



THE MOTOR NEURONE DISEASE
ASSOCIATION OF NEW ZEALAND

STRATEGY 2019-2022



INTRODUCTION

MND New Zealand supports people living with motor neurone disease, their carers, families and whanau, and the health professionals who work with them throughout New Zealand

Motor neurone disease (MND) is a life-shortening neurological disease that can affect anyone. MND causes the muscles that enable us to move, speak, swallow, and breathe to gradually stop working. Eventually, you're locked in a body that can no longer move. MND is also known as ALS or Lou Gehrig's disease in some countries.

New Zealand has one of the highest known rates of MND in the world; two people are diagnosed with MND each week. MND often comes as a shocking diagnosis in otherwise healthy people, frequently in middle age. It is a rapidly progressing disease that requires frequent adaptation to increasing levels of disability, and demands increasing levels of support. One third of people with MND die within a year and more than half within two years of diagnosis.

Despite being heavily researched, the cause of MND is not well understood and there is no cure.

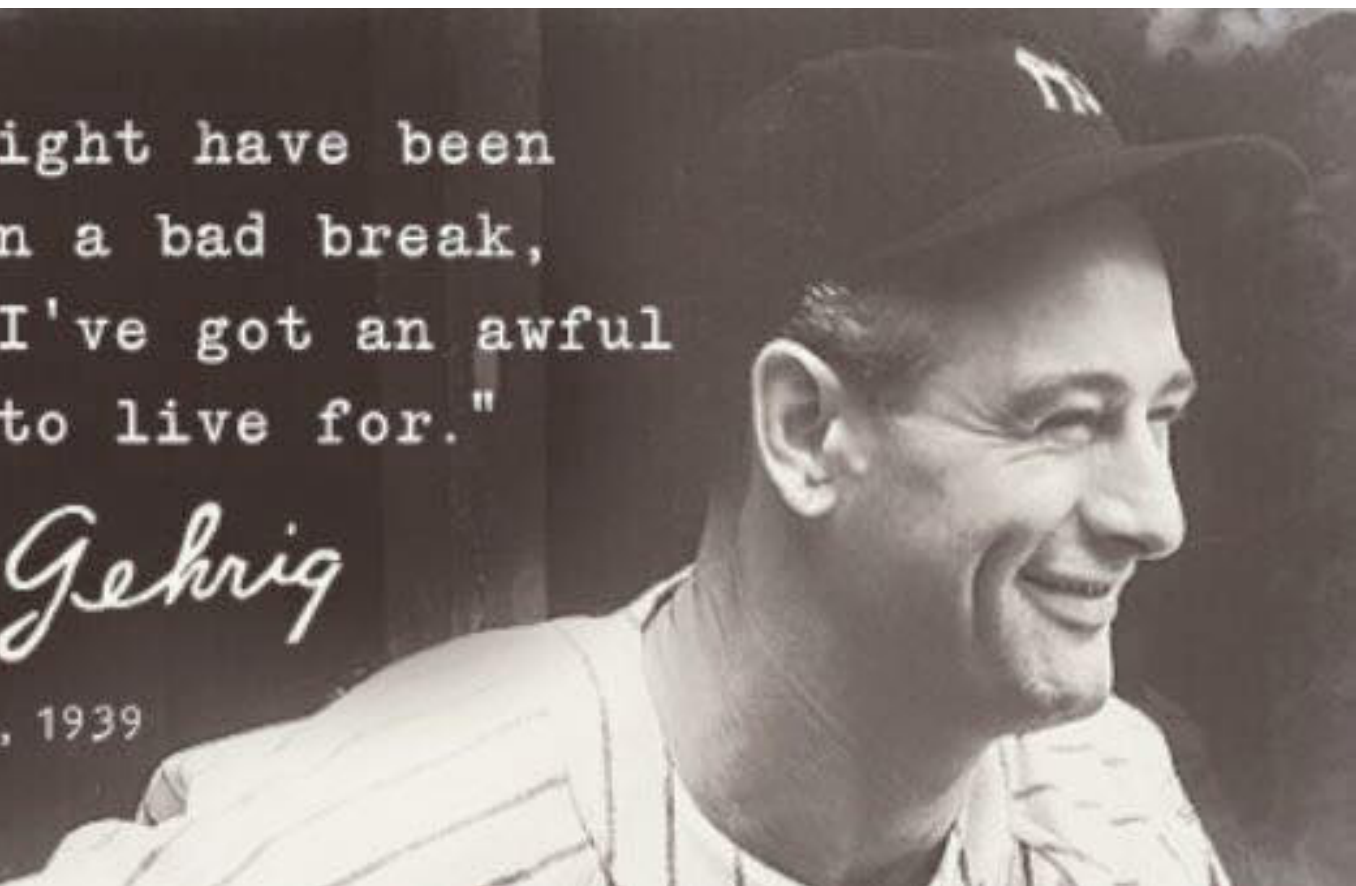
MND New Zealand was founded in 1985 by a group of very determined volunteers who had family or friends battling this relentless disease. We are the only national organisation in New Zealand focused on MND support, awareness, education and information, research, and advocacy. We are a registered charity under The Charities Act 2005, registration number CC35320.

MND New Zealand relies almost completely on the generosity of the New Zealand community via donations and fundraising to continue to provide free, personalised support to people living with MND, their carers and families, and the health professionals who work with them.

"I might have been given a bad break, but I've got an awful lot to live for."

Lou Gehrig

July 4, 1939



This plan is the result of the collaborative work undertaken on behalf of the MND community by MND New Zealand staff and National Council members. It is also a result of in-depth consultation with our wide range of stakeholders via the 2018 MND Community Survey.

The very high response rate to the survey “means that the survey results can be taken as a reliable indication of the support needs of MND New Zealand’s clients.” (Point Research, 2018).

The plan considers the work undertaken on behalf of our clients, families, and carers, as well as the work done by our staff, volunteers, and National Council. It also takes into account how MND Zealand interacts and collaborates with other agencies, health professionals, and researchers.

It sets the direction for our work via our commitment to successfully delivering six strategic priorities, continuing to work towards achieving our vision, and maintaining our values. People living with MND will always remain at the centre of everything we do.

The plan is designed to support not only those living with MND today, but also those who have yet to be diagnosed. It is intended to help not only the person diagnosed, but also their carers, families, and whānau.

It shows how we will maintain our commitment to ensuring that people living with MND, as well as their carers and families, receive the best quality support, at the same time as championing their right to access the best healthcare and social assistance throughout New Zealand. We constantly review and improve our existing services, communication, and information to ensure people living with MND and, their carers and families get

what they need when they need it.

Understanding of MND has grown in recent years, with the pace of global MND research increasing significantly. In New Zealand, MND research is still in its relative infancy. This plan explains how we aim to develop a globally connected, comprehensive, national MND research programme via a three-year research strategy focusing on care, cure, communication, and collaboration.

The New Zealand MND community is united by an overwhelming desire to see people living with MND live longer and better lives. Only by working together can we make this possible. The plan outlines how we will continue to develop new partnerships that will help make a difference and enable our work. We will provide new opportunities for volunteer and community involvement and collaboration throughout New Zealand.

We will review the plan regularly as we evaluate our progress against it over the next three years. We will continue to monitor our work against these objectives, making improvements where required and reporting our impact on an annual basis.

The focus for the next three years is on improvement, development, and sustainability. We are confident that through this plan we can keep working hard to ensure we are making as much difference as possible in the lives of people with MND and their carers and families, right now and well into the future.

Carl Sunderland (General Manager)

Lucy Haberfield (Chairperson)

July 2019

OUR VISION

**Together we provide the best quality support
for those living with MND**

OUR VALUES



WE

- 1** Provide emotional, social and practical **support**
 - Support people living with MND, their carers, families, and whānau to access quality healthcare and social assistance throughout New Zealand
 - Respond to problems identified by people living with MND
 - Complement other services
- 2** Coordinate and provide up-to-date, trusted **information**
 - Ensure people have the right information when they need it
 - Support the interests of MND health professionals through quality information
 - Provide MND educational opportunities for health professionals
 - Disseminate information to the MND community in New Zealand.
- 3** **Advocate** for the needs of people living with MND in New Zealand
 - Ensure health and social agencies are fulfilling their obligations to support people living with MND
 - Advocate at political and community levels for co-ordinated and timely care for people living with MND
- 4** Develop **awareness** and understanding of MND
 - Among organisations providing services for people living with MND
 - Among the wider New Zealand public
 - Among potential donors and supporters
- 5** Encourage and support **research**
 - We value research into all aspects of MND
 - We support research projects in New Zealand
- 6** **Collaborate** with others to get better outcomes for those living with MND
 - Encourage a range of people and organisations to get involved and play an active role in making a difference
 - Develop and promote relationships in New Zealand and the wider global MND community



STRATEGIC GOALS

1

Enhancing our support services

2

Improving our information and engagement

3

Strengthening our Organisational CAPACITY and SUSTAINABILITY

STRATEGIC PRIORITIES

1

To strive to provide the best quality support to people living with MND

4

To develop effective strategic partnerships and collaborations, working together to achieve more for people living with MND

2

To help guide health professionals so they can provide the best support and care for people living with MND

5

To develop a globally connected, comprehensive, national MND research programme

3

To raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand

6

To continue to improve the way we run MND New Zealand with a focus on effectiveness and sustainability, and ensuring our staff have the right tools to do the job.

PRIORITY 1

To strive to provide the best quality support to people living with MND

Objectives. We will work to

- 1.1. provide a high-quality support service to all people living with MND, their carers, family, and whānau throughout both urban and rural New Zealand
- 1.2. ensure our support team has the resources required to provide this service
- 1.3. ensure there is knowledge and understanding across our support team, including best practice in the care and support of people with MND
- 1.4. provide tangible, practical support to all people living with MND, their carers, family, and whānau throughout New Zealand
- 1.5. provide social and emotional support by creating opportunities that increase communication and bring the MND community together, nationally and regionally
- 1.6. empower all people living with MND, their carers, family, and whānau throughout New Zealand to ask for and access high quality health and social care when they need it
- 1.7. communicate a broad range of high-quality information through technology and other channels to support people living with MND, their carers, family and whānau.



PRIORITY 2

To help guide health professionals so they can provide the best support and care for people living with MND

Objectives. We will work to

- 2.1. continue to develop positive relationships with health professionals at all levels to increase awareness, understanding, and value of our services and support
- 2.2. develop education programmes for health professionals to raise their awareness and understanding of MND, and developments in MND care, treatment, and research
- 2.3. ensure that all people living with MND, their carers, family, and whānau have access to our organisation and services via an effective and consistent referral process
- 2.4. continue to facilitate knowledge and information sharing and encourage collaboration between health professionals
- 2.5. advocate for consistent, high-quality care for people living with MND, their carers, family, and whānau throughout urban and rural New Zealand
- 2.6. collaborate with health professionals, researchers, and funding bodies to develop and facilitate research that improves health care and quality of life for people living with MND, their carers, family, and whānau throughout New Zealand.



PRIORITY 3

To raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand

Objectives. We will work to

- 3.1. increase public awareness of MND in New Zealand to enable greater understanding and acceptance of the disease and reduce social isolation for people living with MND, their carers, family, and whānau throughout New Zealand
- 3.2. raise awareness of our organisation and the value of our work by targeting key decision makers who can make a positive difference
- 3.3. continue to grow our own knowledge to be a source of evidence-based, up-to-date, reliable, high-quality information on MND
- 3.4. continue to advocate and be a strong voice for the MND community across New Zealand
- 3.5. continue to build flagship events and campaigns, e.g. Walk 2 D'Feet MND and MND Awareness Week to raise awareness and increase public participation
- 3.6. encourage our communities to play an active role in funding and supporting our work.



PRIORITY 4

To develop effective strategic partnerships and encourage collaboration to achieve better outcomes for people living with MND

Objectives. We will work to

- 4.1. develop existing relationships and build new ones in New Zealand and internationally with people, organisations, and agencies that will help enable our work
- 4.2. develop partnerships with organisations and businesses that can play an active role in making a difference via financial and/or specialist support
- 4.3. develop models for greater community involvement and collaboration and volunteer participation throughout New Zealand.

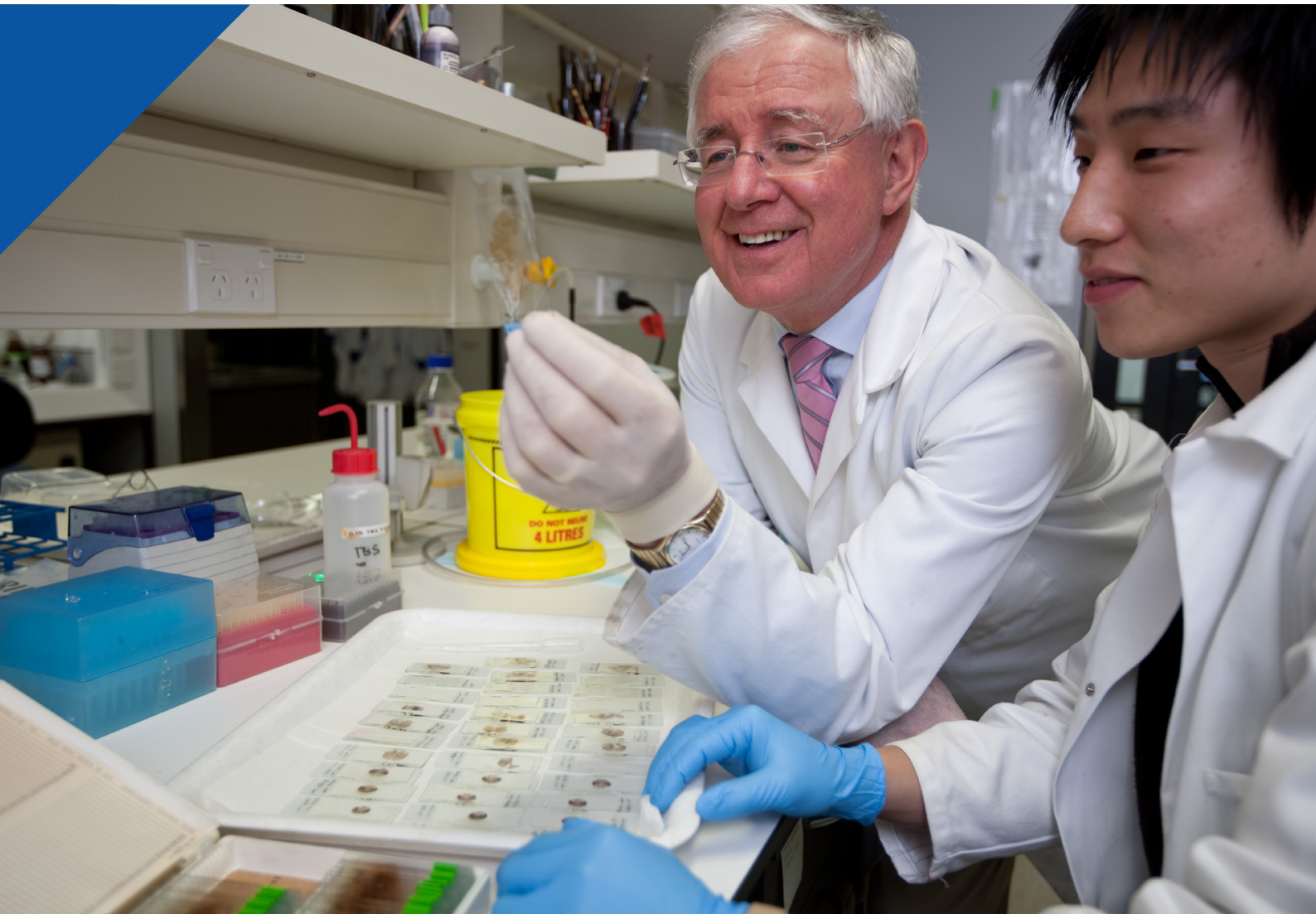


PRIORITY 5

To develop a globally connected,
comprehensive, national MND research
programme

Objectives. We will work to

- 5.1.** support and encourage research to ensure all people with MND living in New Zealand receive the best available evidence-based care and support
- 5.2.** support the best research that will advance understanding of the causes of MND, particularly within the New Zealand environment, and where feasible connect our clients and whānau to future trials and treatments
- 5.3.** ensure New Zealand is connected to the international effort to identify the causes, and ultimately a cure, for MND
- 5.4.** share, as appropriate, the latest advances in research and clinical management of MND with our community in a timely and informative manner
- 5.5.** promote conditions for the growth and development of research into MND in New Zealand by fostering national and international partnerships and exploring opportunities for research funding.



PRIORITY 6

To continue to improve the way we run MND New Zealand with a focus on effectiveness and sustainability, and ensuring our staff have the right tools to do the job

Objectives. We will work to

- 6.1. always demonstrate our organisational values and unity
- 6.2. continue our commitment to provide clear guidelines and consistent processes
- 6.3. demonstrate long-term quality leadership at both management and governance levels
- 6.4. ensure we have adequate training and development for staff, volunteers, and Council members
- 6.5. ensure our organisation and the work we do is adequately resourced, now and in the future
- 6.6. equip our support service staff with the right IT and tools to effectively do their jobs.



Together we provide the best quality support for those living with MND

**If you would like to help us achieve our vision please visit
www.mnd.org.nz or contact us at any time.**

Thank you.