



How healthcare professionals support people with dysautonomia

INFORMATION SHEET FOR PARTICIPANTS.

Thank you for showing an interest in this project. Please read this information sheet carefully 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 the Project?

Dysautonomia is a term used to describe problems with the autonomic nervous system, which helps regulate automatic body functions such as heart rate, blood pressure, and breathing. People experiencing dysautonomia may have symptoms such as dizziness, fatigue, exercise intolerance, difficulty concentrating, and symptoms that worsen when standing.

The purpose of this study is to explore the experiences and perspectives of healthcare professionals who support people with dysautonomia signs and symptoms. We are interested in learning about healthcare professionals' experiences, the challenges they encounter, the knowledge and skills they use in practice, and their views on the services and supports available for people with dysautonomia.

By understanding these experiences, we hope to identify opportunities to improve education, support, and healthcare services for people living with dysautonomia.

What Type of Participants are being sought?

*We are seeking approximately **10 healthcare professionals** from Aotearoa New Zealand who have current or recent experience supporting people with dysautonomia signs and symptoms, such as dizziness, fatigue, exercise intolerance, difficulty concentrating, and symptoms that worsen when standing.*

To be eligible, you must be a registered healthcare professional and have at least six months of current or recent experience working with people who present with dysautonomia signs and symptoms.

*There is **no payment or reimbursement** for participation in this study.*

Although there may be no direct personal benefit from taking part, your experiences and perspectives may contribute to a better understanding of how healthcare professionals support people with dysautonomia. Findings from the study may help inform future education, professional development, and healthcare service improvements. Participants will be offered a summary of the study findings on completion of the project.

What will Participants be Asked to Do?

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

- *Complete an online screening form to confirm that you are eligible to participate.*
- *Read the Participant Information Sheet and complete an online consent form.*
- *Provide your contact details so that an interview can be arranged at a time that suits you.*
- *Participate in one online interview via Zoom with members of the research team. The interview is expected to take approximately **30 to 60 minutes**.*
- *Agree to the interview being audio-recorded and transcribed for analysis.*
- *Share your experiences and perspectives of supporting people with dysautonomia signs and symptoms.*
- *If you wish, review a summary of the preliminary findings and provide any additional comments or reflections.*

This project involves an open-questioning technique. *The general line of questioning includes healthcare professionals' experiences of supporting people with dysautonomia signs and symptoms, the knowledge and skills required to support people with dysautonomia, challenges encountered when providing care, perspectives on current healthcare services and supports, and opportunities for improving care and support.*

The interview will be guided by a semi-structured interview schedule that has been reviewed as part of the ethics application. However, the precise nature of all questions that may be asked has not been determined in advance and will depend on the way in which the interview develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review every follow-up question that may be used.

In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable, you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

This study is considered low risk. However, you may find some questions uncomfortable, particularly when discussing professional challenges, limitations in healthcare services, or areas where you have felt underprepared or unsupported. You are free to decline to answer any question and may stop the interview at any time without providing a reason.

The findings will be de-identified and reported in a way that does not identify individual participants, and any quotations used in publications or presentations will be anonymised. All data will be stored securely and accessed only by authorised members of the research team.

There are no known physical risks associated with participating in this study. The main inconvenience is the time required to participate in the interview.

Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

If you agree to take part, we will collect information that you provide during the study. This will include:

- *Information provided during the eligibility screening process.*
- *Your name and contact details for arranging the interview.*
- *An audio recording of your interview.*
- *A written transcript of the interview.*
- *Any comments you choose to provide during the member reflection stage.*

The information collected during the interview will be used to help us understand healthcare professionals' experiences and perspectives of supporting people with dysautonomia signs and symptoms. Findings from the study may be published in academic journals, presented at conferences, included in reports, or used to inform future research.

*Your interview will be **audio-recorded only**. The audio recording will be used to create a written transcript for analysis by the research team. Interviews will be transcribed using the offline transcription function within Microsoft Word. Audio recordings will be processed locally on a secure university computer and will not be uploaded to external or third-party transcription services. No artificial intelligence (AI) transcription services or cloud-based transcription platforms will be used.*

Your name and contact details will be stored separately from your interview data. Interview transcripts will be de-identified after analysis, and any quotations used in publications or presentations will be anonymised.

Access to identifiable study information will be restricted to the research team:

- *Dr Gerard Farrell (Principal Investigator)*
- *Donna Keen*
- *Associate Professor Cathy Chapple*

Data will be stored securely using University of Otago-approved systems, including REDCap and OneDrive. Only authorised members of the research team will have access to the data.

*The data collected will be securely stored so that only the research team can access it. In accordance with University of Otago requirements, research data will be retained for a minimum of **10 years** following completion of the study. At the conclusion of the retention period, study data will be securely destroyed.*

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time up to two weeks after your interview, without any disadvantage to yourself of any kind. If you withdraw within this period, we will remove any identifiable information you have provided wherever practicable. After this point, data analysis may have commenced and it may no longer be possible to remove your information from the study.

What if Participants have any Questions?

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

Dr. Gerard Farrell

School of Physiotherapy

University Telephone Number: (03) 479 7460

Email Address: gerard.farrell@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee - Te Pae Matatika Tangata, Ōtākou Whakaihu Waka – Reference number: 26/0461. If you have any concerns about the ethical conduct of the research, you may contact the University of Otago Human Ethics Committee through the Human Ethics Committee Administrator (ph +64-3-479-8256 or humanethics@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.