

#HospiceLink

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MOTOR NEURONE DISEASE

This month we are focusing on Motor Neurone disease. This is timely as this month's Palliative Care Lecture Series through Hospice NZ is on MND, and also the new best practice guidelines for MND NZ have just been released in late 2022.

The care of people with Motor Neurone Disease is often complex and varied due to the symptoms they face and the rate of progression. Generally, a high number of people with MND are carried for in your Care facilities due to the high level of care and input required.

MND affects motor neurones (special nerve cells in the brain and spinal cord that send messages that tell muscles to contract) in the brain and spinal column. Without the ability of motor neurones to send messages to muscles, the muscles are unable to work properly and gradually weaken and waste. ([Click here](#))

MND tends to be relentlessly progressive – no true remissions, but plateaux may be reached at times or there may be periods of very slow progression in some cases. Because MND can also progress rapidly the patient and family may benefit from a referral to Specialist Palliative care early if they have complex symptoms, experience a change in physical or cognitive ability, or have emotional or spiritual distress.

Specialist palliative care can provide a crucial source of support as part of the multidisciplinary team and can make a difference to the quality of life.

There is sometimes a lack of recognition that these people may experience cognitive changes so it is important if possible that early conversations are held regarding Advanced Care planning. There is need for careful forward planning and discussions so that decisions can be made after careful consideration and not in an emergency situation. This may include difficult conversations and possible ethical decision making in the future regarding options such as Artificial feeding, possible mechanical breathing support, management of acute events etc.

What are the symptoms of motor neurone disease towards the end of life?

MND affects each person differently, so symptoms, progression and what to expect towards the end of life can vary from person to person. Symptoms may include:

- Mobility and movement deterioration- muscle weakness
- Speech and communication difficulties – Dysarthria
- Changes to thinking and behaviour
- Respiratory problems
- Dysphagia – swallowing difficulties
- Difficulty managing saliva and secretions
- Pain/discomfort/cramping
- Incontinence and constipation

New Best Practice recommendations for MND NZ – I thoroughly recommend that you may like to print this off, as an invaluable resource to have available for your facility/staff. This is extremely thorough and covers EVERYTHING you will need!

Best Practice Recommendations For The Care of People

The MND NZ website also has excellent resources – including these insightful collections of patient, whanau, carer experiences. These are well worth a look.

Living with MND – Your Stories

A reminder the Hospice Taranaki Palliative Care CNS and Family Support team (Counselling) are also available for additional support for the patient and family if required. Please contact [Lisa or Lynne](#) (ACF CNS) or [Kelly Moore](#) (Hospice ACF Family Support)

Upcoming Education

Palliative Care lecture series

6 April 2023:

Neurological Palliative Care (MND)
David Oliver Honorary Professor
Tizard Centre
University of Kent

Time: 07:30 am – 08.30 am

Watch them wherever you are, you'll be able to access all you need for the lecture via a private [webpage](#).

If you wish to listen to earlier lectures, [click here](#)

Syringe Driver Competency

[click here](#)

Wednesday 5 April: 1 pm – 3 pm

Syringe Driver Refresher

[click here](#)

Wednesday 12 April: 1pm–2.30pm

BRAIN TEASER

Each month our newsletter will have a puzzle, activity or brainteaser. Submit your answers to [Paula](#)

Last month's brain teaser:

"Once in a minute, twice in a moment, but never is a Thousand years – What is it??" The letter M
Last month's winner will be announced in the next newsletter

This month's brain teaser:

A man pushes his car to a hotel and tells its owner that he is bankrupt. Why?

