Strategic Plan

2025-2028

Motor Neurone Disease New Zealand Charitable Trust
Charity registration CC60169

mnd
Motor Neurone
Disease NZ

Our story

Motor Neurone Disease NZ is a charitable trust built on the ethos of helping people affected by motor neurone disease — and that remains the cornerstone of everything we do.

Since being established in 1985 by a group of volunteers with personal experience of the disease, we've grown into the vibrant and passionate community we are today.

Motor Neurone Disease NZ is the only organisation in Aotearoa solely dedicated to supporting people with motor neurone disease and their loved ones.

Our strength lies in personal, wraparound support — offering both practical and emotional guidance as we walk alongside people from diagnosis through every stage of their journey.

We offer connection, advocacy, and hope in the face of uncertainty. This tailored support model is central to our identity and underpins all that we do — from education and awareness to research and community-building.

We are committed to making our support accessible across all communities, and the lived experience of people with MND and their whānau continues to shape and guide our work.

> ***He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata.***
>
> ***What is the most important thing in the world? It is people, it is people, it is people.***

Our Vision for the future

We envision a world where no one faces motor neurone disease (MND) alone—where people are supported to live with dignity and hope, and where, one day, MND is treated, cured or prevented.

Our Mission

Making time count for people affected by MND by offering personal support, advocacy, education, and supporting research.

Every day, we work to make a difference through:

Support to make life easier for people living with MND and their loved ones.

Advocacy to drive change and timely access to health and disability services.

Education to increase knowledge, recognition, and understanding of MND.

Campaigning to raise awareness and build trust and support for our cause.

Fundraising to support people impacted by MND now and provide hope for the future.

Investing in research to improve quality of life, aid advocacy, and support research in New Zealand.

Our context

Motor neurone disease (MND) is a devastating, rapidly progressing disease that robs people of everything.

People with MND know how their life will end — trapped inside a body that no longer works, unable to speak, move, and, eventually, breathe. It is a terrifying fate, and it can affect anyone.

MND is aggressive and relentlessly progressive. Around 50% of people die within 30 months of symptom onset, and only about 20% survive longer than five years. There are over 400 people with MND at any given time in New Zealand.

Every week, at least two people are diagnosed — and at least two New Zealanders die from the disease.

MND affects people from all communities, ethnicities, and occupations. There is currently no effective treatment and no known cure.

A diagnosis comes with overwhelming and complex challenges — physically, emotionally, and practically.

The pathway from diagnosis to death is typically around 36 months in Aotearoa, with equipment and support needs often shifting more rapidly than health and disability systems can keep up with.

This is the reality that underpins everything we do.

We exist because the need is urgent, persistent, and growing. We take this responsibility seriously — not just in principle, but in practice. We do what we say we'll do because people with MND don't have time to waste.

We talk about making time count because time is the currency of MND — and it's in short and diminishing supply.

As the only organisation in Aotearoa solely dedicated to the MND cause, we focus on what matters most: delivering tailored support, strong advocacy, practical education, and a clear voice for research and systemic change.

We rely on fundraising, donations, and grants to fund this work — and it's through the generosity of others that we can continue to stand alongside every person affected by MND in New Zealand.

Our priority areas

TAILORED SUPPORT

We will provide a personal, consistent support offering to every person affected by MND in New Zealand, that answers questions and solves challenges quickly.

MEANINGFUL ADVOCACY

We will raise awareness and champion our cause, campaign for change, and lead the way in making a difference.

PRACTICAL EDUCATION

We will provide a broad range of education opportunities to increase knowledge, recognition and understanding of MND.

IMPACTFUL RESEARCH

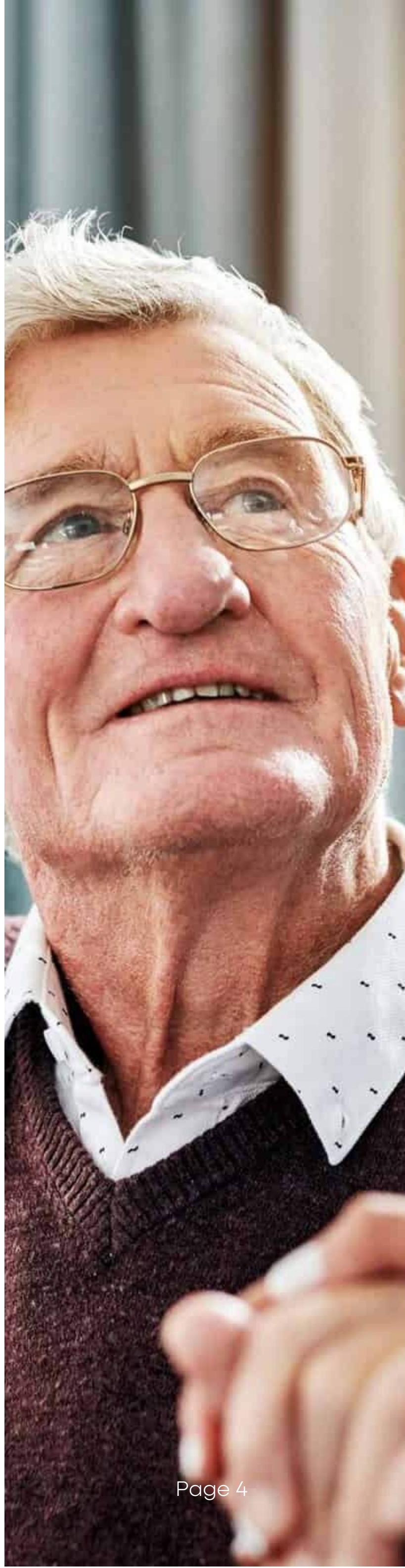
We will adopt a collaborative approach to funding and supporting MND research, with the goal of bringing treatment studies to NZ, supporting policy decisions, improving quality of life, discovering effective therapies, and finding a cure.

INSPIRATIONAL ENGAGEMENT

We will be strong in our brand, engage with clarity and purpose, and achieve sustainable, diverse income for our work. We will grow our community and foster a sense of belonging.

ORGANISATIONAL EXCELLENCE

We will grow our people, nurture collaborative relationships, build our reputation, and embrace a growth mindset. We will grow and develop our cultural competencies.



Our values

The blue cornflower is the international symbol for MND. While the cornflower has a fragile appearance, it is both courageous and determined, able to withstand the most testing of environments.

This vivid blue flower mirrors the remarkable strength shown by people affected by MND in coping with this devastating disease. We draw inspiration from these traits and use them to guide how we work to achieve our mission and vision.

How our values guide us

Resilient

We're not afraid to speak up on the issues that matter. We tackle challenges professionally and with integrity.

Authentic

We are open, transparent and consistent in our work. We use plain and understandable language.

United

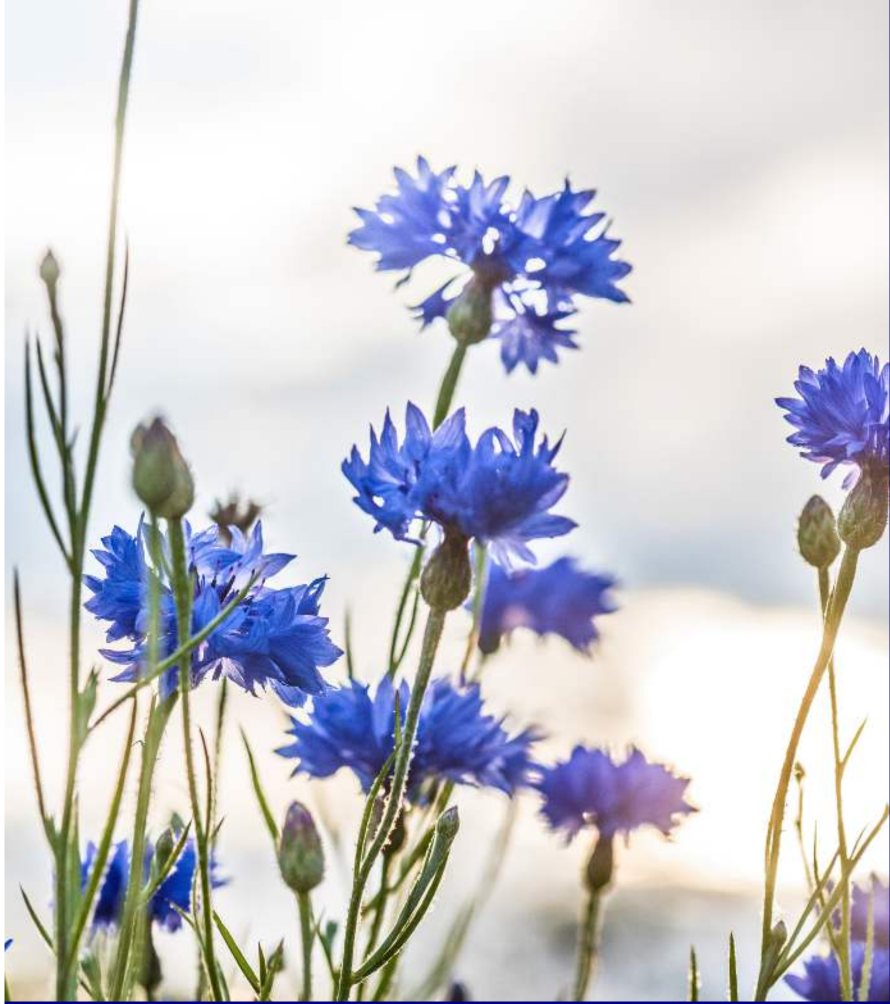
We celebrate and embrace working together. We are respectful, inclusive, and friendly. We listen, we understand, and we don't judge.

Steadfast

We are experts in our field and provide robust, transparent advice and support wherever it is needed.

Bold

The MND community is at the centre of everything we do. We speak with one proactive and dignified voice to represent the views of our community.



We exist because the need is urgent, persistent, and growing. We take this responsibility seriously — not just in principle, but in practice. We do what we say we'll do because people with MND don't have time to waste.

Delivering on our priorities

TAILORED SUPPORT

We will provide a personal, consistent support offering to every person affected by MND in New Zealand, that answers questions and solves challenges quickly.

Over the next three years we will:

- Continue to provide practical and emotional support for people with MND through community-based support advisors.
- Celebrate families and carers with support specific to their needs.
- Provide high quality printed and digital information on MND topics and the support service.

MEANINGFUL ADVOCACY

We will raise awareness and champion our cause, campaign for change, and lead the way in making a difference.

Over the next three years we will:

- Campaign with one voice to influence nationwide change in policy informed by the needs, diversity, challenges and urgency faced by people with MND.
- Champion the individual for access to timely support and care in their region.
- Work collaboratively with like-minded organisations, health agencies, Māori health providers, Te Whatu Ora | Health New Zealand, and other community-support networks.

PRACTICAL EDUCATION

We will provide timely, practical and robust education opportunities to increase knowledge, recognition and understanding of MND.

Over the next three years we will:

- Continue to provide practical education and information on an individual level to people with MND and their immediate families.
- Review and build our education offering for health professionals and those involved with MND care, ensuring those who want to know more, can find relevant and applicable information fast.

Delivering on our priorities

IMPACTFUL RESEARCH

We will adopt a collaborative approach to funding and supporting MND research, with the goal of bringing treatment studies to NZ, supporting policy decisions, improving quality of life, discovering effective therapies, and finding a cure.

Over the next three years we will:

- Continue to fund the NZ MND Registry, providing an important picture of MND in New Zealand.
- Run a comprehensive survey to identify pressing needs of people with MND and family carers.
- Establish a robust research strategy that is clear about our role in the advocacy space, using community needs to inform this work.
- Increased communication about MND-related research happening in Aotearoa and abroad.

INSPIRATIONAL ENGAGEMENT

We will be strong in our brand, engage with clarity and purpose, and achieve sustainable, diverse income for our work. We will grow our community and foster a sense of belonging.

Over the next three years we will:

- Develop our brand, extending our recognition and reach to ensure we are on everyone's radar should they, or a loved one, need us.
- Increase our presence in communities, connecting over local fundraising and awareness events.
- Consistently demonstrate the impact of donations and how it helps people with MND, ensuring supporters can clearly see the value we create with their money.
- Diversify our income streams and events programme to ensure a robust future.

ORGANISATIONAL EXCELLENCE

We will grow our people, nurture collaborative relationships, build our reputation, and embrace a growth mindset. We will grow and develop our cultural competencies.

Over the next three years we will:

- Put teamwork, communication and staff well-being at the core of what we do.
- Attract, develop, and motivate the very best team, ensuring everyone has the appropriate knowledge and understanding to carry out their work.
- Stong strategic leadership that aligns short term decisions with long term objectives.
- Review and develop our governance processes to support transparency and accountability.

Our decision-making approach

To ensure we are always focused on working towards our vision and mission, every decision we make will be assessed against six key questions:

1. **Will it make things easier for people with MND and their loved ones?**
2. **Will it increase our reach to ensure a wider awareness of MND and engagement with our mission of making time count?**
3. **Can the work be done within the current framework of our organisation? If not, what do we need to do to support a solution or decision?**
4. **Does it support our commitment to growing and developing our people?**
5. **Will it improve the diversity, strength, and sustainability of our funding base?**
6. **Does it build on our existing skills and strengths and support sustainable growth?**

Underpinned with feedback

A three-question survey was undertaken in 2024 to understand what is valued most by people with MND, what we doe well, and what we could do better. Below, are some of the areas of strength, and areas of opportunity.

We have strong support for our:

Information Sharing
Regular updates through newsletters, emails, and the website keep the community well-informed, and efforts to raise awareness are appreciated.

> ***"Newsletters with research, how others are coping, keeping MND at the forefront with fundraising and newspaper articles"***

Support Services
Staff are praised for providing practical and emotional support to both people with MND and their families.

Personal Support
Compassionate, individualised support is highly valued.

> ***"Having a support person to guide us through this horrible journey, them knowing what levers to pull and when, who to connect with us – really helps"***

Community and Connection
MND NZ fosters a strong sense of community through support groups, events, and connecting families at similar stages of the MND journey.

> ***"A sense of community and positivity at a challenging time"***

Fundraising and Advocacy
The organisation's ability to fundraise and advocate nationally on behalf of MND patients and their families is well-regarded.

There are opportunities in:

Support Advisor Coverage
Concerns about regional disparities and long wait times for visits, especially in rural areas.

Increased Communication
More regular check-ins and communication between MND NZ and families.

Tailored Regional Support
Certain regions lack sufficient local support networks and coverage.

Increased Awareness and Advocacy
Enhance public awareness campaigns and advocate more strongly for better health services and support for people with MND.