



VICTORIA UNIVERSITY OF
WELLINGTON
TE HERENGA WAKA

AUT



**Looking at the early experiences of
disabled people using the assisted
dying service in Aotearoa New Zealand**



Participant Information Sheet

Published: September 2023

Before you read this document



Assisted dying is a hard thing for many people to read / talk about.



If you are worried or concerned after reading this document you can talk to:

- your family / friends
- your support workers.

NEED TO TALK?



**free call or text
any time**

If you want to talk to someone about how you are feeling you can talk to a trained counsellor at 1737: Need to talk.



A trained counsellor is someone who can help you talk about your feelings.



You can talk to 1737: Need to talk by:

- calling: 1737
- texting: 1737.

1737: Need to talk is free to call or text.

This means it will not cost you any money to call or text 1737: Need to talk.

What you will find in here

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What is assisted dying?



Assisted dying is a new health service in Aotearoa New Zealand.



The assisted dying service started in 2021.



The assisted dying service means that some people who are **terminally ill** can choose to take medicine to make them die.



A **terminal illness** is an illness that:

- cannot be cured
- you will die of.



There are **strict rules** about assisted dying.

Strict rules are rules that:

- have to be followed carefully
- cannot be changed for people even a little.



These strict rules are called the **eligibility criteria**.



Assisted dying is in a law called **End of Life Choice Act 2019**.



About Assisted Dying



Easy Read printed May 2022

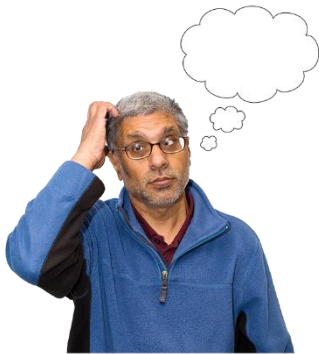
You can find more Easy Read information about the assisted dying service on the Te Whatu Ora – Health New Zealand **website**:

<https://tinyurl.com/yztkxwwa>

What is this study about?



AUT



The Victoria University of Wellington and Auckland University of Technology are inviting you to take part in a study.

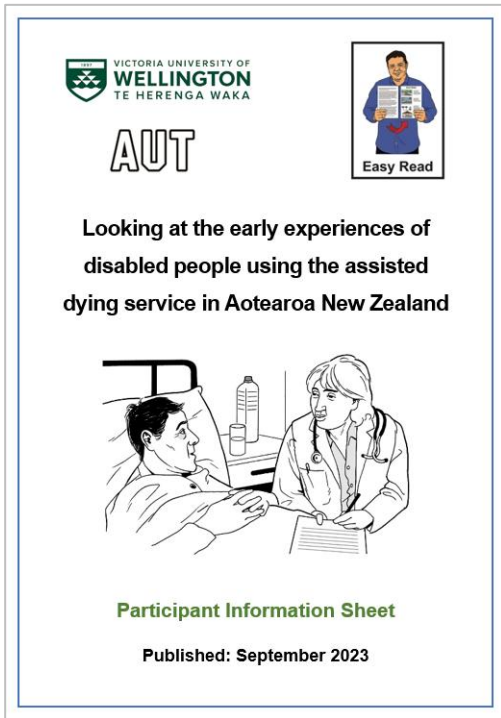
The study is about on what disabled people think about the **accessibility** of the assisted dying service.



Accessibility means disabled people can:

- get information about the assisted dying service
- apply to use to the assisted dying service.

Participant information sheet



This Participant Information Sheet:

- will assist you decide if you want to take part in the study
- tells you why we are doing this study
- tells you what you would need to do to take part in the study
- tells you what happens when the study ends.



The research team will go through the Participant Information Sheet to make sure you understand all the information.



It is your decision if you want to take part in the study or not.

It is okay to say you do not want to take part in the study.



If you do decide to take part in the study it is also okay to change you mind about taking part in the study.

You will be asked to sign a **consent** form to show that you want to take part in the study.

Consent means saying:

- yes to taking part in this study
- you understand what it means to take part in the study.

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Easy Read

Looking at the early experiences of disabled people using the assisted dying service in Aotearoa New Zealand

Consent form

Published: September 2023



You can take home a copy of the:

- Participant Information Sheet
- Consent Form.



If you have any questions about the study you can talk to the research team who are doing the study.

To talk to the research team you can:



Email:

assisteddyingresearch@vuw.ac.nz



Phone:

Dr Jessica Young on 04 886 4513.

Why are we doing the study?



The assisted dying service gives more choices to people with a terminal illness.



There are also some hard things about the assisted dying service for:

- people with terminal illness
- whānau / families
- health workers
- health services.



The study will look at how:

- the assisted dying service is working
- safe the assisted dying service is.





The study will also look to see if the assisted dying service is:

- **mana enhancing**
- accessible
- available to everyone who meets the eligibility criteria.



Mana enhancing means to:

- show respect for the things people know
- build trust
- use what people know in ways that makes things better.



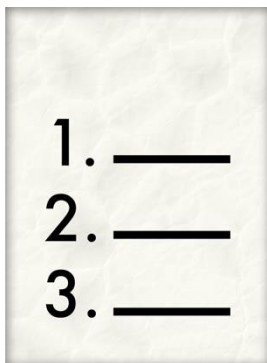


We think it is important to learn about how well you think the assisted dying service is doing for disabled people.



We will use what you tell us to write a report.

In the report there will be **recommendations** about how the accessibility of the assisted dying service could be made better for disabled people.



Recommendations are things that should be done to make things work better for everyone.

Who can take part in the study?



To take part in the study you must:

1. be a disabled / Deaf person

and

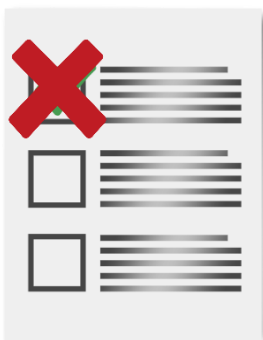
2. be able to make your own decisions about taking part in the study

and

3. have been told you meet the assisted dying service eligibility criteria

or

4. have been told that you do not meet the assisted dying service eligibility criteria.



Who is doing and funding the study?



Dr Jessica Young is leading the research into assisted dying.



Kate Diesfeld and Pip Patston are leading the study on disability and assisted dying.



The 3 researchers have already done a lot of work looking at assisted dying in Aotearoa New Zealand.



The Health Research Council of New Zealand is funding / paying for the study.



The research team is part of:

- Victoria University of Wellington
- Auckland University of Technology
- Otago University
- University of Canterbury
- University of Auckland
- Queensland University of Technology.

This study has been approved by an **independent** group of people called a Health and Disability Ethics Committee.

Independent means the group is not part of the study / research.

How will the study be done?



For this study we want to talk to 15 disabled people about how well they think the assisted dying service would work for them.



You will be given a 50 dollar voucher / gift card as a thank you for taking part in the study.



There will be 1 interview / meeting where we will ask you questions.



You will meet with 2 people at the interview:



- Pip Patston
- Kate Diesfeld.



The interviews will be held on Zoom which is a service that allows people to talk / meet online.



If you live in Auckland Kate may be able to meet you in person for the interview.



Please let us know if you have any **accessibility needs** so that you can take part in the interview such as:

- having a New Zealand Sign Language interpreter on the New Zealand Relay Service
- having a support person of your choice at the interview
- anything else that would make it comfortable for you to take part in the interview.





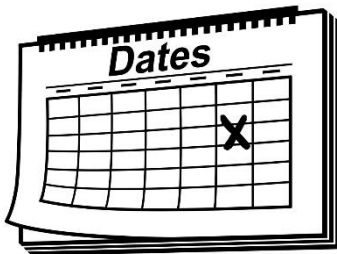
If you would like a Māori interviewer to sit in with Pip and Kate we will invite 1 of our Māori team members.



The interview will last for about 90 minutes.



You can take a break during the interview at any time if you feel tired or upset.



We can also finish the interview another time if you cannot keep going with the interview.



You can stop your interview / information being used up until the start of **data analysis**.



Data analysis means that we look closely at the information that people told us in the interviews.



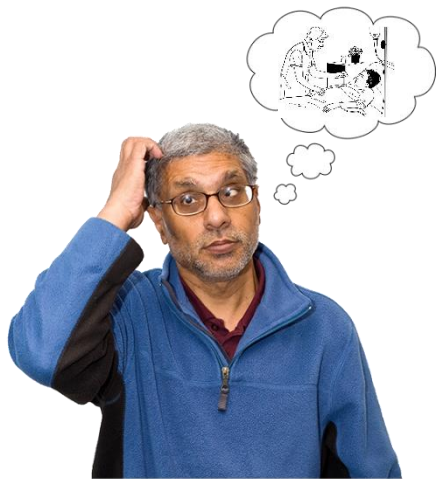
Any information collected about you up to that point may continue to be used.



The interviews will be **audio recorded** which means we will record the things you say.



The audio recordings will then become **transcripts** which are written documents of the things you said in the audio-recording.



Pip and Kate will ask you questions about what you think of assisted dying.

For example:

- Can you please tell me about your experiences so far of the assisted dying service?
- What does a good assisted dying service look like to you?



Looking after how you are feeling



Talking about dying can be upsetting to talk about.



You do not have to answer any questions that you are not comfortable with.



If you do become upset you can:

- take a break or stop at the interview
- ask for audio-recording to be turned off while you take a break.



The day after your interview Kate will contact you to check on how you are feeling.



If you become very upset because of taking part in the study we can pay for you to:

- see your doctor
- see a counsellor.

Confidentiality



Confidentiality means keeping your personal information **private**.

Private means that we will not share any of your **personal information** with other:

- people
- groups.

Personal information means things about you like your name.

We will make sure we keep your personal information private.



Your personal information will not be used in our report.

What you share with us will be treated respectfully.



The only time we may not keep your personal information private is if we are worried about any **risk of harm** to:

- yourself
- others.

Risk of harm means to hurt yourself or others.



We will tell you if we need to tell someone else about the risk of harm.

What will happen with your information?



Your information includes things like:

- your name
- your contact details like your:
 - phone number
 - address / where you live
- audio recordings.

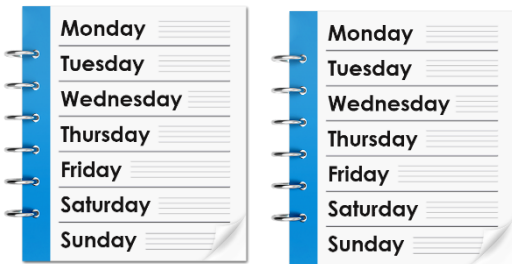


This information will be stored in a secure place with password access only.

Only the research team will see your information.



If you would like to look at your interview transcript please tick the box on the Consent Form.



You will have 2 weeks to tell us about any changes you want to the interview transcript.



The interview transcripts with your name removed will be kept for 10 years.



The interview transcript may be used in other research about assisted dying.



What we find out in the study will be used in:

- media articles like newspapers
- conference presentations
- other reports.



You can ask for a copy of a summary of the study findings / report.



Please tick the box on the Consent Form that asks for a copy of the study findings / report.

Where to find more information



If you have any questions or complaints about the study you can contact:



Dr Jessica Young

Lead Investigator

Phone: 04 886 4513

Email: jessica.young@vuw.ac.nz



Professor Kate Diesfeld

Co-Investigator

Phone: 09 921 9999 then press 7837

Email: kate.diesfeld@aut.ac.nz





If you want to talk to someone who is not involved with the study you can contact an independent health and disability advocate on:



Phone: 0800 555 050

Email:

advocacy@advocacy.org.nz



Website: www.advocacy.org.nz

You can also contact the health and disability ethics committee that approved this study on:



Email: hdecs@health.govt.nz



This information has been written by Victoria University of Wellington.



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