



University of Otago Human Ethics Committee (Health)



Participant Information Sheet

Study title:	Getting help for urine leakage: experiences of people with neurological conditions.	
Principal investigator:	Daniela Aldabe School of Physiotherapy Lecturer	Contact phone number: 03 4795426

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends before deciding whether or not to participate.

If you decide to participate, we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

This research project aims to explore the perceptions of people with stroke, multiple sclerosis, and Parkinson's disease living in Aotearoa New Zealand, about the assessment and management of urine leakage they received within the NZ healthcare system.

Who is funding this project?

This study has been funded by the University of Otago Research Grant.

Who are we seeking to participate in the project?

We are seeking a total of 30 participants who live with the consequences of stroke, Parkinson's disease or Multiple Sclerosis and are experiencing (or experienced) urinary incontinence issues.

If you participate, what will you be asked to do?

Should you agree to take part in this project, you will be asked to:

Attend an interview. The interview will be held via Zoom, or if you prefer, at the School of Physiotherapy (Dunedin or Christchurch). It will take 1-hour max and will be arranged at a time that is suitable for you. You are welcome to have a support person to the interview. If after the interview there are unclear topics, we may need to contact you for further clarification. If necessary, this second contact will be done via phone call. The interview will be recorded and will be transcribed for analysis.

The interview will comprise three stages. First, you will be asked demographic questions (age, ethnicity, level of education, time since stroke event or Multiple Sclerosis and Parkinson's disease diagnosis). Then, you will be asked to fill a questionnaire about your ability to perform activities of daily living. Finally, you will be asked about your experiences with assessment and management received for your urinary incontinence symptoms.

See below some examples of the questions you will be asked:

1. When did you first notice urine leakage symptoms?
2. What are the bladder problems you experience now?
3. What are some of the things you're doing to manage leakage?
4. Who have you talked to about the bladder problems?
5. Which of those people has been involved in finding out why you have these bladder problems?
6. Who's helped explain these bladder problems?
7. What have you found most helpful to manage the problems?
8. Where did you get this help from?

As a thank you for your participation, a \$40 dollar voucher will be given.

Is there any risk of discomfort or harm from participation?

Talking about your experiences around the assessment and management of urinary incontinence you received within the NZ healthcare system might be uncomfortable for you. If you feel uncomfortable or anxious about it, you can take a break from the interview at any time. However, if you find the questions distressing and emotionally overwhelming, you may decline to answer.

What specimens, data or information will be collected, and how will they be used?

We will collect data about you (e.g. age, gender, years of living with a neurological disorder, health service you usually use) and your experiences with the NZ health system regarding assessment and management of urinary incontinence issues.

The interviews will be transcribed and coded by themes. Quotes from the interview will be used but your identity will be kept confidential. The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it.

Data obtained as a result of this research will be retained for at least 10 years in secure storage, i.e. in a password secured computer. Any personal information will be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

If you agree, after this study we will use what you have said to help us write a script for a role-play. Actors will play a person with a neurological condition who has a bladder problem. They might say some of your words in the role play. You will not be named, and nothing that could identify you will be used in writing the script. A video-recording of the role play will be shown to health-care professionals in a second study to find out how they think bladder problems should be assessed and managed.

What about anonymity and confidentiality?

The results of the project may be published, but every attempt will be made to preserve your anonymity. We will provide an electronic copy (or a hard copy if you prefer) of the final report to all participants who wish to receive this document, once the study is accepted for publication by a scientific journal.

If you agree to participate, can you withdraw later?

You may withdraw from the project before its completion and without any disadvantage to yourself before 30th December 2022. If you do wish to withdraw, your interviews will be immediately deleted and will not be included in the final findings of the study or used in the next study. You will not be able to withdraw your information if it has already been integrated into the study.

Any questions?

If you have any questions now or in the future, please feel free to contact:

Daniela Aldabe Lecturer School of Physiotherapy	Contact phone number: 03-4595426 Email: Daniela.aldabe@otago.ac.nz
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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or e-mail gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.



Getting help for urine leakage: experiences of people with neurological conditions.

Principal Investigator: Dr Daniela Aldabe

Email: Daniela.aldabe@otago.ac.nz

Phone number: 03 4795426)

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project before 1st of December, 2022.
6. I know that as a participant, I will be interviewed about my experiences with urinary incontinence assessment and treatment I received in the NZ healthcare system. My interview recorded and transcribed for analyses.
7. I know that this research will explore *my experiences with the assessment and treatment I received for my urinary incontinence symptoms* and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) , and /or may withdraw from the project without disadvantage of any kind.
8. I understand that, if I agree, some content from my interview or direct quote may be used to create a script that will be role-played by an actor and used in another study.

Please tick one:

I agree

I DO NOT agree

9. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.

10. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
11. I understand that the results of the project may be published and be available in the University of Otago Library.
12. I know that a \$40 dollar voucher will be given if I complete the whole interview.

Signature of participant:

Date:

Name of person taking consent

Date:



Getting help for urine leakage: experiences of people with neurological conditions.

This study aims to investigate the experiences of people with stroke, multiple sclerosis and Parkinson's disease about their experiences regarding assessment and management received for urine leakage incontinence within the NZ health care system. By finding out more we hope to improve care for this condition.

We are seeking 30 people with stroke, Parkinson's disease or multiple sclerosis who had or currently have urine leakage. You should also have some experience of discussing or getting some help from a health professional for a bladder problem. Participants should be able to communicate in English.

As an appreciation of your time we will offer you a \$40 dollars voucher.

If you would like to be interviewed please send an email to pelvichealthphysio@otago.ac.nz

This project has been reviewed and approved by the University of Otago Human Ethics Committee, (Health). Reference: H22/033

<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>	<p>Getting help for urine leakage: experiences of people with neurological conditions. pelvichealthphysio@otago.ac.nz</p>
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