

Introducing the Motor Neurone Disease Clinical Working Group (MNDCWG) Information for Health Professionals

Who are we?

The MND Clinical Working Group consists of a group of clinicians across multiple disciplines from all around New Zealand, who have an interest in improving care for people with MND and their families. The group was formed following a national Hui in 2019 which focused on the challenges of delivering timely, coordinated and equitable health services for people with this very complex condition.

What is our purpose?

The 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 providing an integrated & coordinated approach to care and support.

It is the intention of the group that this framework of care be built around “the patient journey” incorporates the following underlying principles:

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

Four key objectives/workstreams

Current areas of focus for the group are:

- Development of New Zealand appropriate guidelines and pathways, adapted from the NICE guidelines (NICE, 2016) for the assessment and management of motor neurone disease (MND), which provide national consistency whilst remaining flexible and adaptable for local DHBs (please see document “ New Zealand Guideline for Motor Neurone Disease Care”)
- Review of current model for delivery of health services and exploring opportunities for improvement including the possibility of centres of excellence and/or clinical networks
- Working with The Ministry of Health to identify and review policies that affect support for people and families living with MND
- Identifying resources required by clinicians to deliver best practice health care including ongoing professional education, peer support and access to expert advice

More information

For more information, including full terms of reference, please contact Dr Claire Reilly, MND Community & Research Advisor, at claire.reilly@mnd.org.nz