

Participant Information Sheet

Exploring the early experiences of the assisted dying service in Aotearoa – Families or close friends

Sponsor: Victoria University of Wellington

Lead: Dr Jessica Young

Study Site: Wellington

Contact phone number: +64 4 886 4513

Ethics committee ref.: 18493

You are invited to take part in a study on your experiences with the assisted dying service. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do want to take part now but change your mind later, you can withdraw from the research up until the time data analysis begins.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. Please feel free to talk about the study with other people and ask the research team any questions before deciding.

Please contact Aida Dekhoda if you have any questions on +64 4 887 3140 or assisteddyingresearch@vuw.ac.nz

If you agree to take part in this study, we will go through this information with you and answer any questions. You will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is seven pages long, including the Consent Form. Please make sure you have read and understood all the pages.

VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS STUDY

Your participation is voluntary. You have the right to decline to answer any questions in the interviews that you don't want to, or to withdraw from the research up until the time data analysis begins, without any disadvantage to you.

If you decide to withdraw from the study, you can decide what happens to the information collected about you up to the point when you withdraw, for example, if you wish your interview transcript will be destroyed and won't be used in the research.

WHAT IS THE PURPOSE OF THE STUDY?

The End of Life Choice Act (2019) legalised assisted dying for people who are assessed as meeting all of the eligibility criteria. While providing new choices for people with a terminal illness, assisted dying also creates new challenges for individuals, health practitioners and the health system.

The purpose of the research is to gain insights into how the assisted dying service is working to inform the review of the assisted dying service to make sure it's safe, people-centred, mana enhancing, accessible, and available equitably to all eligible people. Your perspectives on this issue will help achieve this goal.

The findings of the study will help us make recommendations for service users and their families, health professionals and the health system.

HOW IS THE STUDY DESIGNED?

We are aiming to talk to 20 people, who have supported someone using the assisted dying service (whether assessed as eligible or ineligible by an assisted dying practitioner).

We will conduct the interview via Zoom (or by phone if you don't have access to the internet). There will be two interviewers, Manu Pelayo and Dr Jessica Young or Dr Aida Dehkoda. Please let us know how we can meet any needs you have so that you can comfortably participate. The interview will last up to 90 minutes. If you feel tired or distressed, you can take a break or finish the interview another time.

One of the researchers (Manu) works in the assisted dying service, and you can choose if you'd like Manu to be an interviewer or not.

WHO CAN TAKE PART IN THE STUDY?

You are eligible to participate if you supported a family member or a close friend who

1. applied for assisted dying whether they died by assisted death service; or
2. assessed as ineligible and died a natural death

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

If you choose to participate, we will contact you to arrange an interview at a time that suits you. Interviews will be audio-recorded. In the interview, the interviewer will ask about your experience with the assisted dying service. We will ask you questions like,

‘What does an ideal assisted dying service look like from your perspective?’ ‘How would you best be looked after throughout the whole process and after the death?’

You are welcome to have a support person and a cultural advisor with you during the interview. We are happy to find a cultural advisor if you would like us to.

If you are Māori and consent to us passing on your details, Dr Tess Moeke-Maxwell will interview you through our sister project ‘Waerea: Māori whānau experiences of assisted dying in Aotearoa New Zealand’.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

People’s views on assisted dying vary widely and can be challenging to talk about. You do not have to answer any questions that you find uncomfortable. We will ensure the confidentiality of your participation in the study and the information we collect about you, except where a participant discloses something that causes the researcher to be concerned about a risk of harm to yourself or others. You will not be identified in any publication, and we will remove your name from the interview transcripts by using another name of your choice. No participant’s identity will be revealed to anyone other than the researchers. We will ensure the story you share with us is treated respectfully.

You might find some of the questions difficult to answer, or they may cause you discomfort. **At any point in the interview, you can ask to pause or stop or for the recording to be turned off.** Please see the list of supports on page 5.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

Your participation in the research may benefit others. Your experiences of supporting someone through the assisted dying process are important to learn about and gain insight into. This study will add to the research on assisted dying in New Zealand.

A greater understanding of these issues may improve people's experiences of using and providing assisted dying. The research might inform the delivery of assisted dying services. For example, the study may make recommendations for educating health professionals about how to talk about patient’s preferences, as well as how they want their family/whānau involved.

WILL ANY COSTS BE REIMBURSED?

You will receive a \$50 voucher to say thank you for participating in the interview.

WHAT IF SOMETHING GOES WRONG?

The day after your interview, your interviewer will contact you to check how you are. If you become seriously distressed because of participating in the study, the expenses for a professional counselling session or a GP appointment will be covered by the study.

WHAT WILL HAPPEN TO MY INFORMATION?

The data collected (e.g., your contact details and digital audio recordings) will be securely stored (with password access only) on secure university servers. The interview will be recorded to the Zoom-managed cloud and transcribed using their built-in automated service and then checked by a research team member. We will delete any recordings from the cloud once they are transcribed.

If you would like to review and revise your interview transcript, please check the box on the consent form. We ask that you send any revisions back to us within two weeks.

Any personal information held about you (such as contact details and the interview audio recording) will be deleted at the completion of the research. You can ask for a copy of any of your information and can correct any information about you. The interview transcripts that have all identifying information removed, such as names and places, will be kept for much longer and may be used in other research on this topic. De-identified data will be retained for at least 10 years in secure storage. Only the research team will have access to the data.

The project results will be published in media articles, conference presentations and research articles, and reports will be written for health professionals and educators.

CAN I FIND OUT THE RESULTS OF THE STUDY?

A summary of the results will be sent to you if you wish at the end of the study.

WHO IS RUNNING AND FUNDING THE STUDY?

Dr Jessica Young is leading the research. Dr Young and the research team have made a substantial contribution to the growing field of assisted dying research in New Zealand. Some of the team are members of the government-appointed Support and Consultation for End of Life NZ (SCENZ) Group, although this research is independent of that group.

The Health Research Council funded this study. The research team are affiliated with Victoria University of Wellington, Auckland University of Technology, Otago University, University of Canterbury, University of Auckland and Queensland University of Technology.

WHO HAS APPROVED THE STUDY?

The ethical aspects of this study have been approved by an independent group of people called the Health and Disability Ethics Committee (HDEC). It checks that studies meet ethical standards. The Northern A Health and Disability Ethics Committee has approved this study through the full review pathway [ref 2023 EXP 18493].

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Jessica Young, Lead Investigator
+64 4 886 4513
jessica.young@vuw.ac.nz

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/>

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

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

LIST OF SUPPORTS

All the following services are free and available 24/7.

Te Whatu Ora: "Assisted dying is a sensitive topic and may be difficult for some people. If reading this information raises distressing feelings for you, there is support available. You can call or text **1737** (<https://1737.org.nz>) for free to speak to a trained counsellor at any time." Further information on assisted dying for the public is available on the MoH website: <https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-information-public>

Grief resources: <https://www.griefcentre.org.nz/resources/>

Lifeline: Phone 0800 543 354 (0800 LIFELINE) | www.lifeline.org.nz. Lifeline provides free, private telephone counselling 24 hours a day, 7 days a week.

Suicide Crisis line: Phone 0508828865 | <https://www.lifeline.org.nz/services/suicide-crisis-helpline/>

Consent form – Exploring the assisted dying service

Please indicate your consent to the following.

I have read and understood the Participant Information Sheet.

I have been given sufficient time to consider whether or not to participate in this study.

I have had the opportunity to use a legal representative, whānau/ 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 voluntary (my choice) and that I may withdraw from the study at any time.

I understand that I can withdraw my information up until the start of data analysis and that the information collected about me up to that point may continue to be used. Yes No

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I understand my responsibilities as a study participant.

I agree to the interview being audio-recorded. Yes No

I wish to review a copy of the interview transcript. I understand that if I want to make changes to the transcript, I will need to send that back within two weeks. Yes No

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

Email: _____

Declaration by participant: By writing or typing my name in the Signature box, I hereby consent to take part in this study.

Participant's name: _____

Signature: _____

Date: _____

Declaration by a research team member: 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.

Researcher's name: _____

Signature: _____

Date: _____