence.

The researcher will conduct a face-to-face interview with you and your supporter, and they will arrange a time and place that is suitable for you. The interview will be audio recorded.

The interviews will be transcribed by someone who will have signed a confidentiality agreement.

During the interview you have the right to choose not to answer a question or to stop the interview at any time.

We will provide you with a \$50 voucher at the completion of the interview as a way of compensating for your time and saying thank you.

What will happen to the results of this study?

Researchers in the project team will have access to a copy of your interview to analyse, without your name or any other information that might identify you. This will be stored in an 'Institutional Dropbox'. This is a secure password protected cloud storage for data.

The consent form and other material that includes information that might identify you, such as the original audio file, will be kept securely, and separately from the information you provide in the interview. Any identifiable data will be stored on the University of Auckland managed storage and will only be accessible to the Principal Investigator.

Data collected as part of this project will be stored for three years of the funded project and for a ten-year period beyond. After that, the data will be erased.

The only circumstances under which we would let anyone know you are taking part would be if we felt you may be at risk of harm, harming yourself or someone else. Under these circumstances we would ask you what you would like to happen, and with your consent discuss this with your supporter. If the health problem or safety issue requires immediate action, an ambulance or your GP would be contacted. The researcher may disclose the risk of harm to the lead investigator and medical members of the project team to discuss the situation and develop a plan of action if required. This may include revealing your identity to your GP.



We will write up a report of the study to let professionals know about the results. We are likely to present the findings at conferences, on our website and in journal articles. We will not use your name or any other information that might identify you in these publications. We will send you a summary of the results of the study if you wish.

What will happen if I stop taking part?

You can stop taking part or withdraw from the study at any time without explanation.

If you decide you wish to withdraw your data (the information you provided during your interview) from the study, you may do so for up to 3 months after your interview. After this time, your interview will have been analysed and it will not be possible to extract it from the results. Any requests for withdrawal of your interview 3 months after the researchers visited you, will mean that the copy of the interview will be removed from the University of Auckland file storage (see above).



Who is running this study?



This research is led by Prof Vanessa Burholt. Her contact details are on the front page. The other people in the research team are listed below. You can contact any of them with any questions or concerns. All of their contact details are below.

The research costs are being supported by the Health Research Council of New Zealand (HRC)

Who can I talk to if I have questions or concerns?



If you have any questions or concerns about your interview, you are very welcome to contact the researcher:

Julie Daltrey

School of Nursing University of Auckland

Email: j.daltrey@auckland.ac.nz

Telephone: 09 923 9745

Contact Details of all Named Investigators

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Contact Details of Head of School

Julia Slark, School of Nursing, University of Auckland, Telephone: 09 923 8471, Email: j.slark@auckland.ac.nz

If you would like to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Email: advocacy@advocacy.org.nz
Website: <https://www.advocacy.org.nz/>

For any concerns of an ethical nature, you can contact the Health and Disability Ethics Committee (HDEC) on:

Phone: 0800 4 ETHIC
Email: hdec@health.govt.nz

Approved by Southern Health and Disability Ethics Committee on 28/4/2022 for three years. Reference Number 11658