



Motor Neurone Disease (MND)

Orientation Package

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Motor Neurone Disease (MND)



Orientation Package

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 family/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

There are now podcasts available from the Southern Metro Palliative Care Consortium on various specific topics about MND. Click on this link to access podcasts:

<https://smrpcc.org.au/motor-neurone-disease/>

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

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1. What is Motor Neurone Disease?

MND is a progressive degeneration of motor neurones with no known cure. It leads to wasting and weakness in the muscles that are used for movement, speech, breathing and swallowing.

The average life span for people with MND is 3-5 years. Variations may occur depending on the rate of progression and the type and presentation of the disease. Phenotypes are Amyotrophic lateral sclerosis (ALS), Progressive bulbar palsy (PBP), Progressive muscular atrophy (PMA) and Primary lateral sclerosis (PLS).

- The progression of the disease is different for each person and means that clinical issues are ongoing and complex and need early advance care planning.
- The range of 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.

2. MND affects swallowing and secretions

- Dysphagia will affect 2/3rds 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 with an occupational therapist assisting 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/RIG 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/RIG insertion needs to occur early before respiratory function is reduced and the procedure cannot be performed safely.
- An online guide for managing secretions can be found by using control and click on the heading below...

[Saliva Management in MND | MND Australia](#)

3. MND affects communication and speech

- Health professionals 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 that are helpful for you to learn to be able to communicate during your visits.
- 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.

4. 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 progressive 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.
- MND Victoria has a large equipment lending library - the MND advisor can assist with this.

5. Non- invasive ventilation (NIV)

- People with MND will usually die from respiratory failure.
- Respiratory function is affected by the weakness of the muscles associated with breathing. The slow change increases the levels of CO₂ 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). Any problems with NIV can be assisted by a phone call to the outreach nurses.
- 03 9496 3665
- People with NIV may choose to remove it at some stage 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 from VRSS.

6. 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.
- 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. Ctrl & click on link below to access this document from the SMRPCC website:

[Consider the Carer](#)

7. 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.
- The MND Shared Care Worker is available for assistance with problem solving, information, education and training about MND. The MND Shared Care Worker in each region is available for debriefing and support to those in palliative care working with MND clients. Working with MND clients may impact on the health professionals and it is useful to know which agency or health professional would be helpful for targeted intervention, and to understand the way in which this disease may affect staff both personally or professionally.
- www.mndcare.net.au is a website with educational modules about MND

8. Contact details for assistance:

MNDV	Ph: 1800777175	MND Victoria
Calvary Health Care Bethlehem	Ph: 03 9596 2853	Calvary Health Care Bethlehem
Victorian Respiratory Support Service	office hours: Ph: 03 9496 3665 Outreach Nurses	Austin Health: VRSS services
MND Shared Care Worker, Southern Region	Ph: 0428 264 446	Lee-Anne.Henley@smrpcc.org.au

Example of palliative care nursing care plan for a MND client is provided in this information (see last three pages). 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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Motor Neurone Disease (MND) Care Plan

Care Issue	Action plan	Desired Outcome	Outcome (describe what happened)
1. Vital to discuss Advance Care Plan and Refusal of Medical Treatment Certificate before communication deterioration makes it difficult to ascertain patient wishes	<ul style="list-style-type: none"> Discuss with client and arrange access to assistance to complete documentation Access to relevant medical, legal and financial and counselling services as required 	<ul style="list-style-type: none"> Client's wishes known and documented and distributed Medical treatment decision maker identified Legal and financial issues addressed Client and carer education and support 	<ul style="list-style-type: none"> ACP documented and communicated to all involved with client All measures taken to ensure affairs are completed to client and carers satisfaction
2. Manage PEG	<ul style="list-style-type: none"> Regime of hydration and nutrition as per dietitian Clean and maintain skin integrity around PEG 	<ul style="list-style-type: none"> Client and carer education and support Adequate hydration. 	<ul style="list-style-type: none"> PEG regime satisfactory Skin integrity secured
3. Provide mouth care	<ul style="list-style-type: none"> Assess mouth and tongue regularly 	<ul style="list-style-type: none"> Client and carer education and support for mouth hygiene regime 	<ul style="list-style-type: none"> Mouth clean and moist
4. Mobility	<ul style="list-style-type: none"> Referral and continual reassessment with the physiotherapist/occupational therapist Liaise with appropriate agencies to ensure home modification, equipment and funding is arranged according to needs. Carer and client education and support re transfers and equipment 	<ul style="list-style-type: none"> Future proofing needs to maintain maximum independence and mobility with minimal delays Appropriate funding and equipment /modification secured Carer and client can transfer and operate safely and comfortably 	<ul style="list-style-type: none"> Optimal mobility and independence Describe current status of equipment that is being used and mobility assistance required. Risk of injury, discomfort is reduced and carer burden is lowered
5. Manage secretions	<ul style="list-style-type: none"> Document and describe secretion patterns and symptoms Access to speech pathologist and medical services for information on how to manage secretions 	<ul style="list-style-type: none"> Assisted cough and nebulisation if necessary Regular review of secretions and impact by medical and speech pathology. Interventions through drugs and natural remedies such as papaya and grape juices to alleviate symptoms. 	<ul style="list-style-type: none"> Secretions monitored and symptoms alleviated/managed

Motor Neurone Disease (MND) Care Plan ... continued

6.	Constipation or bowel changes due to tube feeding	<ul style="list-style-type: none"> ▪ Access to physiotherapy re mobility assistance and safety ▪ Monitor bowel function ▪ Regular review by dietician 	<ul style="list-style-type: none"> ▪ Use of aids and equipment and appropriate transfers to ensure mobility and safety for toileting ▪ Adequate hydration and nutrition ▪ Monitor side effects of drugs 	<ul style="list-style-type: none"> ▪ Regular bowel habits ▪ Optimal well-being maintained ▪ Side effects ameliorated
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"> ▪ Regular review by respiratory nurse and physician VRSS service ▪ Be familiar with guidelines for MND clients and NIV ▪ Monitor for chest infections ▪ Monitor respiratory function and client wellbeing ▪ Medications as required ▪ Physiotherapy assessment and assistance e.g. collars, posture, assisted cough ▪ Understand the NIV withdrawal process and clients wishes and if requested follow NIV guidelines 	<ul style="list-style-type: none"> ▪ Monitor and maintain NIV equipment and observe mask fit and potential pressure areas. Nasal cannulas may be preferred at times ▪ Record and document concerns ▪ Observe protocols for pressure area management Bethlehem Calvary Health Care/VRSS ▪ Client and carer support and education re how to manage coughing episodes, NIV ▪ Guidelines followed for NIV withdrawal 	<ul style="list-style-type: none"> ▪ Skin integrity maintained around masks and straps ▪ Hoses secure without leaks ▪ Equipment cleaned weekly ▪ Humidifier water changed daily. Filters changed every three months ▪ Client comfort is maintained and respiratory function optimised ▪ EOL needs documented and communicated as per ACP ▪ Medications in the home as required
8.	<p>Carer strain:</p> <p>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"> ▪ Identify needs ▪ Describe current issues for carer and discuss avenues of added support ▪ Monitor ongoing health and well-being of carers 	<ul style="list-style-type: none"> ▪ Engage and offer carer services, e.g. <ul style="list-style-type: none"> ~ Respite ~ Hygiene assistance ~ Volunteer support ~ Counselling ~ Carers Allowance ~ Financial counselling ~ Education for practical home care issues e.g. managing a syringe driver, ~ Managing a PEG tube ~ Transfer and lifting 	<ul style="list-style-type: none"> ▪ Evaluate support strategies and describe current carer assessment post intervention ▪ Carer strain reduced and carer health and coping maintained ▪ Support services engaged and involved

Motor Neurone Disease (MND) Care Plan ... continued

<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.</p> <p>Some clients will also have frontotemporal dementia which may affect language.</p>	<ul style="list-style-type: none"> ▪ Ensure that the current forms of communication are known and documented and conveyed to team ▪ Ensure those in contact with the client know how to communicate with the MND person and in their preferred mode ▪ Regular assessment and treatment with speech pathologist and neuropsychologist assessment if cognition is affected 	<ul style="list-style-type: none"> ▪ The client can communicate effectively with treating team without explaining it to new staff ▪ Communication equipment is supplied in a timely manner and most suits the needs of the client 	<ul style="list-style-type: none"> ▪ Fatigue is reduced ▪ Communication is optimal ▪ The client feels supported, listened to and is able express their personality, values and wishes
<p>10.</p>	<p>Generalised pain and discomfort due to low body weight, dependant oedema and muscle wasting</p> <p>Check for shoulder pain</p>	<ul style="list-style-type: none"> ▪ Provide equipment and education for safety at home ▪ Monitor level of comfort and pain ▪ Utilise allied health professionals to assist with symptoms related to posture and pressure. ▪ Provide equipment designed to alleviate pressure. e.g., mattresses, cushions, wheelchair accessories 	<ul style="list-style-type: none"> ▪ Allied health team accessed and continuing to assess and maintain symptom control ▪ Pain relieved ▪ Allied health team accessed and continuing to assess and maintain symptom control ▪ Funding and services accessed to provide appropriate equipment. e.g., MNDV, SWEF, NDIS 	<ul style="list-style-type: none"> ▪ Equipment and funding in place that supports quality of life ▪ Symptoms managed and quality of life optimised ▪ Regular review with case managers to maintain dignity and comfort and meet changing needs proactively ▪ Funding secured and equipment appropriate
<p>11.</p>	<p>Monitor quality of life</p>	<ul style="list-style-type: none"> ▪ Access community Top-up funding for quality-of-life issues e.g., massage therapy, entertainment. ▪ 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 	<ul style="list-style-type: none"> ▪ Top-up funding provided ▪ Optimal symptom control ▪ Participation in appropriate therapies and activities 	<ul style="list-style-type: none"> ▪ Increased quality of life