

Participant Information Sheet

Healthy ageing in adults with cerebral palsy

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*This study has been approved by the Northern A Health and Disability Ethics Committee
Feb 2024 for 3 years (reference 18972).*

Kai ora,

This is an information sheet about a research project looking into the health experiences of adults with cerebral palsy.

This study is being done by our research team members. Some of the researchers work from the university and some are adults with cerebral palsy.

The research team members are

Ms. Woroud Alzaher

She is a PhD student at the University of Auckland.

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Dr. Sian Williams

Senior Research Fellow, University of Auckland

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Prof. Susan Stott

Professor and Orthopaedic surgeon, University of Auckland and Starship Hospital

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Ms. Amy Hogan

Researcher, New Zealand Cerebral Palsy Society

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Ms. Jenney Rogers

Māori Advisor, University of Auckland

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You are invited to participate in this research study. It is completely your choice to take part in this research. You do not have to take part if you do not want to.

What is this study about?

We do not know very much about the health of people with cerebral palsy in their adulthood. We want to find out:

- What health changes do adults with cerebral palsy experience?



- What do adults with cerebral palsy need to stay healthy?

How will this research help?

By being part of this research, you will help us learn:

- What health changes adults with cerebral palsy experience as they grow older
- What do adults with cerebral palsy find most important in their health
- What do adults with cerebral palsy need to stay healthy

This information will help us to:

- Understand how health changes over time for an adult with cerebral palsy
- Understand what is important to adults with cerebral palsy as they age
- Find out what helps adults with cerebral palsy age well
- Find out which important health questions to ask adults with cerebral palsy to track healthy ageing



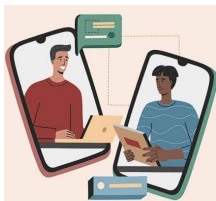
What are we asking you to do?

If you agree to take part in this study, you will be asked to:

- Complete a questionnaire about yourself, and
- Take part in an interview with a researcher

The questionnaire takes about 20 minutes to complete.

The interview takes about 1 hour to complete.



The interview will be over a video call, held over Zoom.

You can have a support person you trust or family member with you during the interview. We will write up what you say during the interview. We will ask you to check what we have written up is right.

We will send you a shopping voucher, worth \$50, to say thank you for taking part.

What are the possible risks of this research?

You may feel uncomfortable or upset at some of the questions we ask. If you do feel uncomfortable or upset during the questionnaire or interview, you can let the researcher know straight away.

You do not have to answer all the questions we ask. You can choose how much or how little to share. You chose when to stop the interview at any point. You do not need to provide a reason.

You can also talk with someone you trust like a family member or talk with your doctor.

You can also get help from these services:



Healthline

Call 0800 611 116 for trusted health advice from nurses, paramedics and advisors.



Lifeline

Call 0800 543 354 for free counselling



For a list of other helpful services, visit the Mental Health Foundation page to find the service that is right for you:
<https://mentalhealth.org.nz/helplines>

If you want to talk to someone who isn't part of this study, you can call a health and disability advocate on:

Phone: 0800 555 050

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>



Can I stop taking part in the research?

You can say no to taking part in this study at any time.

You do not have to answer all the questions we ask.

To stop taking part in this study, talk to the research team. If you stop taking part, we will delete information you gave us.

We might not be able to delete information you gave us after your name is removed (de-identified) and the information you gave is combined with other study information.



How will your information be kept private?

Only researchers who are part of this study can see your information.

We will keep your information private at all times.

We will not talk about your information outside of this research.

We may use your information as part of the research for:

- Talks or conferences
- Write articles about it for publication
- Write easy to read fact sheets or make a video about it to share what we have learnt

We will not use your name when we share information from this research. Your name will be removed and replaced with a number so that your information is

kept private. We will not use any of your information for future research, unless you say it is ok.

How will your information be kept safe?

We will keep your information on a computer that has a password. Your information will be kept for seven years if you finish the study. After that, the information is destroyed.



How will you know how the research went?

At the end of the research, we will send you an easy-to-read report about what we found out.

Ethics Committee Approval

Our research has ethics approval. This means it has been checked over to make sure we are doing it right and doing it safely.

This study has been approved by the Northern A Health and Disability Ethics Committee on 12 Feb 2024 for 3 years (reference 18972).



Questions and concerns

If you have any questions about this research, you can contact Woroud on Woroud.alzaher@auckland.ac.nz or any research team member.

If you want 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
 Fax: 0800 2 SUPPORT (0800 2787 7678)
 Email: advocacy@advocacy.org.nz
 Website: <https://www.advocacy.org.nz/>

If you think we are not doing the research right or safely, you can contact the health and disability ethics committee (HDEC) on:

Email: hdec@health.govt.nz
 Phone: 0800 400 569 (Ministry of Health general enquiries)

Thank you for taking the time to read this information sheet.

If you want to be involved, please contact Woroud on woroud.alzaher@auckland.ac.nz

CONSENT FORM

Please tell us if you need an interpreter.

Healthy ageing in adults with cerebral palsy

- I have read and understood the information about the research.
- I have been given enough time to consider whether or not to take part in this study.
- I have had the opportunity to get legal advice, whanau/ family support or a friend to help me ask questions and understand the study.
- I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.
- I understand that taking part in this study is my choice and that I can stop participating at any time.
- I agree to my discussion being audio recorded.
- If I decide to stop participating after my information is combined with other data (de-identified), information I have shared will still be used.
- I understand that the information I share is private and that I won't be named in this research. I understand that the information collected may be published or written about. I understand that I will not be named in any research products.
- I know that I can contact the research team if I have any questions about this study.
- I understand my responsibilities as a study participant.

If you identify as Māori, I agree to my de-identified information to be made available to Māori organizations if requested Yes ☐ No ☐

I agree to my de-identified information being used in future research Yes ☐ No ☐

I wish to receive a summary of the results from the study Yes ☐ No ☐

Declaration by participant: I, _____ (full name) hereby consent to taking part in this study.

Signature _____ Date _____

Declaration by member of research team: I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Name: _____ Signature: _____ Date: _____