Participant Information Sheet

Motor Neurone Disease (MND) Survey

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Motor Neurone Disease New Zealand

Contact phone number: 021 336 685

Ethics committee ref.: 2025 EXP 21804

Kia ora, Talofa, Shalom, Kia orana, Mālō e lelei, Salaam Alaikum, Namaste, Ayubowan, Vanaakam, Nei hou, Hallo, Welcome.

My name is Natalie Gauld and I'm inviting you to take part in a survey on motor neurone disease (also known as MND). MND is a group of diseases including ALS, PLS and bulbar palsy. I am the lead researcher on this study, and, like you, I have MND, diagnosed in 2022. I work part-time at Motor Neurone Disease New Zealand (MND NZ).

We are doing this survey to learn about what is and isn't working for people with MND. We want to know about healthcare and equipment used, and people's well-being. The more people who do this survey, the better we understand MND in Aotearoa New Zealand (NZ). However, 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, and it won't affect the care you receive.

Whaowhia te kete mātauranga

Fill the basket of knowledge

I hope this Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the survey, what is involved, and what the benefits and risks to you might be. Before you decide you may want to talk about the survey with other people, such as family, whānau, friends, healthcare providers or your MND NZ Support Advisor. Feel free to do this. You can also call me, Natalie Gauld on 021 336 685.

If you agree to take part in this survey, you can do the survey online or on paper. Patients with MND also have a phone option.

This document is 6 pages long. Please make sure you have read and understood all pages. At the end of the document is how to get to the surveys.

VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS SURVEY

You can choose if you want to do the survey or not. Because the survey does not include your name, after you finish the survey, you cannot get your survey information taken out.

WHAT IS THE PURPOSE OF THE SURVEY? HE AHA TE WHĀINGA MŌ TĒNEI RANGAHAU

MND affects about 400 people in NZ at any one time. It includes all ethnicities, perhaps about 20 people who are Māori.

We are doing this survey because we need to know what is and isn't working for people with MND in NZ and their family/whānau.

A summary from this survey will be used to advocate for all people with MND, and their families and whānau. It will show areas for improvement for sharing with health care providers so they can work better with people with MND. It will show areas where more research is needed. It will give a picture of MND in NZ that can be shared with everyone involved in MND.

The more people with MND or their family/whānau carers who do this survey, the better we can understand what is happening with MND in NZ and help address the challenges.

HOW IS THE STUDY DESIGNED?

There are three surveys.

One survey is for people with MND. The survey can be done online, on paper or by phone. We hope to have 300 or more people with MND do the survey. This survey is likely to take 1-2 hours.

The second survey is for family/whānau carers of people with MND – their key supporters. This survey is online or on paper. We hope 200 or more people will do this survey. This survey is likely to take about 30 minutes.

The third survey is for family/whānau carers of people with MND whose person with MND has passed away in the last 2 years. This survey is online or on paper. We hope 200 people or more will do this survey. This survey is likely to take about 30 minutes.

You have about a month to do the survey. The closing date for the survey is 9 April 2025.

You do not need to answer all questions. You can miss a question if you do not want to answer it. But we do need an answer to these questions: the year of diagnosis, age, gender and the region for all surveys please.

WHO CAN TAKE PART IN THE STUDY?

There are three groups.

1. **Survey for people with MND.** We are inviting everyone over 16 years of age with motor neurone disease to take part in this survey. That can include people who have had a diagnosis of MND, amyotrophic lateral sclerosis (ALS), primary lateral sclerosis (PLS), progressive bulbar palsy (PBP), progressive muscular atrophy (PMA) and Kennedy Disease. We are also including people with neuronal intranuclear inclusion disease (NIID).

   Sometimes people with MND can have a diagnosis of “possible ALS”, “probable ALS” or “definite ALS” – this is still a diagnosis and you can all do this survey. You can do this survey even if you have just been diagnosed.

2. **Survey for family/whānau carers of people living with MND.** We are inviting family/whānau carers of people who have been diagnosed with MND to complete this survey. This is for the key supporter/s from the family/whānau of people with MND. Even if your person with MND is quite capable, you can still do this survey.

3. **Survey for bereaved family/whānau carers of people with MND where the person with MND has passed away.** We are inviting family/whānau carers of people who were diagnosed with MND and passed away **within the last two years** to complete this survey. This is for the main supporter/s from the family/whānau of people with MND.

For all three surveys, you cannot take part in this survey if:

- You are under 16 years of age.
- There has not been a diagnosis of MND. If you/your person are undergoing testing for MND, but it has not been diagnosed, do not do this survey.
- You or your person with MND do not live in Aotearoa New Zealand.

- For the family/whānau carers surveys, do not do the survey if you are not the primary supporter/s of that person.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE AND HOW CAN YOU HELP? KA PĒHEA TŌ ĀWHINA MAI

This study is a survey that you can answer how you like: online, on paper or by phone.

The survey will ask people about their experiences with MND. This will include the diagnosis, equipment, house modifications and care – from health care professionals as well as carers. It will also ask about current physical function, sleep, anxiety and mood. There are some questions on the financial impact of MND, hospice and end-of-life care. Patients also have questions on toileting. Family/whānau carers have questions on burden of care. Some questions might be sensitive or cause embarrassment - if you do not want to answer these questions you do not need to.

The survey for people with MND has three parts to it which can be completed separately. Altogether we expect it to take 1-2 hours. For some people it might take longer. If you get tired you can take a break and come back to it another day.

The family/whānau carers surveys are shorter and will take about 30 minutes.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

There is a risk that you might feel upset or embarrassed by a question, e.g. about mood or toileting. You do not need to answer these questions if you do not want to.

If you feel upset by any of the questions in the survey, please talk to your family doctor or your MND NZ support advisor – see: https://mnd.org.nz/support-information/our-services/support-team/ . If you have MND, you can contact the MND NZ support advisor even if you are not a current client of MND NZ.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

There may not be any direct benefit to you of doing this survey. Some people have found it helpful to share their feelings and experiences about MND.

The possible benefits of this study are to increase the understanding of MND in NZ and show areas for improvement. We hope this will help with the care of people with MND and their family/whānau through advocacy to create improvements and sharing the summarised information of the survey to health professionals and others involved in MND care.

The survey results will help to highlight possible improvements for all people with MND. It will help inform health professionals, funders and Support Advisors how they can most help people with MND and their family/whānau. It will also show where more research is needed.

WILL ANY COSTS BE REIMBURSED?

There is no cost to you to do this survey – only your time. There is no payment for doing the survey. However, people with MND doing this survey have the opportunity to win one of three supermarket vouchers for $100 each as a prize draw. Family/whānau carers have the opportunity to win one of three supermarket vouchers for $50 each as a prize draw.

If you enter this prize draw, your name and phone number will be separated from your survey before it gets to the research team.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

WHAT WILL HAPPEN TO MY INFORMATION? KA AHATIA NGĀ KŌRERO KA TUKUNA MAI

By completing the survey you are consenting to the collection of this information.

Researchers will analyse the data that is collected from the survey. To make sure your personal information is kept confidential, no information that could identify you will be included in any report generated by the researcher.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

Your survey will be done as an anonymous survey. This makes it very difficult (but not impossible) to identify the information that belongs to you. Only the researchers and a person entering the information from a written survey or doing the phone survey will see your survey answers.

Future Research Using Your Information.

Your survey information may be used for later analysis by the same researchers, potentially with other researchers involved.

Your survey answers will provide valuable information or taonga that other researchers in NZ or overseas might want to analyse in the future. You will be able to choose when you do the survey whether your survey information is shared or not.

We will ask in the survey if you want your information available to other researchers in the future. This is your choice and you can say no to this request. If you agree, your survey information may be shared with other researchers for future MND research if they ask this research team. Identifying information such as the region lived in and your exact age will be removed first to reduce the risk someone could work out who participants are. It may be added to information from other studies to form larger sets of data.

If you agree to sharing this information, you will not be told when future research is undertaken using your information or get reports or other information about any future research that is done using your information.

If you agree to having your information in your survey shared, it may be used indefinitely for future research. Because the surveys do not have your name, it is not possible to withdraw your consent to this later.

Security and Storage of Your Information.

Your survey information is held by the lead researcher, Dr Natalie Gauld, during the study and stored for at least 10 years, then destroyed. The data will be stored in a password-controlled file on a password-controlled computer. Written surveys will be stored in a locked cupboard then entered into a computer by a person who has signed a confidentiality agreement. The written surveys will then be shredded. All storage will comply with local data security guidelines.

If you are an MND patient and you do the phone survey, your phone number and first name will be collected by the person doing the phone survey. These details will be destroyed after you have completed the survey, or at the end of the survey period if you do not complete the survey.

Risks.

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small, but may increase in the future as people find new ways of tracing information.

This research includes basic information such as your ethnic group, age and gender. It is possible that this research could one day help people in the same groups as you. However, it is also possible that research findings could be used inappropriately to support negative stereotypes, stigmatize, or discriminate against members of the same groups as you.

The lead researcher (Natalie Gauld) has MND and knows some other people with MND. So she might sometimes be able to guess who some surveys might be from. She will not share this information with anyone else. No one else from Motor Neurone Disease New Zealand will see the surveys, so your Support Advisor will not know if you did the survey (unless you choose to tell them). The Support Advisor, health professionals or other people involved in your care will not know what you said in your survey.

Rights to Access Your Information and Withdraw Your Information.

Because the survey is anonymous, you will not be able to access, correct or withdraw your information, even if you change your mind about it being used.

Māori Data Sovereignty

Māori data sovereignty is about protecting information or knowledge that comes from Māori. We recognise the taonga of the data collected for this survey. To help protect this taonga:

- We have consulted with Dr Jo Hikaka and Dr Denise Blake about the collection, ownership, and use of study data.
- We allow Māori organisations to access de-identified study data, for uses that may benefit Māori.
- We have consulted with Māori affected by MND and Jeanette Tioke, Support Advisor for Motor Neurone Disease New Zealand in developing the research.

WHAT HAPPENS AFTER THE STUDY?

After the study a survey report will be written and given to the funder of the study (Health Research Council), Motor Neurone Disease New Zealand, people affected by MND and their families/whānau, health professionals and other people managing MND and people involved with policy relating to MND. Presentations will be done to these groups to share the information.

No one will be identified in this report, published papers or presentations.

CAN I FIND OUT THE RESULTS OF THE STUDY?

A summary of the study will be available on the MND NZ website, or can be requested from natalie.gauld@mnd.org.nz. Support Advisors from MND NZ will have copies of the survey report also.

You can confidentially provide your email address for a summary of the study. The email address will be kept apart from survey information. This summary should be ready June 2025.

WHO IS FUNDING THE STUDY?

This survey is funded by the Health Research Council of New Zealand (HRC). It is also supported by Motor Neurone Disease New Zealand.

WHO HAS APPROVED THE STUDY? HE KŌRERO WHAKAMĀRAMA MŌ HEC

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards. The Central Health and Disability Ethics Committee has approved this study.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS? MEHEMEA NGĀ PĀTAI, HE RARURARU RĀNEI, ME WHAKAPĀ KI A WAI

If you have any questions, concerns or complaints about the survey at any stage, please contact:

Dr Natalie Gauld, Principal Investigator of the Motor Neurone Disease Survey
Phone: 021 336 685 Email: natalie.gauld@mnd.org.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/

For Māori cultural support please contact:

Jeanette Tioke, Support Advisor for Motor Neurone Disease New Zealand
Phone: 029 777 5588
Email: jeanette.tioke@mnd.org.nz

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

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

HOW TO DO THE SURVEY

The survey can be done online (preferred) or on paper. Or by phone for people with MND.

Online. This survey will save as you do it so can be done over days or weeks.

Your progress is automatically saved, allowing you to complete the survey over multiple days or weeks at your own pace.

Paper: A printed version is available upon request (see next page for details).

Phone: People with MND can complete the survey over the phone if needed (see next page).

For people with MND:

To make the survey easier to complete, we have split it into three parts. This helps ensure people with MND can take breaks as needed and complete the survey at their own pace.

You can complete the survey in sections over multiple days or weeks. Each part focuses on different aspects of your experience, and all responses are valuable.

For people with MND, start here:

Survey Part 1: https://mnd.org.nz/pwmnd1

Survey Part 2: https://mnd.org.nz/pwmnd2

Survey Part 3: https://mnd.org.nz/pwmnd3

Remember: Your progress is automatically saved if you use the same computer and the same web browser (e.g. Google Chrome or Firefox), so you can return to the survey any time before the finish date.

For **family/whānau carers of people living with MND** go to: https://mnd.org.nz/family

For **bereaved family/whānau carers of people with MND who passed in the last 2 years** go to: https://mnd.org.nz/bereaved

On paper – email toni.foster@mnd.org.nz and request a paper copy of the survey to be posted out (state if the survey is for a person with MND, for family/whānau carers of people living with MND or for bereaved family/whānau carer). Or you can ask your Motor Neurone Disease New Zealand Support Advisor for a copy. Or text Natalie Gauld on 021 336 685 to request a copy.

Phone survey - People with MND can instead do the survey by **phone** if online or paper is not suitable or too difficult. Text Lynette on 0274 633 824 to request a phone survey. This will be arranged at a time that suits you. Your name and phone number will not be seen by the research team. Sorry, the phone survey is not available for family/whānau carers**.**