



# **Motor Neurone Disease (MND)**

## **Aged Care Information Southern Metro**

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# Motor Neurone Disease (MND)



## Information Package

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Many staff in aged care may not have cared for people with MND. This package provides information about relevant aspects of MND. It includes contact details for further help and information. The example care plan is designed to be a prompt for the types of issues that should be included in a comprehensive care plan.

This package provides:

- 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 **podcasts** available from the Southern Metro Palliative Care Consortium on various specific topics about MND. Click [here](#) to access podcasts or go to: [www.smrpcc.org.au](http://www.smrpcc.org.au)

For further in-depth training, information and assistance please don't hesitate to contact:  
[Lee-Anne.Henley@smrpcc.org.au](mailto:Lee-Anne.Henley@smrpcc.org.au)

### 1. What is Motor Neurone Disease?

MND is 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 expectancy for people with MND is 2-3 years after diagnosis.

- 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, carer burden, equipment needs and symptom management.

## 2. MND affects swallowing and secretions

- Dysphagia (difficulty swallowing) 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. 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 [here](#) or check out the MND Australia website: [mndaustralia.org.au](http://mndaustralia.org.au).
- There is a section for Health Professionals and symptom management.

## 3. MND affects communication and speech

- 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.
- The aim is to maintain effective communication with the person with MND for as long as possible.
- Speech Pathologists and Occupational therapists can advise on methods of communication and aids that maybe required, such as alphabet boards, eye gaze frames, or laptops with specialised communication software.
- Patience is required to allow the MND person to communicate. They may have their own specific gestures or requirements that are helpful for staff to learn to be able to communicate with the person.

## 4. MND affects mobility and independence

- The mobility of people with MND will be affected. The timing of these changes will depend on where their symptoms start and how their disease progresses.
- A range of equipment and support is needed to maintain as much independence and function as possible for as long as possible. This equipment requires constant review due to progressive deterioration.
- MND Victoria has an equipment lending library - the MND advisor can assist with this. There are certain criteria that must be met for a client living in an Aged Care Facility. See the Aged Care Factsheet [here](#) or look up “MND Victoria Equipment Request”.

## 5. Non-invasive ventilation (NIV)

- People with MND usually die from respiratory failure.
- Respiratory function is affected by the weakness of the muscles associated with breathing. The use of NIV reduces symptoms and provides a better quality of life, (but it does not show down the progression of MND). People will often start using NIV at night, or for a few hours during the day, but as the disease progresses, eventually they will become dependent on NIV (24hours/day).
- 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. Ph **03 9496 3665**
- People with continuous 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. It is important if a person is making the decision to remove their NIV that there is discussion and planning with their local specialist palliative care service, to support the person, family, and staff during this process.

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

- The person with MND can register with MND Victoria to have access to a range of services for themselves 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 support and a multidisciplinary team for the management of the disease and ongoing care. This may occur over telehealth if the client cannot attend the clinic.
- Community Palliative Care may provide specialist support for complex psychosocial needs the MND Shared Care Worker can provide education to staff on physical care of people with MND particularly at end of life.
- GPs are a valuable source of support.
- Financial planners and solicitors can provide valuable assistance.
- Carers Quality of Life guide helps health professionals reduce carer burden. Click [here](#) to access this document from the SMRPCC website: smrpcc.org.au.

## 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. Again, this may be via telehealth.
- MND Victoria has a library and information service, MND Information kits, MND factsheets in different languages, top up funding and equipment loans. The MND advisor 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.
- MND Australia has online information for Health Professionals, a wonderful [poster](#) for Personal Carers and a 60-page booklet called "Aspects of Care: for staff in residential aged care facilities". Click [here](#).

- 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 people with MND may have an impact on 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](http://www.mndcare.net.au) is a website with educational modules about MND

## 8. Contact details for assistance:

MNDV	Ph: 1800777175	<a href="#">MND Victoria</a>
Calvary Health Care Bethlehem	Ph: 03 9596 2853	<a href="#">Calvary Health Care Bethlehem</a>
Victorian Respiratory Support Service	office hours: Ph: 03 9496 3665 Outreach Nurses	<a href="#">Austin Health: VRSS services</a>
MND Shared Care Worker, Southern Metro Region	Ph: 0428 264 446	<a href="mailto:Lee-Anne.Henley@smrpcc.org.au">Lee-Anne.Henley@smrpcc.org.au</a>
Palliative Care Advice Service 7am-10pm 7 days week	Ph: 1800360000	<a href="http://www.pcas.org.au">www.pcas.org.au</a>

***Example of an Aged Care nursing care plan for a MND client is provided in this information (see last seven pages). This care plan was developed with the assistance of Jane Newbound RN & Carol Barbeler RN GRPCC. The recording of data on a care plan will be in accordance with the practices and documentation of each agency.***

# Motor Neurone Disease (MND) Care Plan for Aged Care Facilities

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
<b>Communication</b>	<ul style="list-style-type: none"> <li>- Optimise communication with the resident for as long as possible</li> <li>- Ensure the resident's current method of communication is understood and taught to all staff</li> <li>- Maintain communication as condition deteriorates</li> <li>- Resident's needs and preferences are clearly understood by all who plan and provide care</li> <li>- Identify signs of decline/ deterioration and refer to appropriate person for action</li> <li>- Prioritise communication with the person's main carer/family member.</li> </ul>	<p>Is the resident able to verbalise? If so, how much?                      Preferred Language:                      Interpreter required?                      What aids does the resident need to enhance communication</p> <ul style="list-style-type: none"> <li>- Picture boards, writing pad, alphabet board, eye gaze frame, communication chart, computer/ tablet with enhanced verbal response</li> <li>- Train all staff on use of communication tools &amp; methods</li> <li>- Allow resident additional time to respond, face to face, watch lips, eyes, gestures, avoid interruptions, establish Yes/No signals</li> <li>- Referral to Speech Pathologist for ongoing support (and to monitor/respond to changes in communication and swallowing)</li> <li>- Ensure opportunities for communication are enhanced during optimal times of the day when resident can communicate.</li> <li>- Assistive devices for hearing and/ or vision are cleaned and fitted daily</li> </ul>	<ul style="list-style-type: none"> <li>- IT failure, ensure resident always has access to a functioning piece of equipment</li> <li>- Decrease or changes in ability to verbalise or use communication aids (refer to Speech Pathologist)</li> <li>- Casual staff or new staff who are not familiar with resident's specific needs/MND</li> </ul>
<b>Advance Care Planning</b>	<ul style="list-style-type: none"> <li>- Resident's wishes known, documented and distributed at earliest time possible</li> <li>- Medical treatment decision maker identified</li> <li>- Resident and carer education and support with episodes of deterioration</li> <li>- ACD reviewed and updated regularly, with change/decline in health status</li> </ul>	<p>Is the resident/ representative aware of the diagnosis and prognosis?                      Future communication difficulties are expected and resident's wishes regarding medical interventions need to be documented. Have appropriate documents been completed?</p> <ul style="list-style-type: none"> <li>- Advance Care Directives, Goals of Care, Medical Treatment Decision Maker forms etc.</li> <li>- Evidence of any communication/ case conferences</li> </ul>	<ul style="list-style-type: none"> <li>- Representatives have a poor understanding of prognosis (arrange meeting with appropriate staff to explore further)</li> <li>- Deterioration in resident's communication may be rapid</li> </ul>

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
Nutrition and Hydration	<ul style="list-style-type: none"> <li>- Ensure resident’s nutritional status is maintained</li> <li>- Identify intake issues/changes promptly and refer to allied health professional as needed</li> <li>- All staff trained in method of nutritional intake</li> </ul>	<p>Current weight                      Frequency of weight assessment – Weight loss is a risk                      Oral Intake yes/ no                      Fluid thickness (use IDDSI framework)                      Food Grade                      Assistive devices used (2 handled mug, plate guard, assistive cutlery etc.)                      Any supplements being provided (type, amount, and frequency)                      Amount/ type of assistance required – e.g. sitting upright during meals and 30 minutes post feed, staff assist with feeding; teaspoon used for feeds, double swallow between mouthfuls, do not rush feeding, be alert for choking episodes.                      Physiotherapist can teach assisted cough technique</p>	<ul style="list-style-type: none"> <li>- Weight loss refer to dietician</li> <li>- Increased episodes of difficulty swallowing, coughing or choking refer to speech pathologist</li> <li>- Episode of aspiration pneumonia refer to speech pathologist</li> </ul>
PEG tube	<ul style="list-style-type: none"> <li>- Resident’s nutritional needs are being met safely</li> <li>- Safe administration of medications</li> <li>- PEG tube and stoma care provided</li> <li>- Early identification and referral of potential problems</li> <li>- Staff are confident in the administration of PEG feeds</li> <li>- Equipment is maintained in optimal condition for use.</li> <li>- PEG feeding may supplement oral nutrition to maintain a stable weight</li> </ul>	<p>Type of tube inserted and size:                      Frequency of PEG tube changes                      Team responsible for tube change/ maintenance                      Any pumps/ delivery systems used including the name and contact details of repair team.                      Specific regime:</p> <ul style="list-style-type: none"> <li>- Supplement used</li> <li>- Type of feeding (continuous V’s intermittent)</li> <li>- Flushes used, including the amount</li> <li>- Stoma care including specific products or treatments/ dressings used.</li> <li>- Suspected blocked tube management</li> <li>- Management/ care of any equipment including preventative maintenance</li> </ul> <p>Staff education required</p>	<p>Refer to treating team in the event of the following</p> <ul style="list-style-type: none"> <li>- Accidental removal</li> <li>- Blocked tube</li> <li>- Vomiting or nausea</li> <li>- Diarrhoea</li> <li>- Leakage or bleeding from stoma</li> <li>- Excoriation/ stoma breakdown not responding to basic care</li> <li>- Suspected aspiration</li> <li>- Equipment failure refer to repair/ maintenance</li> </ul>

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
Breathing support	<ul style="list-style-type: none"> <li>- Resident’s breathing capability is closely monitored and early referral for any signs of difficulty/ deterioration</li> <li>- Equipment is maintained in optimal condition for use</li> <li>- Staff are confident in use of equipment and identification of the need for referral</li> <li>- PRN orders available &amp; timely administration of medication (benzodiazepines, opiates) to relieve anxiety and dyspnoea</li> <li>- Staff are confident in the use of NIV, and a back-up system exists (power outage)</li> </ul>	<p>Who is the team responsible for reviewing/ evaluation the residents breathing capabilities/ support? (Name and contact details, hours of work etc.)</p> <p>Can the resident breath independently without assistive devices?</p> <p>Does the resident use NIV and how often?</p> <p>What equipment is used and who is responsible for checking/ maintenance and cleaning masks &amp; tubing?</p> <p>Staff are trained in use of NIV &amp; equipment</p> <p>What is the resident’s routine for the fitting and use of any assistive devices/masks?</p> <p>If oxygen being used – amount, frequency and method of delivery including equipment required.</p> <p>How is the facility going to monitor or identify deterioration (regular review by treating team, increase in breathlessness, oximetry, resident/ representative reporting?)</p> <p>Regular assessment for dyspnoea, anxiety &amp; need for PRN medication</p>	<p>Refer to treating team if evidence of</p> <ul style="list-style-type: none"> <li>- Breathlessness on exertion, lying flat, talking &amp; eating</li> <li>- Sleep is disturbed</li> <li>- Morning headache (↑CO2)</li> <li>- Voice becoming quiet</li> <li>- Weakened ability to cough</li> <li>- Increased deterioration in head and neck control</li> <li>- Request from resident/ representative</li> </ul>
Manage secretions	<ul style="list-style-type: none"> <li>- Resident’s secretions are monitored and minimised for comfort</li> <li>- Potential problems are identified and referred for review</li> </ul>	<p>Document and describe secretion patterns and symptoms.</p> <p>Regular review by Speech Pathologist and medical team.</p> <p>Clear instructions on medication management usage and natural remedy use.</p> <p>Nonpharmacological treatment methods described including positioning, head &amp; neck support, oral swabbing,</p> <p>Refer to online resource at <a href="#">Saliva Management in MND   MND Australia</a> for specific details.</p> <p>Preserve resident’s dignity in managing saliva by exploring clothes protectors (that appear as ties or scarves).</p>	<ul style="list-style-type: none"> <li>- Drooling, increase in secretions, aspiration pneumonia/ chest infections to be reviewed by treatment team</li> <li>- Monitor/assess skin around mouth neck for signs of maceration/excoriation</li> <li>- Thick tenacious secretions, unable to cough up</li> <li>- Current medication regime no longer working – refer to treatment team.</li> </ul>

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
<p><b>Mobility</b></p>	<ul style="list-style-type: none"> <li>- Resident is assisted to maximise their independence</li> <li>- Deterioration of functionality is identified promptly and referred to the appropriate treatment team member</li> </ul>	<p>Falls Risk Assessment score</p> <p>Falls risk minimisation strategies</p> <ul style="list-style-type: none"> <li>- Appropriate footwear</li> <li>- Level of assistance/ supervision</li> <li>- Bed height (including low low bed usage)</li> <li>- Sensors required</li> <li>- Frequency of supervision</li> </ul> <p>Resident current capacity is clearly described.</p> <p>What aids are used for mobility (frames, walkers, wheelchairs, electric beds, princess chair etc.)?</p> <p>Does the room need to be “set up” in a way to enhance independence?-- instructions visible for all staff re positioning in bed, chair, wheelchair</p> <p>Transfers:</p> <p>Note careful handling of all joints especially shoulders due to weakened muscles</p> <ul style="list-style-type: none"> <li>- Number of staff required</li> <li>- Equipment needed – sling or standing lifter, transfer sheets, overhead assistive devices, tiger tails etc.</li> </ul> <p>Therapy/ Physio</p> <ul style="list-style-type: none"> <li>- Any therapeutic regime, massage/ exercises are enabled as per the physiotherapy plan</li> </ul>	<ul style="list-style-type: none"> <li>- Changes in the resident’s mobility or transfer status is referred to the physiotherapist for assessment/ management</li> <li>- Changes in physical capacity are to be referred to the treating team</li> <li>- Any new pain should be assessed immediately</li> </ul>

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
<b>Hygiene</b>	Resident's personal hygiene needs are met, consistent with their preferences and ability	Personal Hygiene Frequency Products used (include preferred soaps, shampoo, moisturiser, shaving/ epilation etc) Level of assistance required including number of staff Preferred timing of assistance Mouth Care is very important due to tongue weakness and less effective saliva Include daily oral and dental assessment, check for trapped food, thrush and ulcers Usual routine including products used, low foaming toothpaste is best Level of assistance required Use of swabs etc for oral secretions Importance of positioning	<ul style="list-style-type: none"> <li>- Report any skin tears, bruises or suspected pressure areas to appropriate staff or treatment team</li> <li>- Refer for dental review if reported pain or discomfort</li> <li>- Refer to speech pathologist or treatment team for management of secretions</li> </ul>
<b>Skin Care</b>	<ul style="list-style-type: none"> <li>- Skin is maintained in optimal condition and referral to appropriate treating team is made in response to deterioration.</li> </ul>	Skin Care Assessment Score - Daily review/ check of pressure areas – skin condition /saliva management Report any breaks, tears, wounds, bruises, excoriation for review by senior staff Preferred skin care products and frequency of use Ensure use of emollient creams in skin folds and post continence care	<ul style="list-style-type: none"> <li>- Refer to treating team, wound specialist as required</li> </ul>

Care Need	Goal	Required Assessment/ Action	Alerts/ Red Flags
<b>Elimination</b>	<ul style="list-style-type: none"> <li>- Residents comfort and dignity is maintained</li> <li>- Constipation is prevented or managed appropriately</li> <li>- Catheters are managed appropriately</li> </ul>	<p>Continence Assessment completed                      Pad type and frequency                      Toileting times and level of assistance                      Urine</p> <p>In cases where the resident has a catheter (SPC or IDC)</p> <ul style="list-style-type: none"> <li>- Catheter type, size and frequency of change</li> <li>- Bag usage for day and night described</li> <li>- Team responsible for catheter change</li> <li>- SPC stoma care clearly documented</li> </ul> <p>Bowel</p> <ul style="list-style-type: none"> <li>- Monitor bowel activity each shift and identify usual routine</li> <li>- Identify current management strategies including dietary requirements (fibre and fluids), aperient usage (including preferred brand and frequency of use)</li> <li>- Use of suppositories/ enemas (including usual frequency of use and preferred brands)</li> </ul>	<ul style="list-style-type: none"> <li>- Change in level of continence requires investigation by treating team</li> <li>- Report any elevation in temperature, urine colour or amount or evidence of delirium to the treating team</li> <li>- Monitor bowel activity daily and report if BNO for 2 days to follow management plan report to RN in charge</li> </ul>
<b>Behaviour</b>	<ul style="list-style-type: none"> <li>- Behaviours of concern are identified and managed effectively</li> <li>- Resident's mental well-being is monitored for deterioration</li> </ul>	<ul style="list-style-type: none"> <li>- Monitor resident for any specific behaviours of concern and document risk minimisation strategies</li> <li>- Report any evidence of depression/ anxiety including apathy, sadness, crying, fear, insomnia, excessive sleeping, refusal to leave room, expressions re: dissatisfaction with quality of life and/ or desire to die statements</li> </ul>	<ul style="list-style-type: none"> <li>- Refer to treating team for review</li> <li>- ? to GP for mental health care plan</li> <li>- Pall care team for counselling</li> <li>- Aged persons mental health team if appropriate</li> </ul>

Treating Team

Team Member	Name and Contact Details	Hours of Work/ Availability
General Practitioner		
Neurologist		
Palliative Care Team		
Residential In-Reach Team		
Dietician		
Physiotherapist		
Wound Specialist		
MND Advisor		
Other		
Equipment	Supplier	Repairer Details
PEG Feed Pump		
NIV machine		
Wheelchair		
Communication Aids		
Other		