mnd New Zealand

THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND

COMMUNITY SURVEY

RESULTS & RESPONSE 2019

INTRODUCTION

I am pleased to share the results of the MND Community Survey as well as how we at MND New Zealand are acting on the insights gained from your feedback.

Analysing the findings of the survey and utilising the feedback in a practical way is very important to us. The insights gained from the survey have helped guide the development of our new strategic plan for 2019-2022. We know that it has taken some time to release the findings of the survey and appreciate your patience. We wanted to present not just the findings, but also some tangible actions that we have committed to, which are included in this report.

An integral part of developing our new strategic plan, was collaborating with our whole community to better understand their current and future needs, how we were performing and valued, and how we can continue to achieve our vision – together we provide the best quality support for those living with motor neurone disease. We engaged Point Research www.pointresearch.co.nz/ to develop and conduct the survey, seeking feedback on all aspects of our operation. A total of 4,963 people nationwide were surveyed, including people with MND, their carers, as well as previous carers of people with MND, health professionals and other supporters/stakeholders.

Response rates were very high: people with MND (70%), their families and carers (70%) and health professionals (41%) "which means the survey results can be taken as a reliable indication of the support needs on MND New Zealand's clients." (Point Research, 2018)

Key findings have been grouped into six categories:

- Supporting people with MND, their families and carers
- The needs of people with MND, their families and carers (information needs, practical needs, social and emotional needs)
- Connecting with MND New Zealand – people with MND and Health professionals
- MND New Zealand-supported research
- MND New Zealand's purpose
- Fundraising and Campaigns

Overall, the results show that "MND New Zealand plays an important role in providing care and support to people with MND and their families and carers" (Point Research, 2018), however, the survey also identified a clear need for development in some areas such as information provision, increased practical support and our use of current technology. Recommendations from the researcher are also included in this report.

MND New Zealand is committed to regularly reviewing our work through ongoing collaboration with our community, and I would like to take this opportunity to thank everyone who completed the survey for taking the time to share your experiences with us.

Kind regards
Carl Sunderland
General Manager
October 2019

SUPPORTING PEOPLE WITH MND, THEIR FAMILIES AND CARERS

67% **of people with MND found the support team very helpful.** People with MND who live close to their support workers base were significantly **more likely** to say the organisation was very helpful.

Key Findings

- People with MND said the most helpful aspects of MND New Zealand's services were the support team, information pack, newsletters, website and personal advocacy
- Those who said MND New Zealand was not helpful cited infrequent contact, difficulties making a personal connection with the support team, or needing more or different kinds of information or support than the organisation could provide
- Overall, people with MND found the organisation more helpful than family and carers did, and some reported improvements over the last 2 years
- People with MND, their family and carers, who live close to their support team member's base (with 2 hours' drive) were significantly more likely to say the organisation was very helpful and provides them with a lot of information

> **'They get it. They don't patronise. They offer practical, sensible suggestions. They care. They keep us positive. Thank you. Thank you.'**

Recommendations

See what more the organisation can do to support families and carers.

Consider how technology can help more people connect as and when they want to, including the Support Team connecting with more clients, especially those living further from the support team member's base.

Our Commitments

- Ensuring that we continue to provide a high-quality support service to all people with MND, their family and carers throughout urban and rural New Zealand, by regularly reviewing and improving the support we provide, focussing initially on:
  - Effectively communicating clear expectations of the support we provide
  - A review of the information we provide, including how and when we provide it
  - Understanding how to better support family and carers of people with MND
  - Developing ways of increasing support to those who are not in close proximity to their support team member's base
- Ensuring our support team have all the resources they need to do their job, including up-to-date knowledge and understanding of best practice care and support of people living with MND, gained through regular training and development
- Increasing and improving our use of technology to enhance the support we offer to those living with MND
- Continuing to innovate, exploring better ways to advocate for consistent, high quality health and social care for all people with MND, their family and carers throughout New Zealand

THE NEEDS OF PEOPLE WITH MND, THEIR FAMILIES AND CARERS

Key Findings

Information Needs

60% of people with MND, family and current carers have **unmet information needs.**

People with MND, family and carers get about **as much information from MND New Zealand's website, support workers and publications** as they do from neurologists and other medical specialists.

All respondent groups wanted **information in a timely manner**.

People with MND needed **more information about the disease and treatments**.

Family and carers needed to know **how to help** the person with MND, practically and emotionally. They also wanted to know how to cope, and how to help other family members cope.

90% In addition, 90% of **previous carers** stated they had unmet information needs.

Recommendations

Consider how the organisation might do more to meet unmet information needs, including how technology can help more people with MND, families and carers to find information about MND, research, advice and tips for day-to-day living, treatment and support. Also, how technology can help people with MND, families and carers to connect with each other and community news.

Our Commitments

Reviewing the current information and resources we provide to people with MND, their families and carers to ensure people get the information they want in the right format, when they want it and carers throughout urban and rural New Zealand, by regularly reviewing and improving the support we provide, focussing initially on:

- Continuing to increase our knowledge so that we are to be the source of evidence-based, up to date reliable, high-quality information on MND – globally, nationally and regionally
- Improving information, resources and communication channels through development of a new communications and engagement strategy
- Exploring better use of technology so we can improve the access and availability of information electronically.
- Sharing the latest advances in research and clinical management with our community in a timely and informative manner
- Developing community information/education sessions to share information face-to-face or via online webinars
- Continuing to grow participation in the online MND forum to provide additional peer-to-peer support and information sharing

Key Findings

Practical Needs

40% of people with MND, family and current carers have **unmet practical support needs**

Help with practical needs included assistance with **work around the home** and **equipment** for home-based care and movement.

Many people said practical support is provided through their DHB and its allocated service provider.

Younger respondents reported needing more help with **transport, personal care, financial hardship and employment issues.**

Older people and people with MND living alone reported **daily struggles** and **safety concerns** caused by these unmet practical support needs

> I desperately needed general help in the house so I could help my husband more…he needed 24-hour attention

Recommendations

Practical support was prioritised by all respondent groups. Consider how the organisation might do more in this area.

Our Commitments

- Launching the 'Fulton Hogan MND New Zealand Support Fund' to provide additional support to people living with motor neurone disease (MND), their families and carers, to maximise their quality of life. The fund provides financial grants for practical support such as work around the home, equipment, modifications, transport and respite care
- Reviewing whether current funded equipment provision and availability for people with MND is sufficient, relevant and timely, aiming to identify 'gaps' and make appropriate recommendations for improvement
- Continuing to advocate for statutory entitlements for people with MND, including reviewing current legislation and Government funding
- Developing relationships with people, organisations and businesses who can play an active role in providing financial and/or practical support

Key Findings

Social and Emotional Needs

People with MND, family members and carers, and previous carers reported **needing less social, relationship, emotional and psychological support** than physical and information support.

Young people with MND, family members and carers (i.e. people under 55 of age), however, reported a **need for more social and emotional support** than older people with MND or family and carers.

40% of people with MND, family and carers said they know of, or **use a local support group**. Those who do use the groups find them helpful.

Previous carers reported having **more unmet social and emotional needs during the later stages** of the disease.

Some people with MND said they had become **isolated** and **lonely** because they were no longer able to work, and connect with people who understood.

> **Caring people, good advice. Friendships and understanding. [on MND support groups]**

Recommendations

Consider how MND New Zealand:

- can provide better social and emotional support to younger people with MND, families and carers
- might provide more facilitated local support groups
- could provide or connect people with MND, families and carers with low-cost, trained counsellors
- can use technology to help more people connect with each other and community news

Our Commitments

- Exploring ways to improve social and emotional support, especially for younger people with MND, their families and carers throughout New Zealand
- Reviewing all MND specific and other relevant support groups currently operating in each region
- Developing guidelines for MND New Zealand facilitated MND support groups, including training programmes for volunteer-run support groups
- Investigating ways to facilitate improved connection to and/or funding for counsellors
- Developing regional activities to bring more MND families together, including community events and education/awareness sessions
- Continuing to grow participation in the online MND forum to provide additional peer-to-peer support and information sharing
- Reviewing how we can make better use of technology to improve communication and connection within the MND community, including advocating for consistent and easy access to up-to-date augmentative and alternative communication technology

CONNECTING WITH **MND NEW ZEALAND**

PEOPLE WITH **MND** AND **HEALTH PROFESSIONALS**

Key Findings

- Most people with MND (63%) said they heard about MND New Zealand at diagnosis with over half (54%) being told by their neurologist
- Fewer families and carers said they heard about MND New Zealand at diagnosis (41%) and many discovered MND New Zealand via the organisation's website (30%)
- People who found out about MND New Zealand after diagnosis said earlier connection with the organisation would have been useful
- Most health professionals said they (or their colleagues) tell people about MND New Zealand at diagnosis or at their first consultation and refer people as soon as possible thereafter

Most **health professionals** (84%) reported that **MND New Zealand works well or very well** with them to care for and support people with MND. The majority said MND New Zealand adds **valuable care and support** in addition to what clinical services provide.

- A small number of health professionals said they have a referral policy or guideline, but more said they use their discretion to decide when and if they tell patients and family about the organisation
- They also valued the support team's helpfulness, reports and regular catch-ups
- Healthcare professionals who said MND New Zealand did not work with them well supposed that it was because the support team were stretched too thinly over a large geographical area

Recommendations

- Work with MND health care services to ensure that referral happens as early as possible for those who want it.
- Consider how technology can help more health professionals access information about MND, research, advice and tips for day-to-day living, treatment and support.
- Consider establishing professional development opportunities for those working in health care, increasing their skills and increasing MND New Zealand's integration into the health care system.

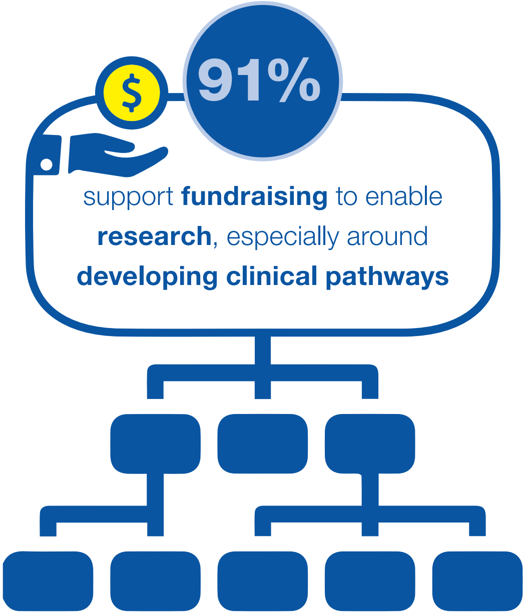
Our Commitments

- Consulting with health professionals to develop an effective and consistent referral process, ensuring everyone with MND, their families and carers are aware of and can access MND New Zealand services and information
- Collaborating with health professionals and researchers to establish consistent models of care and clinical pathways for people with MND throughout New Zealand
- Creating new resources outlining the MND New Zealand support service for health professionals for distribution at diagnosis and consultations
- Continuing to raise awareness and understanding of MND, our organisation and the value of our work through regular campaigns, up-to-date information, education programmes and development of relationships with health professionals
- Continuing to develop positive relationships with health professionals at all levels to increase awareness, understanding and value of our services and support via
  - Consistent and clear two-way communication and cooperation including regular attendance at multidisciplinary team (MDT) meetings
  - Developing education programmes and resources for health professionals to raise their awareness and understanding of MND and developments in MND care, treatment and research
- Collaborating with health professionals and researchers to facilitate research that improves health care and quality of life reviewing ways to improve the use of technology to support health professionals throughout urban and rural New Zealand

MND NEW ZEALAND-SUPPORTED RESEARCH

Key Findings

- Most people with MND, families and carers said they want future generations to be relieved of the symptoms, or cured, of MND
- Respondents who were against MND New Zealand funding research usually said that more money was needed to support current people with MND instead, and/or that there was considerable funding for research overseas
- Overall, respondents indicated all research objectives listed in the survey as very or reasonably important, with ‘Developing clinical pathways’ (91%) rated as most important, followed by ‘Improving quality of life’ (86%), ‘Finding a cure’ (85%), and ‘Connecting New Zealand to global MND research’ (84%).



> **If you don’t fundraise for MND research in New Zealand, who will?**

Recommendations

Fundraise to support research and consider whether all MND New Zealand research funding should be allocated to all or to only some of the research objectives listed in the survey.

Our Commitments

- Implementation of the MND New Zealand Research Strategy 2019-22 to develop a globally connected, comprehensive, national MND research programme
- Supporting and encouraging New Zealand MND research that will improve the quality of life for people living with MND today and those yet to be diagnosed
- Working closely with health professionals and researchers to develop consistent, standardised models of care and clinical pathways for people with MND, throughout New Zealand, starting with the inaugural MND Hui in September 2019
- Ensuring New Zealand is connected to the international effort to identify the causes, and ultimately a cure for MND by co-funding the 3-year genetics study at the University of Auckland
- Working to connect people with MND and their families to national and international research by continuing to fund and develop the New Zealand MND Registry
- Promoting conditions for growth and development of MND research in New Zealand by continuing to fund and work closely with the New Zealand MND Research Network, fostering national and international partnerships and exploring opportunities for research funding. Including holding the inaugural MND New Zealand Research Conference in December 2019

MND NEW ZEALAND'S PURPOSE

MND New Zealand asked for feedback on 'what we do' or our purposes, namely:

- Co-ordinate and provide up-to-date **information**
- Provide emotional, social and practical **support**
- **Advocate** for the care and support of people living with MND
- Develop **awareness** and understanding of MND
- Encourage and support **research**

All MND New Zealand's key purposes were considered important, but **support services**, **advocacy and research** were considered the most important of all.

Key Findings

- Support (37%) was rated as most important, followed by advocacy (27%) and research (21%)
- Compared with other respondent groups, fewer people with MND rated support as most important, and fewer health professionals rated research as most important

> **To me, each objective is extremely important to the individual, family and friends.**

Recommendations

Continue to endorse all purposes and complete regular surveys with the MND community to ensure MND New Zealand's work remains relevant and valued.

Our Commitments

- Ongoing collaboration and communication with our community via open discussion, regular surveys and community events
- Continuing to endorse our purposes to strengthen our presence and capacity as the leading authority in MND in New Zealand. Our Strategic Plan 2019-22 states, we

1. Provide emotional, social and practical support
2. Coordinate and provide up-to-date, trusted information
3. Advocate for the needs of people living with MND in New Zealand
4. Develop awareness and understanding of MND
5. Encourage and support research
6. Collaborate with others to get better outcomes for those living with MND

FUNDRAISING AND CAMPAIGNS

90% of supporters have **participated** in MND New Zealand events. More than half of these took part in **Walk 2 D'Feet MND**.

Key Findings

- Overall, almost twice as many respondents have participated t in the Walk 2 D'Feet MND (57%) than other local community events (24%)
- 94% of supporters have participated in MND New Zealand events and about 50% of health professionals already have participated, or intend to in the future
- More previous carers have participated in MND New Zealand events than people currently living with MND, their family and carers

Recommendations

- Consider how the promotion of MND New Zealand events and fundraising appeals can be more impactful and personal
- Consider additional, diverse long-term funding streams, for instance partnerships with businesses or large community organisations
- Consider ways to raise MND New Zealand's profile, such as engaging high-profile New Zealanders to champion the organisation

Our Commitments

- Developing and implementing new strategies to increase the success (awareness, participation and fundraising) of our flagship events and campaigns, Walk 2 D'Feet MND and MND Awareness Week
- Implementation and ongoing evaluation of our fundraising strategy to increase long term fundraising income with development of regular giving, major gift and bequest programmes
- Developing models for increased community and volunteer involvement, participation and collaboration throughout New Zealand
- Developing our relationships with current partners Fulton Hogan and Emirates Team New Zealand to raise greater awareness of MND increase our organisation's profile
- Seeking new partnerships with organisations and businesses who can play an active role in making a difference through financial and/or specialist support