MND New Zealand - Improving Care, Improving Lives

Terms of reference

Background

In 2018, MND New Zealand commissioned a national community survey to identify the care and support needs of people with MND and their family/whanau and carers, as well as their access to health services and information, and preferred areas of research.

The survey found 40%, of respondents with MND, their family and current carers said they had unmet practical needs including assistance with mobility, lack of equipment for home-based care and inadequate support for work around the home. People with MND also wanted to see increased advocacy at a national level to improve health care.

In response to these findings MND New Zealand facilitated a national meeting, or Hui, of clinicians in September 2019 to provide a forum for key parties to begin work together on improving health services for individuals and families living with MND. Gathering clinicians, members of the MND New Zealand team, representatives from various DHB's and Ministry of Health in one place was an excellent first step in understanding what is needed to improve the health care needs of people with MND. What evolved from this discussion was the idea of a need for a 'strategic framework of care' for people with MND, underpinned by following key principles:

- *Patient centred care*
- *Equitable access*
- *Quality of care*
- *Care coordination*
- *Clear communication*

Several clinicians have expressed interest in being part of a working group to further develop this framework, and the MND Clinical Working Group was formed with the first meeting in November 2019.

Purpose

This MND Clinical Working Group has been established by MND New Zealand to provide the specific knowledge and expertise to inform and guide the development of a strategic framework of care for motor neurone disease with the aim of improving the quality of life for people with MND and whanau by providing an integrated & coordinated approach to care and support.

Vision

People with motor neurone disease, their families and whanau are provided with optimal evidence-based health and social care and support throughout their journey with MND, enabling them to lead the best quality of life possible.

The following key principles will form the foundations for this framework:

- *Patient centred care*
- *Equitable access*
- *Quality of care*
- *Care coordination*
- *Clear communication*

Functions and Roles

The project is being led by MND New Zealand who will provide a secretariat function for the WG.

The main objectives of the project are to:

1. Improve understanding of the level of need for and current provision of care for patients with motor neurone disease

2. Review of current model for delivery of health services and explore opportunities for improvement including the option of centres of excellence and clinical networks

3. Develop New Zealand appropriate guidelines and pathways for the effective management of patients with motor neurone disease:

    a. Using a multidisciplinary best practice approach across the continuum of care, including an outpatient model of care
    b. focused on early diagnosis and appropriate & timely referral for specialist interventions such as NIV & nutritional support
    c. integrating social support & management within the community, including primary care
    d. Providing national consistency whilst remaining flexible and adaptable for local DHBs

4. Work with The Ministry of Health to identify and review policies that affect support for people and families living with MND

5. Identify resources required by clinicians to deliver best practice health care including ongoing professional education, peer support and access to expert advice

Membership

The MND Clinical Working Group should include the following members/disciplines to ensure consideration of all aspects of a model of care

- Palliative care
- Nurse specialist
- Neurologist
- Geriatrician
- Respiratory physician
- MND New Zealand representative
- Occupational therapy
- Physiotherapy
- SLT
- Dietician
- Social worker

Additional expertise may be co-opted at any time as needed, including Talklink, genetic counselling, gastroenterology, general practice & DHB Planning and Funding

Other interested parties and consumer groups will not be part of the Group but will be invited to provide feedback on drafts for discussion by the working party before the drafts are circulated for endorsement.

Chairperson

All meetings must be presided over by a chairperson(s). In the event of the chairperson being absent, an alternative will be elected as acting chairperson by those members present.

Quorum

Half the group

Conflicts of interest

Conflicts of interest will be declared at the commencement of the meeting, and will be managed by the Chair. An interests register for all members to complete is attached.

Decision making

Decisions and recommendations will be consensus agreement of the group. Where a conflict of interest is identified, the relevant parties will abstain from decision making. The Chair will manage situations where consensus cannot be reached.

Accountability

Each member is accountable to his/her organisation. They shall inform their organisation of the WG activities, and communicate both agenda and minutes.

Working arrangements

It is expected the project will be of 12-24 months duration, and that there will be 2 -3 face to face meetings, and teleconferences as required to progress the agreed work plan. Minutes will be issued within a week of the meeting, and finalised at the next meeting.

It is hoped that DHBs will support the attendance of their staff at the meetings, however where this is not possible reasonable travel costs (flights, taxi and lunch) will be met by MND New Zealand. Flights must be booked 6 weeks in advance to ensure lowest cost possible or the flight cost will not be reimbursed.