



# Motor Neurone Disease (MND)

## Information for the Palliative Care Team

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### 1. Introduction

Many new staff in palliative care services may not have come across people with MND. This package is designed with summary information to help them care for people with MND and their carers. It includes contact details for further help and information. The example care plan is designed to be a prompt for the kinds of issues that should be included in a comprehensive care plan.

This package is designed to provide:

- information and education about MND and its management
- a list of contacts and resources for health professionals
- an example of a nursing care plan for someone with MND
- A 22-minute podcast discussing the mental health and well-being of health professionals generally, and nurses in particular, during the Coronavirus pandemic. Please access here
- <https://smrpcc.podbean.com/e/health-wellbeing-for-health-professionals/>
- There are now various podcasts available from the Southern Metropolitan Palliative Care Consortium on various specific topics about MND: [www.smrpcc.org.au](http://www.smrpcc.org.au).

For further in-depth training and information please don't hesitate to contact:

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### 2. What is Motor Neurone Disease?

MND is a progressive neurological condition with no cure.

The average life span for people with MND is 3-5 years from onset of symptoms. Variations may occur depending on the rate of progression and the type and presentation of the disease.

- The disease and its progression mean that clinical issues are ongoing and complex and need forward planning.
- The symptoms mean that a variety of health professionals must be involved for best care.

- Early referral to palliative care is important for the complex issues that arise. These may include frontotemporal dementia, legal and financial issues, carer burden, equipment needs and symptom management.

### 3. MND affects swallowing and secretions

- Dysphagia (difficulty swallowing) will affect 30% of people with MND due to weakness of the lips, tongue, facial muscles, pharynx and larynx, resulting in impaired swallowing and reduced airway protection.
- Issues arise with drooling, aspiration of food, fluids and saliva, ineffectual coughing, pneumonia, choking episodes, malnutrition and dehydration.
- Choking episodes can occur - encourage the person to stay calm. Physiotherapists can teach assisted cough technique and optimal head and neck support and posture. Death from choking is rare in MND.
- A multidisciplinary approach is needed. An occupational therapist may assist with eating equipment for independence, speech pathologist assessing swallow and diet modification, and a dietician monitoring nutritional and PEG intake.
- Some people will opt for the insertion of a PEG tube to assist with hydration and nutrition to extend their life, reduce fatigue with meals, stabilise weight, aid medication management and reduce carer burden. They may still be able to eat food and drink liquids. PEG insertion needs to occur early before respiratory function is reduced and the procedure cannot be performed safely. Not all people with MND will choose to have a PEG tube inserted.
- An online guide for managing secretions (which can be complex) can be found at MND Australia's website at this link: <https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/managing-symptoms/saliva-management-in-mnd>
- Or see MND Australia's website: <https://www.mndaustralia.org.au/>, which includes a section about symptom management for health professionals.

### 4. MND affects communication and speech

- Speech and Occupational Therapists devise assisted communication devices as required. Patience is required to allow the MND person to communicate. They may have their own specific gestures or requirements; it is important to learn these for ....
- Speech may be impacted by reduced respiratory volume, mechanical issues with muscles of the face, tongue and jaw, secretion production, frontotemporal dementia affecting the language centre in the brain and fatigue.

### 5. MND affects mobility and independence

- The mobility of people with MND will be affected, depending on where their symptoms commenced and how their disease progresses.
- A range of equipment and support is required to maintain as much independence and function as possible for as long as possible. This equipment requires constant review due to constant deterioration.

- Funding is available for equipment and care. If the person with MND is over 65 years they will receive this from aged care packages. If they are under 65 years, they will receive funding from the National Disability Insurance Scheme.

## 6. Non-invasive ventilation (NIV)

- People with MND will die from respiratory failure.
- Respiratory function is affected by the weakness of the muscles associated with breathing. The slow change increases the levels of CO<sub>2</sub> with resulting symptoms which can be alleviated by NIV and provide better quality of life. People will eventually become dependent on NIV.
- The assessment and NIV equipment will be managed by Victorian Respiratory Support Service (VRSS - Austin Hospital).
- People with NIV may choose to remove it and this will result in their death. Accurate assessment of respiratory function will affect the timing of withdrawal and will ensure that removal will result in a short period of time until death occurs. This is a planned event with protocols and guidelines available.

## 7. Support for the person with MND and their carers

- The person can register with MND Victoria to have access to a range of services for them and their carers. These include a support worker, information sessions about MND, funding assistance, equipment loans and networking.
- Calvary Health Care Bethlehem provides ongoing neuro-palliative rehabilitation and a multidisciplinary team for the management of the disease and ongoing care.
- Victorian Respiratory Support Service (VRSS) will assess suitability for NIV and provide ongoing support for the duration of its use. VRSS provides assessment and support for its withdrawal if required.
- Palliative care provides specialist support for complex psychosocial needs and physical care of people with MND particularly at end of life.
- Respite services and home care services assist with daily and routine care and help to relieve carer burden.
- GPs are a valuable source of support in the community.
- Financial planners and solicitors can provide valuable assistance.
- Carers Quality of Life guide helps health professionals reduce carer burden.

## 8. Support for Health Professionals when working with MND

- Calvary Health Care Bethlehem provides clinical assistance with symptom management and ongoing assessments via their multidisciplinary team and secondary consultation.
- MND Victoria has a library and information service, top up funding and equipment loans. The regional advisor/support worker allocated to the family will have access to up-to-date information about the client's current status and issues and is available for advocacy as well as information.
- VRSS provides guidelines for NIV removal.
- The MND Shared Care Worker/ Palliative Care Clinician is available for assistance with problem solving, information, education and training about MND and which agency or health professional would be helpful for targeted intervention. The MND Palliative Care Clinician in

each region is available for debriefing and support to those in palliative care working with MND clients.

- [www.mndcare.net.au](http://www.mndcare.net.au) is a website with educational modules about MND.

## 9. Contact details for assistance

MND Victoria	<a href="http://www.mnd.asn.au">www.mnd.asn.au</a>	9830 2122
Calvary Health Care Bethlehem	<a href="http://www.bethlehem.org.au">www.bethlehem.org.au</a>	9596 2853
Victorian Respiratory Support Service	<a href="https://www.austin.org.au/victorian-respiratory-support-service/">https://www.austin.org.au/victorian-respiratory-support-service/</a>	Outreach team 03 9496 3665
MND Palliative Care Clinician, Southern Region	<a href="mailto:jane.turton@smrpcc.org.au">jane.turton@smrpcc.org.au</a>	0428 264 446

**An example of a Palliative Care nursing care plan for a MND client is provided in this information. This care plan was developed with the assistance of Deborah Williams and Denise Rogers of Peninsula Home Hospice. The recording of data on a care plan will be in accordance with the practices and documentation of each agency.**

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## 10. Motor Neurone Disease Care Plan example

	Priority	Action plan	Desired Outcome	Outcome (describe what happened)
1.	Discuss Advance Care Plan, Medical treatment decision maker and Refusal of Medical Treatment before communication deterioration makes it difficult to ascertain patient wishes	<ul style="list-style-type: none"> <li>Discuss with client and arrange access to assistance to complete documentation</li> <li>Access to relevant medical, legal and financial and counselling services as required</li> </ul>	<ul style="list-style-type: none"> <li>Client's wishes known and documented and distributed</li> <li>Medical treatment decision maker identified</li> <li>Legal and financial issues addressed</li> <li>Client and carer education and support</li> </ul>	<ul style="list-style-type: none"> <li>ACP documented and communicated to all involved with client</li> <li>All measures taken to ensure affairs are completed to client and carers satisfaction</li> </ul>
2.	Manage PEG	<ul style="list-style-type: none"> <li>Regime of hydration and nutrition as per dietitian</li> <li>Clean and maintain skin integrity around PEG</li> </ul>	<ul style="list-style-type: none"> <li>Client and carer education and support</li> <li>Adequate hydration.</li> </ul>	<ul style="list-style-type: none"> <li>PEG regime satisfactory</li> <li>Skin integrity secured</li> </ul>
3.	Provide mouth care	<ul style="list-style-type: none"> <li>Assess mouth and tongue regularly</li> </ul>	<ul style="list-style-type: none"> <li>Client and carer education and support for mouth hygiene regime</li> </ul>	<ul style="list-style-type: none"> <li>Mouth clean and moist</li> </ul>
4.	Mobility	<ul style="list-style-type: none"> <li>Referral and continual reassessment with the physiotherapist/occupational therapist</li> <li>Liaise with appropriate agencies to ensure home modification, equipment and funding is arranged according to needs.</li> <li>Carer and client education and support re transfers and equipment</li> </ul>	<ul style="list-style-type: none"> <li>Maintain maximum independence and mobility with minimal delays</li> <li>Appropriate funding and equipment /modification secured</li> <li>Carer and client can transfer and operate safely and comfortably</li> </ul>	<ul style="list-style-type: none"> <li>Optimal mobility and independence</li> <li>Describe current status of equipment that is being used and mobility assistance required.</li> <li>Risk of injury, discomfort is reduced and carer burden is lowered</li> </ul>

5.	Manage secretions	<ul style="list-style-type: none"> <li>Document and describe secretion patterns and symptoms</li> <li>Access to speech pathologist and medical services for information on how to manage secretions</li> </ul>	<ul style="list-style-type: none"> <li>Assisted cough and saline nebulisation if necessary</li> <li>Regular review of secretions and impact by medical and speech pathology.</li> <li>Papaya and dark grape, pineapple juices/crushed ice to alleviate symptoms.</li> </ul>	<ul style="list-style-type: none"> <li>Secretions monitored and symptoms alleviated/managed</li> </ul>
6.	Constipation or bowel changes due to tube feeding	<ul style="list-style-type: none"> <li>Access to physiotherapy re mobility assistance and safety</li> <li>Monitor bowel function</li> <li>Regular review by dietician</li> </ul>	<ul style="list-style-type: none"> <li>Use of aids and equipment and appropriate transfers to ensure mobility and safety for toileting</li> <li>Adequate hydration and nutrition</li> <li>Monitor side effects of medications</li> </ul>	<ul style="list-style-type: none"> <li>Regular bowel habits</li> <li>Optimal well-being maintained</li> <li>Side effects ameliorated</li> </ul>
7.	<p>Cough, dyspnoea and NIV</p> <p>Increasing respiratory involvement requires regular assessment</p> <p>Secretions may cause coughing/difficulty clearing chest</p>	<ul style="list-style-type: none"> <li>Regular review by respiratory nurse and physician VRSS service</li> <li>Be familiar with guidelines for MND clients and NIV</li> <li>Monitor for chest infections</li> <li>Monitor respiratory function and client wellbeing</li> <li>Medications as required</li> <li>Physiotherapy assessment and assistance e.g. collars, posture, assisted cough</li> <li>Understand the NIV withdrawal process and clients wishes and if requested follow NIV guidelines</li> </ul>	<ul style="list-style-type: none"> <li>Monitor and maintain NIV equipment and observe mask fit and potential pressure areas. Nasal cannulas may be preferred at times</li> <li>Record and document concerns</li> <li>Observe protocols for pressure area management Bethlehem Calvary Health Care/VRSS</li> <li>Client and carer support and education re how to manage coughing episodes, NIV</li> <li>Guidelines followed for NIV withdrawal</li> </ul>	<ul style="list-style-type: none"> <li>Skin integrity maintained around masks and straps</li> <li>Hoses secure without leaks</li> <li>Equipment cleaned weekly</li> <li>Humidifier water changed daily. Filters changed every three months</li> <li>Client comfort is maintained and respiratory function optimised</li> <li>EOL needs documented and communicated as per ACP</li> <li>Medications in the home as required</li> </ul>

<p>8.</p>	<p>Carer strain:  Carers of people with MND have worse outcomes for anxiety, depression and long-term well-being than other carers.</p>	<ul style="list-style-type: none"> <li>▪ Identify needs</li> <li>▪ Describe current issues for carer and discuss avenues of added support</li> <li>▪ Monitor ongoing health and well-being of carers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Engage and offer carer services, e.g.                         <ul style="list-style-type: none"> <li>~ Respite</li> <li>~ Hygiene assistance</li> <li>~ Volunteer support</li> <li>~ Counselling</li> <li>~ Carers Allowance</li> <li>~ Financial counselling</li> <li>~ Education for practical home care issues e.g. managing a syringe driver,</li> <li>~ Managing a PEG tube</li> <li>~ Transfer and lifting</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Evaluate support strategies and describe current carer assessment post intervention</li> <li>▪ Carer strain reduced and carer health and coping maintained</li> <li>▪ Support services engaged and involved</li> </ul>
<p>9.</p>	<p>Communication can be impacted upon by MND through affecting the voluntary muscles of the tongue and face, as well as the facial nerves, secretions and fatigue.  Some clients will also have frontotemporal dementia which may affect language.</p>	<ul style="list-style-type: none"> <li>▪ Ensure that the current forms of communication are known and documented and conveyed to team</li> <li>▪ Ensure those in contact with the client know how to communicate with the MND person and in their preferred mode</li> <li>▪ Regular assessment and treatment with speech pathologist and neuropsychologist assessment if cognition is affected</li> </ul>	<ul style="list-style-type: none"> <li>▪ The client can communicate effectively with treating team without explaining it to new staff</li> <li>▪ Communication equipment is supplied in a timely manner and most suits the needs of the client</li> </ul>	<ul style="list-style-type: none"> <li>▪ Fatigue is reduced</li> <li>▪ Communication is optimal</li> <li>▪ The client feels supported, listened to and is able express their personality, values and wishes</li> </ul>
<p>10</p>	<p>Generalised pain and discomfort due to low body weight, dependant oedema and muscle wasting  Check for shoulder pain</p>	<ul style="list-style-type: none"> <li>▪ Provide equipment and education for safety at home</li> <li>▪ Monitor level of comfort and pain</li> <li>▪ Utilise allied health professionals to assist with symptoms related to posture and pressure.</li> <li>▪ Provide equipment designed to alleviate pressure. e.g., mattresses, cushions, wheelchair accessories</li> </ul>	<ul style="list-style-type: none"> <li>▪ Allied health team accessed and continuing to assess and maintain symptom control</li> <li>▪ Pain relieved</li> <li>▪ Allied health team accessed and continuing to assess and maintain symptom control</li> </ul>	<ul style="list-style-type: none"> <li>▪ Equipment and funding in place that supports quality of life</li> <li>▪ Symptoms managed and quality of life optimised</li> <li>▪ Regular review with case managers to maintain dignity and comfort and meet changing needs proactively</li> </ul>

			<ul style="list-style-type: none"> <li>▪ Funding and services accessed to provide appropriate equipment. e.g., MNDV, SWEP, NDIS</li> </ul>	<ul style="list-style-type: none"> <li>▪ Funding secured and equipment appropriate</li> </ul>
<p><b>11.</b> Monitor quality of life</p>		<ul style="list-style-type: none"> <li>▪ Access community Top-up funding for quality of life issues e.g. massage therapy, entertainment.</li> <li>▪ Ongoing assessment of quality of life Consider therapies that will assist with self –expression and meaning making such as art, music therapy, counselling, pastoral care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Top-up funding provided</li> <li>▪ Optimal symptom control</li> <li>▪ Participation in appropriate therapies and activities</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased quality of life</li> </ul>