Motor Neurone Disease

Aspects of Care

for staff of residential care facilities

mnd Australia

Motor Neurone Disease Aspects of Care: for staff of residential care facilities

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This document was compiled following many requests from care providers, residential care staff and from people with motor neurone disease (MND) and their carers for information about caring for people with MND in the residential care setting.

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The Motor Neurone Disease Association welcomes suggestions from people using this document so that it can be improved over time.

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In regard to symptom control: this publication is not an exhaustive source of information on symptom control. The medication suggested is not guaranteed to be effective or appropriate in all cases. Naturally, the decision rests with the prescribing doctor and/or nurse, taking into consideration the needs, wishes, and susceptibility of the patient.

Table of Contents

Table of Figures

Section 1 - What is motor neurone disease?

Motor neurone disease (MND) is a fatal disease with no known cure and limited treatment. MND is the name given to a group of diseases in which the nerve cells (neurones) controlling muscles that enable us to move around, speak, breathe and swallow, deteriorate and die. With no nerves to activate them, muscles gradually weaken and waste away. The person with MND, therefore, becomes increasingly disabled. Walking, talking and swallowing may become impossible. Intellectual function and sensation are rarely affected, however, there may be some subtle changes in personality, decision making and thought processes for some people with MND. The patterns of weakness in MND vary from person to person and usual life expectancy is two to three years after diagnosis.

Motor neurone disease is referred to as Amyotrophic Lateral Sclerosis (ALS) in the United States of America. In this publication the term Motor Neurone Disease (MND) will be used.

What does a nerve cell (neurone) do?

Nerve cells or neurones are the electrical wires of the human body. These nerves carry messages to, or from, other cells.

MND is a disorder of specific nerves — nerves that tell the muscles what to do. These nerve cells take messages away from the brain; sensory nerve cells take messages to the brain.

Because muscles make us move, the nerves that control movement are called motor nerves or neurones (the words nerves and neurones have the same meaning).

Without the ability of motor nerves to send messages to muscles, the muscles do not work properly and a person becomes progressively weaker.

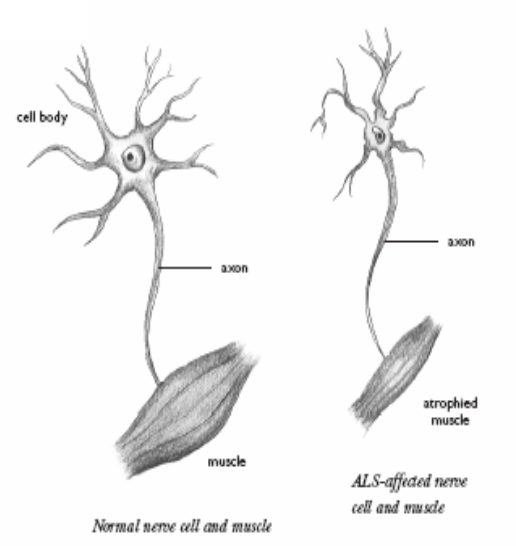


Figure 1: Nerve Cells
ALS Association 2002

What muscles are affected by MND?

It is important to know that MND only affects voluntary muscles – the muscles that we can control. For example, we can voluntarily move our arm to comb our hair, our legs to walk and our tongues to speak.

MND does not affect the sensory nerves – the nerves involved in detecting sensations such as seeing, hearing, touch, taste and feeling pain.

MND also does not affect muscles that we cannot control voluntarily. For example, we cannot make our hearts beat faster or slower. The heart is not a voluntary muscle and it is not affected by MND. MND does not usually cause incontinence.

Breathing may seem to be involuntary. Remember, though, while we cannot stop our hearts, we can hold our breath - so be aware that MND will eventually have an impact on breathing.

Are there different types of MND?

Motor Neurone Disease is a general term applying to a group of diseases of the motor neurones. These include:

Amyotrophic Lateral Sclerosis (ALS)
ALS is the most common form of Motor Neurone Disease. In ALS there may be weakness, wasting and stiffness of muscles.

Progressive Bulbar Palsy (PBP)
This form of MND first affects the muscles of speech and swallowing. The speech and swallowing muscles are controlled by motor neurones that come from the bulb – the lower part of the brain (brain stem). When these muscles become weak and uncoordinated, the diagnosis of Progressive Bulbar Palsy is made. Eventually this condition progresses to ALS and causes the weakening of arm, leg and respiratory muscles.

Progressive Muscular Atrophy (PMA)
Progressive Muscular Atrophy is slower to progress. People with PMA show muscle weakness, wasting and weight loss.

Primary Lateral Sclerosis (PLS)
Primary Lateral Sclerosis results in stiffness and spastic paralysis of limbs. This is a very rare form of MND and is slower in its rate of progression.

Familial ALS (FALS)
MND is usually sporadic, occurring randomly throughout the world. However, familial MND (occurring in families) accounts for approximately ten per cent of all people with MND.

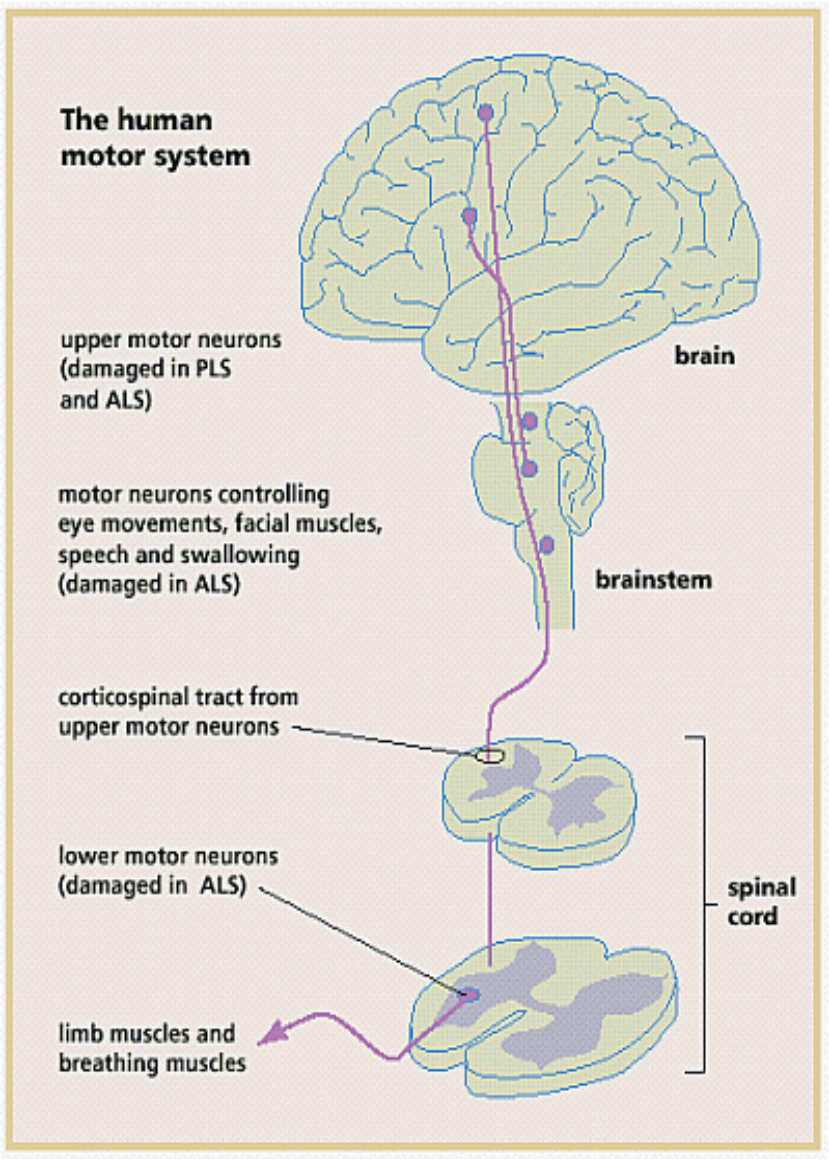


Figure 2: The Central Nervous System showing the different nerve tracts affected in PLS and ALS
Shaw 2001

Who is affected by MND?

Slightly more men than women are diagnosed with MND, most commonly in the 50 to 60 year age group. However, MND may be diagnosed in adults at any age. At any one time there are around 1400 people in Australia living with MND. More than one person dies each day of MND in Australia.

Can other people catch it?

There is no evidence that MND can be transferred from person to person.

Is there a treatment for MND?

As yet there are no known causes or a cure for MND. Current research includes investigation of environmental and toxic triggers, viral infection and anti-immune mechanisms.

Treatment remains focused on best quality care and symptom relief. Research trials for drug treatments give hope for the future.

Riluzole (Rilutek) is the only medication found to prolong survival, on average for 3 to 12 months, but it does not improve muscle strength. Riluzole is available in Australia through the Pharmaceutical Benefits Scheme (PBS) but some medical restrictions apply. Not everyone with MND is eligible to receive riluzole.

What are the symptoms?

It is important to understand that MND is very different for every person diagnosed. MND may start in different areas of the body and progress in different patterns and at different rates.

Remember that not everyone with MND becomes weak in all of his/her muscles. For example, although about 25 per cent of people with MND start with weakness of the legs, some people may never need a wheelchair. Also, although some people will never have weakness of the bulbar (speech and swallowing) muscles, MND will start with bulbar symptoms in about 25 per cent of those diagnosed.

There is therefore no 'recipe' for managing MND. It is a matter of looking at the particular symptoms and needs of each person with MND and trying to reduce the difficulties caused by these symptoms.

If a person with MND is placed in residential care his/her symptoms are likely to be advanced and complex.

Figure 3: Symptoms of MND

Symptoms of MND	
• progressive upper and lower limb weakness	
• speech problems	• thick saliva
• swallowing difficulties	• breathing problems
• weight loss	• fatigue
• emotional lability	• drooling of saliva

What remains unaffected by MND?

Sensory symptoms, that is, disturbances of touch, taste, smell, sight and hearing are rare. It is also important to understand that although the person with MND may have difficulty in speaking, his/her understanding and intellectual function are usually not affected.

Eye muscles, bowel and bladder control are usually not affected, however, constipation is often caused by lack of mobility, dietary changes and inadequate fluid intake.

What is the cause of death in MND?

The usual cause of death in MND is breathing failure. For some people, breathing difficulties may occur early in the course of the disease and the person may die before the level of general disability becomes very severe. Others will lose the use of their arms and legs, communication and swallowing before breathing muscles become involved.

Distressing symptoms such as breathlessness, discomfort and pain are best managed in consultation with palliative care teams. See Section 6 - End of life care for people with MND, for more detail on terminal care of a person with MND.

Summary of Section 1

- In MND the motor nerve cells die
- This leads to increasing muscle weakness and paralysis
- Sight, hearing, touch and taste are not normally affected
- The mind is not usually affected
- Everybody is affected differently
- MND is a terminal disease
- There is no known cure

Aim is to provide good care and symptom relief

Section 2 - Settling into residential care

The decision to accept residential care can be extremely difficult for both the person with MND and the family as there is a fear that the person's individual and complex needs will not be understood by the residential care staff.

Placement in residential care is often the final blow in a process of loss of independence for the person with MND. In a residential care facility, he/she may feel isolated from the community and cut off from social interaction. Separation from family and friends may cause loss of hope. These feelings are likely to be more intense if the person is young and most of the other residents are elderly and have dementia. Although dementia is not usual in MND difficulty with communication is often mistaken for dementia and this may be terribly demoralising for the person with MND.

When the person with MND is admitted to a residential care facility it is important that aspects of care are discussed with the person and his/her family carers. Trust can be established by frank discussion about priorities of care and what may or may not be possible within the residential care setting.

Weakness and disability is progressive in MND. The needs of people with MND are complex. Providing the best care for the person with MND requires assessment and review by a team of medical, nursing and allied health professionals. This multi-disciplinary team may include a neurologist, general practitioner, respiratory physician, nurse, occupational therapist, physiotherapist, speech pathologist, dietitian, social worker, and palliative care team. Ideally, some members of this team will consult with residential care staff to review the person with MND as his/her needs change during the course of the disease.

The person with MND may have been receiving care from a multi-disciplinary team while living in the community. If this is the case it may be very helpful to invite members of this team, as well as family members, to discuss the person's particular needs with residential care staff. If a multidisciplinary team has not seen the person with MND before admission, it may help both the person with MND and the residential care staff to have appropriate allied health professionals (for example, occupational therapist, physiotherapist and speech pathologist) assess current needs. This is likely to improve the level of care for the resident with MND and allow the resident and family to feel more confident.

Invite the carer and family members to write down specific care needs. Information about the person's particular care needs obtained from family carers and appropriate allied health staff can be used to establish Care Plans before, or at the time of, the person's admission.

The person with MND may feel vulnerable, especially if he/she is unable to move or use a buzzer to call members of staff. If speech is affected there is a fear of being unable to explain needs.

If the person with MND has lost the ability to speak he/she may have a communication aid or special means of communicating. It is important for staff to take time to learn the means of communication used by the person with MND and to establish a means by which he/she can call for attention.

It is also important for all staff to be aware that MND is a progressive disease and the person's needs will change as he/she becomes more disabled. This change in the level of function can be quite rapid. Therefore, the person with MND may find that he/she is suddenly unable to perform an activity, for example, lifting food to the mouth. Staff must be aware that it is unlikely that the person with MND is being lazy – it is simply that MND has progressed.

Case conferences can be very helpful if there are particular issues to discuss or to review care plans as the person's needs and abilities change. These could include family members, the resident's general practitioner and allied health professionals as well as residential care staff.

A checklist of needs (*MND Care/Nursing Alert*) can be provided by the Motor Neurone Disease Association for people with MND who have severe communication difficulties.

Regional/care advisors from the Motor Neurone Disease Association are available in most states to provide support, information, de-briefing and in-service education to nursing home staff and attend case conferences when needed. This service is provided free of charge.

Summary of Section 2

- Try to understand the persons feelings of vulnerability, loss and isolation
- On admission take the time to talk to the person with MND and his/her family carer/s about current needs and routine
- Remember that each person with MND is affected differently
- Try to 'problem solve' the needs of the person with MND
- Recognise the need for a multi-disciplinary team approach
- Work out how to communicate even if the person cannot speak
- Make sure he/she has a way of calling for help
- Remember that weakness and disability will progress in MND
- Establish written care plans and review regularly
- Plan regular team meetings to review needs and to discuss care
- Use the MND Association's Nursing/Care Alert
- Ask the regional/care advisors from the Motor Neurone Disease Association to assist with care planning, team discussion, staff education and debriefing

Remember that the person with MND can understand and hear you

Section 3 - The importance of multidisciplinary care for people with MND

The needs of people with MND are complex and vary from person to person. It is important that a variety of health professionals be involved in their care, enabling regular assessment and review of changing needs.

It is also important that these health professionals share knowledge and experience to 'problem solve' difficulties with each individual with MND and his/her carer. When the person with MND is admitted into residential care the staff of the facility become an essential part of the team.

Who may be involved in the care of people with MND?

The General Practitioner provides the link between the extended care team and the residential care facility. The GP, residential care staff, allied health professionals and palliative care staff can work together to develop the best quality care management.

Occupational therapists can investigate the person's best means of using communication aids including buzzers or call bells to let staff know they need help. Occupational therapists can also help with advice on comfort, positioning, pressure area care, splinting, mobility aids and ways to help with personal care activities such as showering and dressing.

Physiotherapists have an important role in the comfort and care of the person with MND. They can help with positioning. Physiotherapists can give exercises for muscles groups that are not affected by MND and exercises to help keep affected joints flexible. Physiotherapists can also demonstrate the assisted cough technique to help people who have a weak cough reflex and swallowing difficulty. They can help provide neck collars, foot splints and mobility aids to help prevent falls.

Speech pathologists can assess the person's swallowing and communication needs. They can recommend the best food and fluid consistency for the person and suggest ways to help with safe swallowing and to maintain food and fluid intake. They can assess ways to help communication. Speech pathologists work with occupational therapists to find the best 'set-up' and positioning if a communication device is being used.

Dietitians assess the person's nutritional needs and make recommendations to achieve the best level of nutrition and fluid intake.

Social workers help with referring people to appropriate services and benefits. They may also provide short term counseling and emotional support for people with MND and their families. Residential care facilities may be able to access social workers through local palliative care teams.

Palliative care specialist and clinical nurse consultants can help with symptom control including advice and medications to manage breathing difficulties and pain (if pain is experienced).

MND Association regional/care advisors can help residential care staff to contact appropriate health professionals and teams. Regional/care advisors can provide further MND information and education for staff. They are able to visit the residents with MND to offer information and support and can maintain contact with the family.

Multidisciplinary MND Clinics and Services

There are now several established MND specific clinics and programs of care throughout Australia. These specialised clinics provide an integrated approach to the management and clinical care of an individual with MND.

MND specific clinics and programs give the person with MND access to a range of health professionals who work together to provide a coordinated response to care. Team members may include the neurologist, rehabilitation specialist, palliative care specialist, respiratory specialist, physiotherapist, dietitian, social worker, occupational therapist, speech pathologist and registered nurse. In some states of Australia, MND Association regional/care advisors also attend these clinics to provide information and support. MND specific clinics and programs often provide telephone consultancy for care providers within their designated health area.

Contact the Motor Neurone Disease Association in your state or territory for details.

Summary of Section 3

- The needs of people with MND are complex and varied
- A team of health professionals is needed to provide regular assessment and to review changing needs
- Be guided by the needs and wishes of the person with MND and his/her family carer
- The team needs to share knowledge and experience
- The staff of the residential care facility are a part of the team
- Other team members include:

  General practitioner

  Occupational therapist

  Physiotherapist

  Speech pathologist

  Dietitian

  Social Worker

  Palliative care consultant/nurse

The MND Association regional/care advisors can help with contacting other health professionals if necessary

Section 4 - Managing MND in residential care

Emotional aspects of care

MND is a disease that has no cure and limited treatment beyond supportive care. Therefore the focus is on providing nursing care that helps people with MND and their families cope with the progressive nature of MND and the ever-increasing disability it causes. Total care should include meeting physical, emotional and psychological needs. Major goals are to maximise communication, maintain comfort and prevent further complications of immobility such as contractures and pressure sores.

Emotional distress

MND has been described as a 'disease of losses'. Care tends to focus on the physical aspects of the disease and the tremendous emotional impact is often neglected. Losses experienced in MND include loss of independence, role within the family, self-esteem, self-image and social interaction. Fears include increasing disability, suffocation, choking and isolation, fear of the dying process and fear of the unknown.

Anxiety is emotional pain and worry. People with MND may have multiple causes for anxiety. These may include financial planning for their own and their family's future, how the family will cope, as well as how they will be cared for as the disease progresses. Spending time with the person with MND, talking through fears and worries can be very worthwhile. If at all possible, fears should be expressed and openly discussed. Social workers, pastoral care workers or members of the palliative care team can help in providing counselling.

Depression is common (as it is in any devastating disease) and can be treated if persistent. Remember though, that a lack of facial expression may be due to weakness of the facial muscles, not depression. We rely so much on non-verbal response that an expressionless person may appear angry, disinterested or depressed.

What is emotional lability?

Emotional lability is the reduced control over emotional responses and is a common symptom of MND. It is not a mood disorder but it does cause excessive laughing or crying which may be very embarrassing for the person with MND. This response may also be physically distressing if it interferes with breathing. It is important to recognise that this response is part of MND and to create a calming environment.

Requests for euthanasia

The majority of people with MND want to live to the last moment. However, some people with MND may talk about euthanasia. Requests for euthanasia are often associated with a wish to keep control. It is therefore extremely important for people with MND to have as much control over what happens to them as possible. It is also important that they know that they are not alone and that there are people who have their interests at heart, on whom they can rely.

While many people with MND fear that they will choke to death, such a possibility is extremely rare. They can be reassured that death in MND is generally due to breathing failure which, in the majority of cases, results in a gradual and peaceful lapse into unconsciousness prior to death.

Primary symptoms of MND

The primary symptoms of MND include:
1. Immobility, discomfort and pain
2. Speech difficulties
3. Swallowing problems
4. Drooling and thickened saliva
5. Breathing difficulties

Immobility, discomfort and pain

Why do people with MND feel uncomfortable?

The actual loss of motor neurones is not painful, but the weakened muscles and joints may become stiff and sore. This is made worse by immobility as the disease progresses. The sensory nervous system remains intact and the person with MND will feel the need to change position.

In addition muscles and ligaments may become stretched because the muscles are no longer supporting the skeleton. As the disease progresses, muscle support for joints, especially the shoulder joint, is greatly reduced and strains can easily happen during activities of daily living.

It is important to avoid pulling on the arms when moving the person.

Why do people with MND need regular turning in bed?

Inability to move and weight-loss can cause severe discomfort and skin breakdown. When lying in bed, the person with MND may need frequent turning. This can be as frequent as hourly repositioning. Very specific positioning of arms, legs and head may also be needed to maintain comfort. The person with MND may be grateful for a small move of an arm or leg as you pass by. This can make a huge difference to his/her comfort.

A fear of being unable to communicate feelings of discomfort can be helped by making sure the person has an effective way of calling for assistance when needed and, if possible, a prompt response to calls. Time taken to make the person comfortable may mean the difference between a good night or a bad night for the person with MND and for the staff.

What about positioning when seated?
Seating position needs careful attention with adjustments to the positioning of limbs.

It is important to involve the family carer or therapists in helping residential care staff to achieve comfortable positioning. Staff already experienced in managing the person's positioning needs should teach new staff as these can be very individual.

Useful comfort aids include medical electric beds, Roho or air mattresses, reclining and water chairs or tilt-in-space wheelchairs. Pressure cushions can be a great help in maintaining comfort and preventing pressure sores.

It is important to remember that people with MND do need regular changes of position due to the nature of the disease - they are not simply being demanding. It is a good idea to ask about every two hours which limbs the person would like moved.

What about pressure care?
Pressure sores are less common for people with MND than for other immobilised patients. One reason is that people with MND have full sensation. Pressure areas become very painful before breaking down. As long as the person can communicate, pressure areas are unlikely to be allowed to reach the point of breaking down.

Pressure relief cushions, mattresses and elbow pads can help early in the course of the disease. In the later stages the person with MND may be thin from muscle wasting, poorly nourished because of swallowing problems and unable to communicate discomfort. The risk of pressure sores increases and more frequent repositioning and skin checks become necessary.

Does MND cause pain?
Pain and discomfort in motor neurone disease come from the complications of muscle weakness, stiffness and immobility. Pain may also be caused by muscle cramps, spasticity and skin pressure.

What are cramps?
Muscle cramps usually affect a single muscle and the pain, although intense even in small muscles, is limited in area. Muscle cramps are most common early in the course of the disease. The cramping becomes less severe with time as general muscle strength weakens.

What is spasticity?
Spasticity affects larger areas of the body - arm, leg, trunk, and neck. All the muscles in the area tighten up and the entire area may be so tight that it hurts.

How can spasticity be managed?
Regular physiotherapy, for example, passive stretching of the limbs, may be helpful. Medication can help but careful assessment of the effect of the medication with advice from the person's doctor and physiotherapist is essential. For some people the stiffness caused by spasticity may actually be useful, for example, stiffness of the legs can help weight bearing when transferring from a bed to a chair.

Can Range of Motion exercises help?
Passive range of motion and gentle stretching exercises are important. A physiotherapist can show the staff some simple exercises they can do safely with the person with MND to help reduce stiffness of joints and muscles. Although these exercises do not improve muscle function for the person with MND, they are very important in preventing pain.

Physiotherapists and occupational therapists can advise on the best positioning, transferring techniques and pressure relieving equipment.

What about neck weakness in MND?
Neck and shoulder weakness can cause back and neck pain. It can also make swallowing more difficult. Additionally, neck and shoulder weakness can make walking unstable due to change of balance.

Muscle strength in the neck may change over time. A physiotherapist can help find a suitable neck support to hold the head up and prevent aching of the muscles at the back of the neck but this may be tolerated for only short periods of time. A head support should be introduced with tact and sensitivity, sooner rather than later, before the muscles and ligaments are irreversibly stretched. Neck supports include soft collars, plastic collars and under chin supports. A heat pack can sometimes give comfort.

Time spent in an electric reclining chair may provide relief from neck pain.

Is massage helpful?
Physiotherapists, nurses, relatives and remedial massage therapists who have appropriate training can give massages. Massage should be gentle and it must be understood that the ligaments which hold the bones together do not have normal muscle support. Massage of the neck muscles is particularly important as these become very stretched and painful.

Speech difficulties

Speech difficulties can start at different times for different people with MND. For people with Progressive Bulbar Palsy (see p.4) difficulties with speech and swallowing will be the first symptoms. Many, but not all, people with other forms of MND will experience difficulty with communication in the later stages of MND.

What can go wrong with speech in MND?

The difficulty people with MND experience in speaking is called dysarthria. Dysarthria means slurred and distorted speech due to weakness and reduced co-ordination of muscles of the face, tongue and throat.

Why is communication important?

The ability to communicate is important to our sense of dignity and the ability to have control over what happens to us. Intellect is usually maintained in MND so that loss of speech leads to a strong sense of isolation. The comfort needs of people with MND are considerable and the frustration experienced by not being able to control one's own situation can lead to behaviour that appears to be demanding.

It may require patience to concentrate while the person with MND slowly expresses his/her needs and thoughts. However, establishing effective communication also helps to build a sense of trust and will ultimately help the staff caring for the person with MND. An anxious resident will be tense with staff and a vicious cycle of frustration can result.

How can staff help the person with MND communicate?

Remember that despite severe difficulties in communication, the person with MND is not deaf and he/she can understand you. It is important not to shout at the person, to speak 'down' to him/her or to speak about the person as if he/she cannot understand.

To help communication if speech is slurred:

- make eye contact with the person
- watch facial expression and gestures
- ask questions that can be answered by a 'yes' or a 'no'
- ask the person to speak slowly or to say one word at a time
- ask the person to say the 'key' (main) word that the sentence is about – or the first letter in the word he/she is trying to communicate
- the person may be able to write down a letter or a word to help you to understand

What equipment can help with communication?
If a speech pathologist has not been involved previously, arrange a consultation so that the best means of communication can be assessed. The speech pathologist will review the person's communication needs and look into alternative communication.

This may include:

Writing:

- A white board
- Magna Doodle
- A small notebook to hang around the neck.

Electronic communication devices:

Lightwriter – a keyboard device with voice output and a screen that shows typed messages.

Message Mate - enables pre-recorded messages to be placed under picture keys.

Computer programs and communication devices with a scanning function can be used if the person becomes unable to use fingers to type messages.

Laser head pointers - can be useful if the person has no hand function. A laser torch and switch is fixed to a headband or cap. The red dot from the torch is directed by head movement to letters, words or phrases on a chart.

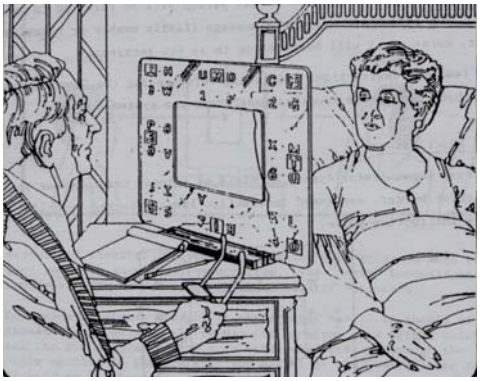
Communication charts - can be made up according to each person's need. These may include, phrase, letter and picture charts. Sample communication charts, like the one to the right, are available from a speech pathologist or may be available from the Motor Neurone Disease Association. For further information ask the regional/care advisors for your area.

The person with MND and the person he/she is communicating with should agree upon a way of indicating 'yes' and 'no'. The table below lists some common methods (from www.alsa.org/adaptive).

Common Communication Methods

Method	Indication for 'Yes'	Indication for 'No'
Blink	One blink	Two quick blinks
Facial expression	Smile	Frown
Head movement	Up and down	Left and right
Eye expression	Raise eyebrows	Squint/close eyes
Eye contact	Look at partner	Look away/close eyes
Vocal sound	One grunt/sound	Two grunts/sounds

Eye gaze boards - Even in the later stages of MND people can usually move their eyes. Eye movements can be used to point to letters or words on perspex board. The ETRAN board (see right) is a perspex letter board.



Perspex eye gaze boards for communication of the person's every day needs can be made by attaching words, phrases and pictures to the board.

The board is held up so that the person with MND can communicate words, letters and numbers using eye movements.

It is usually a good idea for the other person to have a pencil and paper to write down letters and numbers as they are communicated.

How can a person with MND call for help?

It is very important that a person with MND, who may not be able to use his/her hands and fingers or call out, has a way of alerting the staff when he/she needs help.

An occupational therapist can help to find the person's best means of operating a 'call device' or intercom. This may be operated by a switch, which uses the person's best-preserved muscles. An occupational therapist will also be able to suggest the best set-up and positioning for the person to be able to use the call device or communication aid.

Special switches can be used with call devices and communication aids. Small movements of hand, finger, foot, elbow, chin etc can activate these switches.

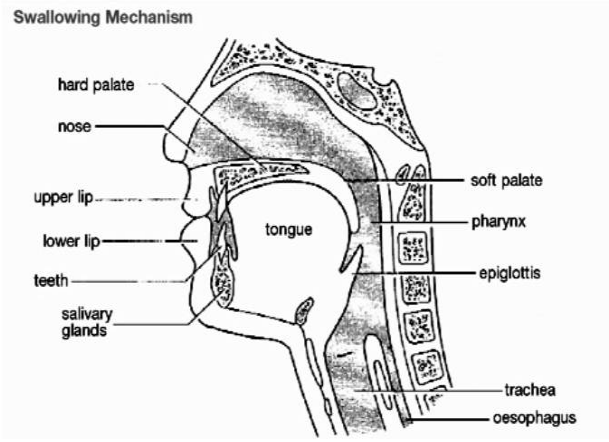
Some Motor Neurone Disease Associations have a range of communication devices available for loan following referral from a speech pathologist. Contact the MND Association in your state or territory for details.

Figure 4: Jelly Bean Switch which can be used by elbow, foot or chin

Swallowing problems

Normal swallowing involves a complex series of movements. These require fine control of muscles of the lips, tongue, soft palate, muscles of the throat (pharynx and larynx). Muscle weakness caused by MND interferes with this process and reduces the person's ability to swallow.

Figure 5: Human Swallowing Mechanism



Difficulty with swallowing (dysphagia) means that it is hard for the person to take in enough food and liquid. Swallowing difficulty and reduced airways protection during the swallow can cause food or liquid to enter the airways. This is known as aspiration and may result in a chest infection or aspiration pneumonia.

Communication and swallowing difficulties appear early for people with Progressive Bulbar Palsy (see p.4) but may occur later in other types of MND.

What can be done to manage swallowing difficulties?

Assessment and review of swallowing by a speech pathologist who will advise on the following:

1. Foods that are easier to swallow

The full range of food consistencies includes normal, soft, mashed/minced or puree with puree usually being the easiest to swallow. If the person is on a pureed diet it is important not to make the puree consistency too runny or lumpy. The person with MND can help to determine the best food consistency for his/her own needs. Attention should be given to the way food looks. It is important to keep the food types separate and to make sure food is kept warm.

2. Thickening fluids

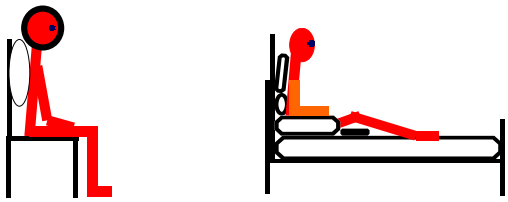
Water and other thin liquids can be the most difficult things to swallow. Thickening fluids makes them easier to control in the mouth and safer to swallow. Fruit nectars and milk shakes have natural thickness. This can help in cases of mild difficulty with swallowing. Liquid thickeners such as Supercol U, Thicken Up, Nutilis and Guarcol can be used to gradually increase thickening of drinks as swallowing deteriorates.

3. Strategies to help manage swallowing difficulties

Correct positioning is very important to ensure airways protection. Usually, the best position for swallowing is for the person to be sitting as upright as possible.

Carefully arranged pillows, special chairs and tilt-in-space wheelchairs can be helpful in achieving the best position. A physiotherapist may be able to help with correct positioning and with head and neck support.

Figure 6: Positioning



Tucking the chin slightly towards the chest can help the swallow.

The speech pathologist can help with guidelines for managing the person's swallowing difficulty and training the staff in the best way of feeding the person.

General guidelines for feeding people with swallowing difficulties:

- Make sure that the person's breathing is settled before starting the meal
- It is important to create a calm, quiet environment at meal times
- Allow sufficient time for eating. People with weakened mouth muscles need more time to move the food into position for swallowing
- Be sure that one mouthful has been swallowed before placing more food in the mouth
- Remember that swallowing muscles can tire from the effort of eating
- Small frequent meals throughout the day may be easier for the person than three large meals
- Mixed consistencies can be very hard for the person with swallowing difficulty to manage. Soups should be smooth and thick
- Smaller tablets can be taken with custard or yogurt
- Some tablets (but not slow-release tablets) can be crushed or given in a liquid form

Can other health professionals help with eating and drinking difficulties?
A physiotherapist can train staff in the assisted cough technique. This can help the person to clear his/her throat and upper airways.

A dietitian can give advice about nutritional intake and food supplements.

An occupational therapist can help with modified plates, cups and cutlery.

The Motor Neurone Disease Association of NSW has produced a recipe book as a guide to help people with swallowing difficulties.

The Motor Neurone Disease Association of Victoria has produced a DVD about swallowing difficulties in MND. This is very useful for staff training.

What can be done when swallowing problems are severe?
As MND progresses, eating may become increasingly tiring and stressful. Some people may decide to accept alternative feeding by tube via Percutaneous Endoscopic Gastrostomy (PEG).

PEG is a procedure, performed under a light general anaesthetic, during which a feeding tube is placed directly into the stomach through a small hole in the skin. The tube is left in place.

It is important that the person with MND knows about the possibility of a PEG in time to receive the most benefit. It is also important for a respiratory physician to assess the person with MND before a PEG placement is planned because breathing difficulties can complicate the procedure.

Some people with MND may choose not to have a PEG placement. A few may even choose to discontinue eating and drinking. The person with MND should be supported in the decision he/she makes, following full and frank discussion of options (normally with the visiting doctor, medical or palliative care team).

People may accept gastrostomy when some oral feeding is still possible and may be given 'top-up' food and fluid supplements through the tube.

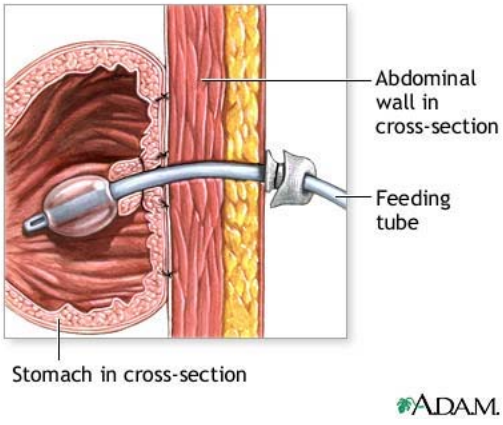


Figure 7: Diagram of PEG Insertion

There are different ways of giving special formula food through a PEG. This depends on the physical condition of the person. Dietitians help to decide the best type of formula food and the best method of tube feeding for each person.

In the first few weeks after placement of a PEG the tube site should be checked carefully. There is usually a flange at right angles to the tube; this may dig into the skin. The crossbar can be pulled further along the tube to release the pressure. A doctor should do this. The flange should be rotated through 90 degrees each day to minimise pressure on the skin.

Drooling and thickened saliva

People with MND who have swallowing difficulties usually experience problems with thick saliva or controlling thin saliva which leads to drooling.

Drooling – what can help?

When control of thin saliva is a problem, drooling may occur. It is important to protect the person's skin and clothing by the use of convenient absorbent face wipes or bibs.

Some medications can help to control drooling. These include tricyclic anti-depressants and anticholinergics (eg Atropine and Hyoscine).

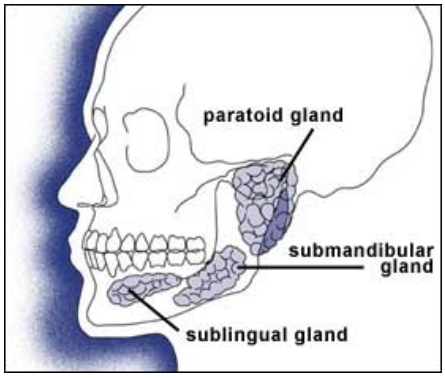


Figure 8: The Salivary Glands

Palliative care teams may be able to help trial a medication called Glycopyrolate (Robinul). This is given by injection subcutaneously. A very small dose is given at first and then the dose can be increased very gradually to find the very best level for the individual.

Botox injections into the salivary glands are now being used in some MND Clinics. This treatment has helped reduce drooling for many of those who have tried it. However, Botox is expensive and available only at some specialist Clinics.

Some people with MND are helped by suction. However, suctioning can cause the production of even more saliva and those using suction need careful training.

Thick saliva - What can help?
People with MND may experience thick or ropey saliva as the disease progresses. This can be uncomfortable and distressing as it is difficult to clear from the throat and can make it more difficult to swallow and breathe.

Things that make thick saliva worse include, mouth breathing (particularly overnight), failure to drink enough liquids and a weak cough.

Some natural products may help with thick saliva including:

- Pineapple juice
- Lemon juice
- Dark grape juice (can also be used as a mouth wash)
- Paw-paw (papaya) extract - tablets can be bought at Health Food shops. “Nature’s Own” produce Papaya Enzyme tablets.

Other ways to help manage thick saliva include:

- Increased intake of fluids
- Discourage drinks containing caffeine (tea, coffee)
- Use of humidification/vaporiser
- Assisted cough technique (physiotherapist will demonstrate)
- Chest physiotherapy
- Propping the person up on pillows a 30 degree angle when in bed

Do people with MND experience dry mouth?
A dry mouth can be a problem even when the person has difficulty with drooling. This can be caused by medications taken to reduce excess saliva. It can also be due to mouth breathing during the night and difficulty drinking enough fluids.

Dry mouth can be helped by:

- Checking medications
- Sipping fluids frequently
- Using 'drymouth' products

Biotene has a range of dry mouth products that can be purchased at a pharmacy. These include Oral Balance Gel, which can be rubbed onto dentures, teeth and soft tissue in the mouth frequently during the day, before mealtimes and before bedtime to alleviate dry mouth. An artificial saliva spray can also be used to help relieve a persistently dry mouth.

Is mouth care important?
Mouth care is very important for people with MND who have swallowing difficulties. Immobility of the tongue decreases the natural ability to move food particles around the mouth. Food can become trapped in the cheek pockets and this can cause mouth ulceration. The person's mouth should be inspected each day for signs of oral thrush or ulcers. Teeth should be brushed carefully after meals. It is important to make sure that excess secretions do not collect in the mouth, as this can cause problems swallowing. It may be helpful to use an electric toothbrush.

Spitting out the foam from toothpaste can be very difficult when a person cannot spit due to muscle weakness. Biotene low foaming toothpaste reduces the need to clear foam from the mouth. Swabbing the mouth with a cotton wool bud soaked in bicarbonate of soda and water (half a teaspoon to a glass of water) will help keep the mouth clean.

Breathing difficulties

As MND progresses, the nerves that control the muscles involved in breathing become weaker. This weakness will eventually lead to respiratory failure and death. Careful management of breathing difficulties will have an enormous impact on the person's quality of life.

What is morning fatigue?

Some people with MND experience disturbed sleep and morning fatigue. They may wake up feeling tired - sometimes with a headache and shortness of breath. This may be caused by a weakness in the diaphragm.

When standing upright, the diaphragm moves down when we breathe in. When we lie down, the organs in the abdomen press against the diaphragm and more strength is needed for the diaphragm to move down during breathing. When MND weakens the diaphragm, breathing at night becomes less effective.

What can be done to help with breathing difficulties?

Positioning

To help manage breathing difficulties the person's head and shoulders should be raised during sleep. This can be done by carefully arranging two or more pillows under the head and shoulders, using a wedge-shaped pillow or by raising the head of an adjustable bed. This position helps the intercostal muscles and diaphragm to work better.

During the daytime, a carefully adjusted seating position can reduce breathlessness. People with respiratory weakness often find being restricted in the sling of a hoist or lying flat to dress reduces their ability to breath. Careful consideration of handling techniques for transfer and during personal care is therefore essential.

Saliva management

Reducing excess/thick saliva (see Drooling and thickened saliva p.29) and careful use of an assisted cough technique, supervised by a physiotherapist, can help to keep a clear airway and help breathing. People who have trouble breathing are more likely to get chest infections.

Room ventilation

Improved ventilation of the room and/or the use of humidifiers, nebulisers and fans may also help to relieve symptoms.

Assisted ventilation

Non invasive positive pressure ventilation (NIPPV) provides respiratory assistance without the insertion of a tube into the windpipe.

A non invasive positive airway pressure (NIPAP) machine delivers a constant stream of air through a small mask which is placed over or under the nose and held in place with Velcro straps. The positive airway pressure (PAP) kit may also include chinstraps to keep the mouth closed.

There are various types and brands of NIPAP machines. These include continuous positive airway pressure (CPAP), variable positive airway pressure (VPAP) and bi level positive airway pressure (BPAP, BiPAP®, Harmony and Synchrony). Variable and bi level positive airway pressure machines are most commonly used for a person with MND because they can provide a lower level of pressure during exhalation. In addition, these machines can be adjusted to provide increased respiratory support when this is needed.

A respiratory specialist usually prescribes the NIPPV machine following a respiratory assessment in hospital.

Figure 9: Using Non Invasive Positive Pressure Ventilation

Anxiety management

It is important to understand that it is normal for anyone experiencing breathing difficulties to feel anxious and, at times, frightened. It is essential that the person with MND is listened to and included in the planning of his/her care. Use of anti-anxiety drugs can also help to reduce the stress and anxiety experienced by a person with breathing difficulties.

Can medications affect breathing?

It is important to remember that some medications for pain can affect breathing. This may create a problem at night when pain is often experienced more intensely and the person is lying down. Medications such as morphine, however, can be useful in helping to reduce feelings of breathlessness.

Palliative care teams may be able to help the visiting GP with careful 'fine-tuning' of medications for the management of anxiety, pain and breathing.

Many people with MND have been told that they will die from respiratory failure. They may think that this means suffocation. However, although respiratory failure may cause their death, there is no need for the person with MND to have a sense of suffocation.

Palliative Care teams can help - they advise about appropriate use of medications and they can also provide emotional support to the person who is dealing with the end stages of their life.

Summary of Section 4

EMOTIONAL ASPECTS

- MND is a 'disease of losses'
- The emotional pain should not be neglected
- The person with MND may experience anxiety and fear
- Spend time with the person with MND talking through fears and worries
- Depression is common and needs to be treated if persistent
- Loss of facial expression may occur
- Small things may trigger crying or laughter

IMMOBILITY DISCOMFORT AND PAIN

- Muscles become progressively weaker
- Joints become stiff and sore
- The person with MND can still feel pain and discomfort
- Do not pull on the arms when moving the person with MND
- The person with MND will need very frequent changes in position
- Take time to listen to how he/she would like to be positioned
- Take care with pressure areas
- Gentle exercises and massage may help ease stiffness and discomfort
- Physiotherapists and occupational therapists can assist

SPEECH DIFFICULTIES

- Communication is very important
- The mind is usually not affected
- The person with MND is not deaf – he/she can hear you
- Work out the best ways to communicate with the person
- Use the communication charts and equipment
- Work out a way for the person to call for help
- Speech pathologists and occupational therapists can assist

SWALLOWING DIFFICULTIES

- Watch food and liquid intake – the person with MND may not be able to eat or drink enough
- Foods and fluids will need to be modified
- Sit the person as upright as possible when giving drinks and meals
- Allow time for eating
- The person may have a PEG for some or all food and liquid intake
- Speech pathologists, dietitians and occupational therapists can assist

DROOLING AND THICK SALIVA

- If drooling occurs protect the person's skin and clothing
- Medications can help
- A suction machine may be useful
- Natural products and a humidifier may help with thick saliva
- Keep up fluid intake
- Physiotherapy may help
- The person may also have a dry mouth
- Mouth care is very important
- Speech pathologists, general practitioners, palliative care teams and physiotherapists can assist

BREATHING DIFFICULTIES

- The nerves that control breathing muscles become affected
- The person may become short of breath
- The person may get more tired, have headaches and restless nights
- Propping the person up in bed will help
- An open window or a fan in the room may help
- Reassure the person and spend time with them
- Medications can help
- The general practitioner and specialist palliative care team can assist

The MND Association regional/care advisors can help with information and education about symptom management

Section 5 - Managing secondary symptoms of MND in residential care

The secondary symptoms of MND include:

6. Fatigue (tiredness)
7. Dry eyes
8. Swelling of hands and feet
9. Bowel and bladder problems
10. Cognitive change

Fatigue (tiredness)

Fatigue (tiredness) is a common symptom of MND. It is caused by a number of factors. As MND attacks motor neurones, they become unable to send commands from the brain to the muscle cells that they control. A smaller number of muscle cells must then try to perform jobs usually done by the full number. This means that muscles tire quickly.

Other metabolic changes take place and the person with MND can feel very tired. Weight loss and reduced food intake due to swallowing difficulties are likely to affect the person's energy levels.

When MND affects breathing muscles, less air is drawn into the lungs. When activity increases, it becomes more difficult for the lungs to supply enough oxygen to the body causing general fatigue.

The person with MND will need to rest following physical activity. In the later stages of MND washing or dressing or using the hoist may exhaust the person and it may take some time for them to recover.

Dry eyes

As immobility spreads, the person with MND can develop weakness of the muscles of the eyelids. Most commonly the problem is an inability to close the eye. This quickly leads to severe drying of the cornea. Redness, itchiness, infection, scarring and vision loss can result. The eyelid does not have to be wide open all the time for this to begin. Early weakness can leave the eyes open just a little during sleep. A simple observation of the person during sleep will identify the beginning of the problem and allow early treatment including frequent eye drops while awake.

Swelling of hands and feet

One very common source of discomfort for a person with MND is swelling of the feet and ankles. This can start when leg weakness prevents walking because muscle action is needed to help pump the blood back up the legs. When muscle movement is lost, blood pools in the veins. Water leaks from the distended veins into the surrounding tissue creating the swelling (oedema). With repeated episodes of swelling, water seeps into the tissues even more easily. At the same time, the one-way valves that help to move blood upward and back to the heart are collapsing from the weight of pooled blood. This damage is permanent and swelling occurs even more quickly.

What can be done for swollen feet?

Raising the feet above the level of the heart for some time during the day helps to reduce oedema. This may be achieved in an electric reclining armchair, a Tilt-in-Space wheelchair or a hospital bed.

Massage of the feet very gently away from the toes can help. Do not massage unless swelling has been checked by a doctor or RN to exclude other causes such as Deep Vein Thrombosis (DVT).

Swollen ankles combined with footdrop can cause real misery. Footdrop pulls the skin on the top of the foot until it feels like it will tear.

Figure 10: Electric raiser recliner chair. Note the good support for legs without too much pressure on calves

What about swelling of the hands?

Swelling of the hands can sometimes occur and can be treated in a similar way, starting with massage under the armpit and then moving to the elbows above the bend, then gently massage hands and fingers.

Although swollen legs and hands feel cold and the impulse is to warm them, heat will only increase the swelling. Many people with MND find that just a few minutes of sitting with feet by a heater or in hot sunshine will dilate blood vessels and set off the fierce burning pain of extreme swelling.

Bowel and bladder problems

Does MND cause urinary incontinence?

Sphincter muscles are not usually weakened by MND and incontinence is not common.

Occasionally there is increased urinary frequency and urgency and some difficulty in emptying the bladder. Sometimes pre-existing conditions may need to be taken into consideration.

Regular toileting routines are important as the person becomes less mobile.

If there are consistent problems with getting to the toilet on time the following aids can be helpful:

- Uridomes can be useful for males. Female urinals are also available
- Easy to manage clothing
- Continence pads and pants

What about constipation?

Constipation can occur in MND due to lack of mobility, modified diet, poor fluid intake and medications. Weak abdominal and chest muscles and difficulty taking or holding a deep breath make it hard to bear down and supply the push needed to support a bowel movement. A person with MND has no loss of sensation. Muscle wasting in the buttocks offers little padding on a hard toilet seat. Comfortable seating will help the person to concentrate on achieving a good bowel movement.

What can be done to help constipation?

Encourage regular drinks if the person is still able to swallow normally, without severe coughing. If the person is unable to use his/her arms, help will be needed to lift food and drink to the mouth. It is important that the staff member assigned to care for the person with MND realises the need for regular fluid intake. Not only does it help in management of constipation but also in management of thickened saliva.

It is also important to be aware that sometimes a person may not wish to drink because he/she does not want to trouble staff by having to ask to be helped with toileting. It will help if the person knows that someone will come every couple of hours to attend to their toileting needs. The person may then drink a little more.

Can medications help with bowel care?

A regimen of medications can be introduced to help maintain bowel activity. If the bowel regimen used in the residential care facility is not effective, palliative care teams can be consulted.

Cognitive change

Some people with MND may experience changes within the brain - up to 15% will have dementia, most commonly, a frontotemporal dementia (Oliver 2007).

Symptoms of fronto-temporal dementia

(Kerkvliet 2000)

- Changes in personality (rigidity or aggressiveness)
- Slowing down of psychological processes like decision-making, answering questions, memory
- Emotionality (uncontrollable crying, laughter or anger)
- Difficulties with taking in new information, due to distractions
- Difficulties with problem solving and generating new ideas and strategies when old ones prove unsuccessful
- Difficulties in divided attention (being unable to do two things at once, like walking and talking)

However, there is increasing evidence that over 60% of people with MND will show signs of frontal lobe dysfunction. The person with MND may have problems with planning activities, learning new things, concentration and generating thoughts and words (Oliver 2007).

Managing cognitive change

It is helpful to understand that if a person with MND has cognitive change they may have difficulties with planning, concentration, language and learning. Changes need to be assessed and may require further management. Often, however, change is slight and understanding the cause of the cognitive change can assist. Strategies such as task simplification and reduction in distraction may be useful.

Summary of Section 5

FATIGUE

- Tiredness is a common symptom
- The person will need to rest after physical activities
- Washing and dressing may exhaust the person with MND

DRY EYES

- The person may not be able to close his/her eyes
- The eyes will then become dry and sore
- Watch out for signs of dryness and infection
- Eye drops may help alleviate symptoms

SWELLING OF HANDS AND FEET

- Raise the feet for some part of the day
- Use an electric recliner chair or tilt in space wheelchair
- Massage may help – if recommended by a health professional
- Heat may increase the swelling

BOWEL AND BLADDER PROBLEMS

- MND does not cause incontinence
- Inability to use legs and hands may cause accidents
- Regular assistance to use the toilet is important
- Monitor for signs of constipation
- Assist with fluid intake
- Introduce bowel regimen

FRONTO-TEMPORAL DEMENTIA

- A small number of people with MND may have a form of dementia
- The changes may be very slight
- May cause difficulties with concentration and making decisions

Remember that most people with MND remain mentally alert throughout the disease

Section 6 - End of life care for people with MND

So how do people with motor neurone disease die?

Progression of the disease is different for each person. Some people deteriorate rapidly and die quickly, others progress more slowly.

In the final stage of MND, two things are important in determining prognosis - the ability to breathe, and to a lesser extent, the ability to swallow and to cough.

People with swallowing difficulties and a weak cough are at risk of developing chest infections through aspiration of food and fluids. This in itself can trigger the terminal stage of the disease. One of the greatest fears for people with MND is that they will choke to death. They can be reassured that recent research has shown this is extremely rare. It is more likely that a gradual reduction of breathing muscle function will cause a loss of consciousness and a peaceful death.

Palliative care teams have expertise in managing the more distressing symptoms of MND including, pain, breathing difficulties and drooling.

In the later stages of MND attention should continue to be given to the control of symptoms and the visiting doctor may prescribe small doses of morphine to relieve breathlessness. This can also help to reduce some of the muscular pain. Morphine can help the person to sleep more comfortably and can reduce the anxiety caused by breathlessness during the night.

The person with MND is likely to have fears and questions about death, choking or breathlessness and about how he/she will be cared for as the disease progresses. It is important for these fears to be discussed and palliative care professionals can help with this. The community palliative care team should be involved and can provide welcome support to both the person with MND and his/her family.

The family of the person with MND should be included in discussions whenever possible. They may also request spiritual support from a representative of their chosen faith.

The main goal of care is to help the person with MND live well right through to the end of life.

Helping the person with MND achieve the best possible quality of life can be a challenging but very rewarding experience.

People with MND can play a very important role in helping to solve many of their own complex needs. Nursing staff and other care providers often say that they have learned a great deal from the people with MND they have cared for. People with MND and their families can provide inspiration in the way they cope in very difficult circumstances.

It is not unusual for particular members of staff working with people with MND to develop a strong relationship with the person in their care. It is important that staff work together to help and support each other. This involves case discussions, problem solving and debriefing sessions with colleagues and supervisors.

Regional/care advisors from the Motor Neurone Disease Association can also help in this process.

Thank you for your interest in reading this manual and for your care of people living with MND.

Summary of Section 6

- Some people progress rapidly and die quickly, others progress more slowly
- It is very unlikely that a person with MND will choke to death
- Most people with MND have a peaceful death
- The general practitioner can help with medications
- The specialist palliative care team can help with emotional support and symptom control
- The person with MND may request spiritual support
- Take time to 'be with' the person with MND and his/her family

The main goal of care is to help the person with MND live well right through to the end of life.

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Appendix

MND Symptom Management Chart

Index

Index

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