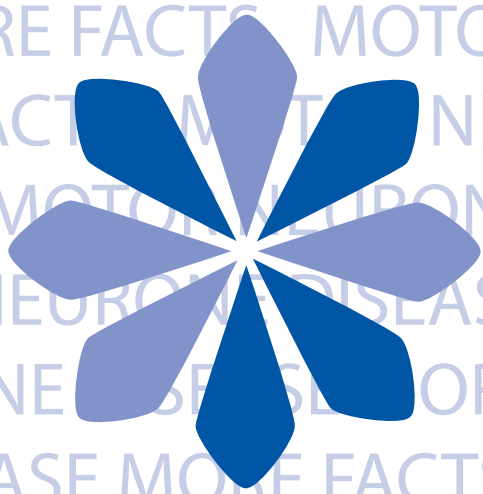


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Introduction

Although there is currently no cure for motor neurone disease (MND), research has shown some interventions can help people living with motor neurone disease to live better for longer.

How people manage their earlier symptoms of motor neurone disease can affect management of symptoms that may arise later. Early discussion about symptom management helps people with motor neurone disease to plan ahead.

This booklet provides a brief overview of motor neurone disease symptoms, symptom management, medications, multidisciplinary care and community care services. It also includes information about accessing assistive technology (aids and equipment), funding programs, support networks and other information sources.

MND Associations in each state and territory provide information, education, advice and support for people with motor neurone disease, families, carers and health and community professionals.

To find out more about MND, support services and research, phone your state MND Association Freecall 1800 777 175 or visit the websites of MND Australia and state MND Associations (see back cover).

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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 and wishes of the patient.

What is motor neurone disease?

Motor neurone disease (MND) is a progressive, degenerative, neurological condition with no known cure. MND is the name given to a group of diseases in which the nerve cells – neurones – controlling the muscles that enable us to move, speak, breathe and swallow undergo degeneration and die.

Motor function is controlled by upper motor neurones (UMN) in the brain that descend to the spinal cord; these neurones activate anterior horn cells – lower motor neurones (LMN). The LMN exit the spinal cord and directly activate muscles. With no nerves to activate them, muscles gradually weaken and waste.

Motor neurone disease is also known as amyotrophic lateral sclerosis (ALS) and Lou Gehrig's disease in other parts of the world.

What are the symptoms?

Early symptoms may be mild at first. They may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles or slurring of speech and swallowing difficulties due to weakness of the tongue and throat muscles.

Emotional responses may be more easily triggered and the person with MND may be aware of laughing and crying more readily than previously.

Cramps and muscle twitching are also common symptoms.

The effects of MND – initial symptoms, rate and pattern of progression, and survival time after diagnosis – vary significantly from person to person. The average life expectancy after diagnosis is two to three years.

How is it diagnosed?

The diagnosis of MND is often clinically difficult, and sometimes it is necessary to review a person for some time before the diagnosis can be confirmed.

A general practitioner may suspect a neurological problem and organise referral to a neurologist (a doctor who specialises in disorders of the nervous system). Several other neurological conditions resemble MND, especially in the early stages, and need careful exclusion. The diagnosis can be assisted through a range of tests, including some which eliminate other conditions:

- » nerve conduction studies (NCS) involve analysing neural function by electrical stimulation of nerves and recording muscle activity
- » electromyography (EMG) consists of inserting a needle electrode into various muscles to measure their electrical activity

What causes MND?

Most cases of MND (90-95%) are sporadic – meaning occurring in scattered or isolated instances without clearly identifiable causes. There are many theories about the causes of MND. These include exposure to environmental toxins and chemicals, infection by viral agents, immune mediated damage, premature ageing of motor neurones, loss of growth factors required to maintain motor neurone survival, ageing and genetic susceptibility. Ongoing research throughout the world is looking for causes.

Is it hereditary?

Familial (hereditary) MND accounts for about 5-10% of cases. The first gene mutation (SOD1) was discovered in 1993 and accounts for around 20% of familial MND. Since 2006 more gene mutations have been discovered. In 2011 the discovery of mutations in the C9orf72 gene was announced and has since been found in about 40% of all families with familial MND. The pace of gene mutation discovery has accelerated in recent years with advancements in technology. Known genetic mutations now account for over 60% of familial MND. For more information on familial MND and genetic testing speak to your neurologist, contact the MND Association or visit the MND Australia and state association websites.

Can other people catch it?

There is no evidence that MND is transmissible from person to person.

How common is it?

MND occurs at similar rates in most countries of the world. It is estimated that there are presently more than 2,000 people with MND in Australia. 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.

What are the different types of MND?

MND can be classified into four main types depending on the pattern of motor neurone involvement and the part of the body where the symptoms begin.

Types

1. Amyotrophic lateral sclerosis (ALS)

- » both upper and lower motor neurones are affected
- » limb muscle weakness and wasting

ALS is the most common type, characterised by muscle weakness and stiffness, over-active reflexes and, in some cases, rapidly changing emotions. Initially the limbs cease to work properly. The muscles of speech, swallowing and breathing are usually also affected later. ALS is the term commonly applied to MND in many parts of the world.

2. Progressive bulbar palsy (PBP)

- » both upper and lower motor neurones are affected
- » speech and swallowing muscle weakness and wasting

When ALS begins in the muscles of speech and swallowing it is designated PBP. Progressive bulbar palsy, mixed bulbar palsy and pseudo-bulbar palsy involve the muscles of speech and swallowing. The nerves that control these functions are located in the bulb (the lower part of the brain), hence the term bulbar palsy (paralysis). The limb muscles may also later be affected.

3. Progressive muscular atrophy (PMA)

- » lower motor neurones are affected
- » slower rates of progression and significantly longer survival compared to ALS and PBP

PMA is characterised initially by lower motor neurone signs resulting in more generalised muscle wasting and weakness, absent reflexes, loss of weight and muscle twitching.

PMA can be the hardest form of MND to diagnose accurately.

Recent studies indicate that many people diagnosed with PMA subsequently develop upper motor neurone signs. This would lead to a reclassification to ALS.

PMA may begin in the arms (flail arm type) or the legs (flail leg type).

4. Primary lateral sclerosis (PLS)

- » upper motor neurones are affected
- » very rare and diagnosis is often provisional

MND/FTD

A small proportion (5–15%) of people with MND will receive a diagnosis of 'motor neurone disease with frontotemporal dementia' or MND/FTD. Often the symptoms of dementia precede the motor symptoms, sometimes by a number of years.

Kennedy's disease

Kennedy's disease is a disorder of motor neurones which is not motor neurone disease. It is an inherited disorder affecting adult males causing slowly progressive weakness and wasting of muscles with only lower motor neurone involvement and other features.

What remains unaffected by MND?**Sensory function**

For most people with MND the senses of sight, hearing, taste, smell and touch are not affected.

Bladder and bowel

The bladder is not usually directly affected by MND; however, some people experience changes to bladder control. Constipation can occur, especially when people become less mobile or have to change their diet due to swallowing difficulties.

Is there a cure or treatment for MND?

There is no cure for MND yet, but a medication is available in Australia for the treatment of amyotrophic lateral sclerosis (ALS) and progressive bulbar palsy (PBP) – the most common types of MND. This medication, riluzole (sold as Rilutek™, APO-Riluzole or its liquid form Teglutik), is available on the Pharmaceutical Benefits Scheme for people who meet defined eligibility criteria. Riluzole can be prescribed by a neurologist initially and then by a general practitioner. Research has shown it:

» probably prolongs median survival by two to three months (median is the mid point – half those taking riluzole have survival prolonged by more than two to three months)

» may slow disease progression

People started on riluzole soon after diagnosis show the greatest benefits. As with all drugs, some people may have a better response to riluzole than others. It is impossible to predict the benefits that each individual will gain. Neurologists will be able to provide guidance on the suitability of this treatment.

The most common side effects of riluzole are fatigue and nausea. Liver function may be impacted. Doctors can provide guidance on managing any obvious side effects and may arrange for people to have regular blood tests to ensure that riluzole is

not causing side effects of which the person is not aware.

Costly and unproven therapies for MND are often advertised on the internet or may be recommended by well-meaning people. It is important to discuss the likely benefits of any unproven therapy and the risk of side effects, adverse events or life-shortening effects with your GP or neurologist.

MND Associations keep a close watch on current clinical trials and research progress and findings, and have the latest information available. They support and promote any new treatments that have been proven through research and scientific peer review to improve survival or symptom management for people with MND.

Researchers globally are currently developing and trialing many potential therapies. Recently the intravenous therapy, Edaravone (Radicava), was approved in the USA and has been available in some countries in Asia for a number of years. It has been shown to slow down disease progression in a subset of people with MND. Studies are ongoing and results of these studies will inform whether approval will be sought in Europe and Australia. Although there is currently no cure, it is not true to say that, 'nothing can be done for the person with MND'.

A great deal can be done to maintain quality of life and address many of the effects of MND.

For further information speak to your neurologist, contact your state MND Association or check out the MND Australia and state MND Association websites (see back cover).

Who can assist?

In addition to support from family and friends, other people who may help include general practitioners, neurologists, occupational therapists, orthotists, physiotherapists, speech pathologists, psychologists, dietitians, palliative care services, nurses, social workers and MND Association advisors. This list is not exhaustive. The needs of people living 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.

The **general practitioner (GP)** is usually the first and primary person of contact for a person with MND. GPs can carry out the basic neurological examination, and recognise symptoms which indicate the need for referral to a neurologist. The GP will then liaise with the neurologist, other specialists and allied health care providers in order to provide the best possible standard of care and to maintain quality of life.

The role of the **neurologist** is to undertake tests which diagnose MND and exclude other conditions which may be amenable to different treatments. The neurologist will be able to monitor the progress of the disease and help to initiate supportive care at appropriate times. Major questions should be referred to the treating neurologist.

Sometimes, the neurologist may encourage a person to seek a second opinion from another neurologist.

An **occupational therapist (OT)** helps to maintain mobility, function and independence. OTs can visit people in their home to advise on

- » different ways of performing tasks
- » the selection and adaptation of assistive technology (aids and equipment).

- » home modifications

A **physiotherapist** helps to maintain the physical activity and mobility of the body, make the most of muscle strength and alleviate or prevent joint stiffness and pain caused by wasting, spasticity and cramps. Physiotherapists can instruct carers in a range of passive exercises, and the techniques of positioning and transfer to avoid injury to themselves or the person with MND.

An **orthotist** can construct and fit braces and splints that provide support and increase mobility.

A **speech pathologist (SP)** helps in the management of communication and swallowing problems. Communication aids range from simple manual systems such as alphabet boards, to voice banking and voice-synthesising computers that can be operated from a single switch. Speech pathologists can assess and advise on different swallowing techniques, food selection and preparation.

A **dietitian** provides dietary and nutritional advice.

A **community or district nurse** provides a range of nursing and ancillary services for people in their own homes, following referral from a health professional such as a GP. Provision of services varies from state to state so check with a GP or your state MND Association.

A **social worker, psychologist, or accredited counsellor** provides counselling on the psychological and emotional aspects of MND. Social workers may also offer advice on legal and accommodation services and financial supplements available in the local community, or through federal, state, territory or local government programs.

Palliative care specialists can help with symptom management, emotional support and advance care planning. They can also advise about medications to manage breathing difficulties and pain.

MND Association advisors offer information about living with MND and local health and community care services. The MND Association advisor can also provide information about accessing government financial support and equipment/assistive technology (see page 16).

The MND Associations conduct education programs for people with MND, their family and carers and inservice/education programs for health and community care professionals.

The **MND Associations** provide support and other services based on a wide understanding of the issues associated with the disease.

To find out more about MND and support services call **1800 777 175** or visit the of MND Australia and state MND Associations websites (see back cover).

Are there multidisciplinary MND clinics and services?

There are several established MND specific clinics and programs of care throughout Australia.

These specialised clinics provide a coordinated and integrated approach to the management and clinical care of an individual with MND.

Multidisciplinary teams 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 advisors also attend these clinics to provide information and support.

Using the Internet to access health information

The Internet can be a valuable source of health information that can help you understand health issues as well as those of your friends or families. However not all online information available is reliable, and health information on web sites should not take the place of your health provider/patient relationship, and should not be used for self-diagnosis.

There are many factors that need to be considered in relation to your health and the diagnosis of any condition. You may choose to use the internet as an information resource and ask a health professional about any issues raised by the information or anything that you don't understand.

You should avoid any online health practitioner who proposes to diagnose or treat you without a proper physical examination and a full consultation regarding your medical history.

From healthdirect, a government funded gateway, providing quality approved health information:
www.healthdirect.gov.au

Managing symptoms

Pain

The neurones carrying sensory messages of pain, touch, heat, cold and pressure from the skin and deeper tissues back to the spinal cord and brain are usually unaffected.

Immobility and weakness can lead to pain and discomfort such as:

- » cramps in the muscles, especially in the legs. These are most common in the early stages of the disease and may occur with exercise or at rest
- » pain and stiffness in joints can occur because weakness of the muscles around a joint allows excessive strain to be transmitted directly through the ligaments and soft tissues. The shoulder joint is most commonly affected. Care should be taken not to pull on the arms when assisting a person with MND to change the position of their body. It is also important not to leave a person's weak arm hanging unsupported
- » 'frozen shoulder' – where movement at the shoulder causes pain – can occur through inactivity of muscles of the shoulder
- » pain in the muscles of the neck, shoulder, hip and knees can occur with the loss of normal postural control, which occurs when muscles are weak. The discomfort is characteristically improved by postural or positional change.

- » This problem is worse in people who are too weak to readily move or reposition themselves

Pain can be treated using a number of physical measures. These treatments are best accessed with the help of a physiotherapist.

- » Special cushions and mattresses can provide extra 'padding' and pressure relief, especially if the person has lost weight.
- » Gentle passive exercise of those limbs which are too weak to be moved by the person's own efforts can prevent pain arising from stiff shoulders and other joints.
- » Warm packs and baths are often useful, but care needs to be taken with temperature control.
- » The general practitioner, neurologist or palliative care specialist can prescribe a range of medications for pain.

Mobility

Most people with MND develop mobility problems.

It is unlikely that people living with MND will stay in bed for long periods, but they may need help moving around. Some people have a tendency to fall, sometimes without warning. Occupational therapists and physiotherapists can advise about access around the home and assist in the provision of appropriate aids to improve mobility and safety (see *Obtaining assistive technology*, p.16 for more information).

Fatigue

Fatigue is common in MND. By recognising the factors that worsen symptoms and by learning how to conserve energy, people with MND can improve their quality of life. Some strategies are:

- » plan activities in advance
- » take regular rest periods
- » rest between activities and before going out
- » do not exercise to the point of excessive fatigue, cramps, or muscular weakness
- » discuss, with a physiotherapist, exercises to alleviate stiffness, muscular tension, or pain
- » move slowly, with frequent rests, taking a few breaths before recommencing a task
- » keep heavier tasks for times of greater energy
- » stop if breathlessness occurs
- » discuss with an occupational therapist aids and equipment that can make tasks easier
- » take shortcuts where possible and sit rather than stand
- » try to establish a regular sleeping pattern
- » make the personal environment safe and easy to move around in
- » a sleep study may be useful when people with MND wake up regularly during the night and don't feel refreshed by sleep

Sleep

Sleeping difficulties may be caused by a variety of reasons, for example, discomfort because of immobility, pain due to stiffness of joints or muscles, excessive saliva or dry mouth, or breathing problems. Breathing problems can impact on sleep quality and lead to frequent waking during the night and morning headaches.

People with MND may find it useful to have regular respiratory assessments, including sleep studies. These are most useful at a relatively early stage and their timing depends upon the level of abnormality detected.

It may also be helpful to consider non-invasive respiratory support to improve sleep and day time exhaustion or sleepiness.

Different sleep strategies work for different people:

- » try not to remain in the same position in bed for too long.
- » an electric bed can be adjusted to a variety of positions at the push of a button
- » side rails, bedside furniture and extra pillows can give added support
- » a segmented overlay mattress and specialised pillows distribute body pressure more evenly
- » muscle spasticity or pain from muscle tightness and joint stiffness may be relieved with medication prescribed by the GP

- » non-prescription analgesics such as aspirin or paracetamol can relieve mild discomfort
- » before retiring, joint pain may be relieved by stretching or range-of-motion exercises – a physiotherapist may be able to find the origin of the problem and recommend a remedy
- » breathing may be helped by elevating the head and chest with an extra pillow or two, or raising the head of the bed on blocks; this relieves pressure on the diaphragm and improves lung expansion
- » before going to bed, avoid over-exertion, caffeinated drinks, smoking and heavy meals – too much food puts pressure on the diaphragm and can aggravate breathing problems
- » retire at the same time each night and reduce daytime napping
- » make sure the bedroom is quiet, cool, dark and comfortable
- » light bedclothes and satin or silk sheets allow easier movement in bed
- » impaired swallowing reflexes may cause a buildup of saliva or mucus – sleep with the head elevated to prevent secretions from pooling in the upper airway
- » a slow rhythmic back rub or a light massage of aching muscles promotes relaxation
- » deep abdominal breathing may reduce stress

- » soft music or reassuring conversation can promote sleep
- Many people will experience difficulty sleeping because of the emotional distress of receiving a diagnosis of MND or the stress of living with MND. In these circumstances the person with MND should be encouraged to speak with their neurologist or GP about counselling, ongoing support and medications to relieve anxiety or depression.

Breathing difficulties

Many people with MND have decreased lung capacity because of respiratory muscle weakness, making any activity that requires increased respiratory effort harder. Respiratory muscle weakness can develop at any stage of disease progression and may cause shortness of breath, frequent waking during the night, fatigue, impaired quality of life and sleepiness.

Referral to a specialist respiratory physician should take place soon after diagnosis. A baseline measurement of breathing function can be helpful for future treatment.

Some people may also find their cough is less forceful than before, making it more difficult to clear their throat.

People with MND may experience the feeling of not being able to get enough air, rather like the sensation of being in an overcrowded room.

- » Position is important. Sitting in a slumped position restricts lung capacity. Sitting up may be better than lying down.
- » When sitting, the bottom should be well back in the chair, the back straight and well supported.
- » If excessive saliva or mucus is a problem, seek the advice of the GP and speech pathologist about controlling it. A physiotherapist can also teach assisted cough techniques.
- » Avoid contact with people who have colds or flu and consult the GP about the need for a flu vaccination.
- » Try to keep the bedroom and living areas at a comfortable, steady temperature (around 18 and 21 degrees respectively). Keep the rooms well ventilated and avoid smoking or being in the presence of smokers.
- » Shortness of breath may be helped by breathing in a calm and purposeful way until the sensation has passed.
- » Routine chest physiotherapy can be beneficial, but should not be too vigorous. The physiotherapist may also suggest a program of breathing exercises to help maintain lung expansion.
- » A mechanical cough assist device can be helpful when coughing is difficult, and/or during a respiratory tract infection. If

prescribed, a respiratory specialist will be able to determine the exact treatment regimen needed. Training should also be provided to the person with MND and any carers who may operate the device.

If shortness of breath cannot be managed, the GP or neurologist should be consulted immediately.

- » Medications can be prescribed to relieve feelings of breathlessness.
- » Referral to respiratory specialist can be beneficial for reassessment and discussion about non-invasive ventilation.

Non-invasive ventilation (NIV)

If the symptoms related to increasing respiratory muscle weakness impact on quality of life some people will choose to use NIV. This involves being referred to a respiratory specialist for assessment and regular review. The respiratory specialist will prescribe the appropriate machine to use and the settings required. NIV is delivered via a mask usually at night initially and then, as MND progresses, as required during the day. NIV has been shown to improve quality and length of life for people living with MND. There are a number of implications to consider that should be discussed with the specialists involved.

Over time NIV will be less effective in controlling respiratory symptoms.

Invasive ventilation

Life support via continuous ventilation with a tracheostomy (invasive ventilation) is not commonly used in Australia for a person with MND as their respiratory function will not recover and their disease will continue to progress. Some people may wish to speak to a respiratory specialist to be informed about and consider invasive ventilation.

Oxygen

Oxygen is not usually recommended but is sometimes prescribed if there is an underlying lung problem unrelated to MND. Oxygen for home use should be discussed with a neurologist, palliative care or respiratory physician. High levels of oxygen in the blood can affect the natural drive to breathe.

Swallowing problems

Some people with MND experience swallowing difficulties which require adaptation of the process of eating and drinking. Referral to a speech pathologist and a dietitian should occur as soon as any swallowing or saliva difficulties are experienced. The following suggestions might be useful:

- » modify the texture and consistency of food and drink
- » thickened drinks flow more slowly and are thus easier to control
- » puréed (vitamised or blended) foods that are smooth, moist and free from lumps, but not runny, are usually easier to swallow
- » purée different foods separately and serve attractively, providing a contrast of colours and flavours at each meal
- » try a lightweight cup with a wide, flared top
- » it is usually easier to eat from shallow spoons
- » small amounts of food and drink per swallow reduce the risk of inhalation – in most cases drinks should be sipped
- » reduce the size of each mouthful until the person with MND finds what is best for them – some people find that teaspoon sized mouthfuls are easier to manage
- » allow more time to eat and drink; do not try to keep pace with others during meals
- » eat and drink in private if desired
- » people with MND should eat foods that they like – taste is a strong stimulus for the swallow reflex
- » swallowing is generally easier when the person is sitting as straight as possible with the head upright; avoid tilting the head back or bending it forward towards the chest – some people find swallowing easier if the head is slightly forward, as if sniffing the air
- » more specialised eating utensils, such as spouted cups and syringes are also available – a speech pathologist or occupational therapist can provide advice

- » the presence of ropery, tenacious secretions in the mouth and pharynx can make swallowing more difficult – drinking fruit juices, particularly grape juice, and sucking papaya enzyme tablets can help to break down the secretions
- » seek GP or palliative care advice on medications to help manage excess saliva

People experiencing swallowing difficulties can be more prone to chest infections.

An excellent DVD regarding swallowing difficulties is available from MND Victoria or your state MND Association.

Gastrostomy (PEG and RIG)

If swallowing becomes too tiring, or too difficult, the person may choose to have a gastrostomy. This entails having a tube surgically inserted through the upper abdominal wall into the stomach under a light anaesthetic.

There are two types of gastrostomy available depending on the surgical method used – a percutaneous endoscopic gastrostomy (PEG) and a radiologically inserted gastrostomy (RIG). Food, usually a proprietary liquid feed, is put into the tube (known as PEG or RIG feeding). Having a gastrostomy does not necessarily mean that the person with MND cannot consume food orally.

Often, a small amount of food for pleasure can be consumed while most of the nutritional intake occurs via the gastrostomy. This approach may reduce fatigue and should be considered by those who experience marked problems in eating or drinking.

Speech and communication

Not everyone living with MND experiences problems with their speech but for some people the muscles in the face, mouth, throat and chest are affected.

Muscle weakness caused by MND can create speech difficulties such as slurring, difficulty producing certain sounds, hoarseness or a weak voice. Muscle weakness of the upper limbs can impact on non-verbal communication including hand gestures, writing and typing.

Your GP or multidisciplinary team can arrange a referral to a speech pathologist or occupational therapist who can provide advice on how to modify communication as symptoms progress. They can also provide information on voice banking and recommend strategies, and assistive technology for alternative ways of communicating.

Difficulties with communication can lead to decreased social interaction and feelings of isolation, vulnerability, loss of control and frustration.

The following may assist with communication:

- » speaking more slowly
- » creating a calm relaxed atmosphere where possible and avoiding interrupting or trying to finish sentences
- » writing key words or using symbols for communication
- » planning ahead with the multidisciplinary team and support services to enable familiarisation and smooth transition with assistive technology as required

Cognition and behaviour

In the past, it was thought that MND only affected the nerve cells controlling the muscles that enable us to move, speak, breathe and swallow. However, approximately 50% of people with MND may experience some change in cognition (thinking), language, behaviour and personality. When cognitive and behaviour changes occur in MND, it is because there have been changes in specific areas of the brain called the frontal and temporal lobes. Most people experience relatively mild changes, however, a small proportion (5–15%) of people with MND will receive a diagnosis of 'motor neurone disease with frontotemporal dementia' or MND/FTD (see page 5). Some people may, at times, experience uncontrollable laughing or crying. This is known as pseudobulbar affect and is associated with upper

motor neurone involvement.

The general practitioner, neurologist or palliative care specialist will be able to prescribe medications and discuss strategies to assist with some of these symptoms.

Obtaining assistive technology

An occupational therapist, speech pathologist or physiotherapist can advise about assistive technology (aids and equipment) items for comfort, mobility, function, communication, independence and carer safety.

Some government funded programs provide reduced cost access to assistive technology however eligibility criteria may apply. Assistive technology is also available from other sources including most MND Associations. Contact your state MND Association for information about accessing assistive technology.

Financial support

You may be eligible for financial payments and benefits such as pensions and benefits through Centrelink if you have motor neurone disease. Financial payments and carer respite may also be available for carers.

General financial advice is available from a range of non-government sources such as financial advisers, banks and self-funded retiree associations.

Fact sheets on financial matters and planning ahead are available from the state MND Associations.

Government support

Government programs to assist people living with MND to live at home vary depending on an individual's personal circumstances.

- » The National Disability Insurance Scheme (NDIS) is designed to provide reasonable and necessary supports for people under the age of 65 years who have a permanent disability and this includes people living with MND. The scheme is currently being rolled out across Australia.
- » My Aged Care is the entry point to all services for people aged 65 years and older in Australia. My Aged Care provides information about domestic assistance, personal care, meal and nursing care services. Costs of these services may be subsidised through a Home Care Package although this depends on the availability of packages and an individual's financial situation. My Aged Care is also the entry point for assessment for residential care.

Carer support

As most people with MND remain at home, the needs of the primary carer must be taken into account. Many MND carers find that contact with others in the same situation can be a great source of information and support.

Support groups affiliated with state MND Associations exist in all states and the ACT. In some states, these support groups provide an opportunity to learn from or talk with professionals and other support staff. Irrespective of what the different groups offer, they all bring together people living with MND and their carers to share experiences, learn from each other, share a few laughs and maybe even shed some tears together.

Other initiatives designed to support and assist relatives and friends caring at home for people who are unable to care for themselves because of disability or frailty, are conducted by various government and non-government organisations. For more information contact your state MND Association.



MND Associations

Motor Neurone Disease Australia is the national voice representing all Australians who share the vision of a world without MND.

MND Australia works to improve the lives of people impacted by motor neurone disease by:

- » influencing policy
- » providing trusted information
- » raising awareness and
- » promoting and funding the best research.

The MND Research Institute of Australia (MNDRIA) is the research arm of MND Australia. MNDRIA funds the best MND research with the greatest chance of leading to the development of effective treatments and improving the lives of people with MND.

The six state Associations representing all states and territories, are members of MND Australia. The MND Association of New Zealand is an associate member of MND Australia. MND Australia is an active member of The International Alliance of ALS/MND Associations, which represents ALS/MND Associations from around the world.

State MND Association objectives are:

- » to ensure that people affected by MND secure the care and support they need
- » to promote research into causes and treatments of MND

State MND Association funds are used to support the care of people with MND by:

- » providing trusted information, education, advice and support to people with MND, their families, carers and health and community professionals
- » providing equipment at low, or no, cost to the person with MND – the range of equipment available from State Associations varies
- » supporting research into the disease and its management
- » recruiting and training volunteers who are involved in supporting people living with MND

State MND Associations offer services in all states and territories.

For more information or contact details of the associations please see back cover.

mndcare.net.au

mndcare.net.au is a website developed by MND Australia for health and community care professionals involved in the care of people living with MND. MNDcare:

- » provides evidence based and best practice motor neurone disease information
- » provides links to further related resources, for both the professional and the person living with MND
- » provides referral pathways for each identified need to assist with referral to the appropriate provider or service as soon as the need is identified
- » promotes a process of regular, timely review and assessment of needs
- » helps Australian health professionals and community care workers to assist people living with motor neurone disease to live better for longer

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