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Introduction

Although there is no cure for motor neurone disease yet, research has shown some interventions can help people living with motor neurone disease to live better for longer. These include getting multidisciplinary care, having good nutrition and using non-invasive ventilation.

There is one medication approved for treatment of motor neurone disease in Australia - riluzole (Rilutek). Riluzole prolongs median survival by two to three months. It has also been shown to keep people with motor neurone disease in the milder stages of the disease for longer, if they start taking it early in the disease progression.

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

MND Associations in each state of Australia provide information, education, advice and support to people with MND, families, carers and health and community professionals in all states and territories.

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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.

What is motor neurone disease?

Motor neurone disease (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.

The patterns of weakness vary from person to person.

What are the symptoms?

Early symptoms are mild and may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles and slurring of speech or 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.

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 becomes reasonably certain. A general practitioner may suspect a neurological problem and organise referral to a neurologist. 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) and electromyography (EMG) are often performed and may help in establishing the diagnosis. NCS involve analysing neural function by electrical stimulation of nerves and recording muscle activity. EMG consists of inserting a needle electrode into various muscles to measure their electrical activity.

What causes MND?

Most cases of MND occur spontaneously. These are said to be 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 and genetic susceptibility. Ongoing research throughout the world is looking for causes.

Is it hereditary?

Familial (hereditary) MND accounts for about 10% of cases. In 1993 mutations were identified on the superoxide dismutase (SOD1) gene on chromosome 21. These mutations are believed to be present in about 20% of people with familial MND. Several other gene mutations have recently been discovered linked to MND and these include - TARDBP (TAR DNA-binding protein 43, also known as TDP 43) and FUS (fused in sarcoma/translated in liposarcoma). Current research aims to identify further genes linked to MND and to understand how these mutations cause damage to motor neurones.

Can other people catch it?

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

How common is it?

MND is an uncommon, but by no means rare disorder. It occurs at similar rates in most countries of the world. It is estimated that there are presently about 1400 people diagnosed 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 forms does MND take?

MND takes several forms. For some people, the symptoms are widespread from the onset. However MND usually begins by affecting a single limb or aspect of motor function, becoming more generalised as the disease progresses. There is usually evidence of wasting and weakness in some muscles and fasciculation (twitching) of parts of the muscle may be visible under the skin.

Fasciculation may be a sign of damage to LMN. There are many other causes of fasciculation, some less serious. Involvement of UMN results in stiffness of muscles (spasticity) and slowed movements.

People may have only LMN or UMN signs early in the illness but typically develop a combination of the two as the disease progresses.

The disease 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.

1. Global Type

- » both upper and lower motor neurones are affected
- » includes amyotrophic lateral sclerosis (ALS) and progressive bulbar palsy (PBP)

ALS is the most common form, 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 later affected. ALS is the term most commonly applied to MND in the USA, where it is also known as Lou Gehrig's disease, after the famous baseball player.

PBP, mixed bulbar palsy and pseudo-bulbar palsy are forms that 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.

2. Flail Arm Type and

3. Flail Leg Type

- » lower motor neurones are affected
- » slower rates of progression and significantly longer survival compared to ALS and PBP
- » characterised by absent reflexes, muscle wasting and weakness

Flail Arm begins in the arms.

Flail Leg begins in the legs.

4. Primary Lateral Sclerosis Type

- » upper motor neurones are affected
- » very rare form of the disease and diagnosis is often provisional

Progressive muscular atrophy

Progressive muscular atrophy (PMA) is a form of MND characterised initially by lower motor neurone signs resulting in more generalised muscle wasting and weakness, 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.

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?

For most people with MND the intellect and memory are not affected, nor are the senses of sight, hearing, taste, smell and touch.

Fronto-temporal cognitive changes (a type of dementia) have been associated with MND and are prominent in 5-10% of cases. Neuro-psychological studies also suggest that approximately two-thirds of people with MND may have very mild changes in cognitive skills and processes.

The bowel and bladder are not directly affected by the disease. Incontinence is not a usual feature of MND, but 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, including PBP) - the most common form of MND. This medication, riluzole (Rilutek), is available on the Pharmaceutical Benefits Scheme for people who meet a defined eligibility criteria.

Riluzole can be prescribed by a neurologist initially and then by a general practitioner. It can:

- » prolong 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)
- » slow disease progression
- » keep people in the milder stages of disease for longer, thus contributing to quality of life

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 weakness, nausea, a mild liver dysfunction and headache. 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 are sometimes recommended by well meaning people.

Professional advice should be sought before embarking on unproven therapies. It is important to discuss the likely benefits of expensive therapy compared with, for example, changes to the home, employment of additional home assistance, or the peace of mind of the person who wishes to leave their family well provided for.

Researchers are developing and trialing other drugs to slow down the progression of the disease or combat some of the symptoms. For further information speak to a neurologist, contact the Motor Neurone Disease Association or visit the MND Australia website at www.mndaust.asn.au.

Motor Neurone Disease Associations keep a close watch on research progress and findings, and always have the latest information available.

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.

Health professionals who can assist

In addition to support from family and friends, other people who may help include general practitioners, neurologists, occupational therapists, physiotherapists, speech pathologists, psychologists, dietitians, palliative care services, home care nurses and social workers. 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. 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 advise on different ways of performing tasks and the selection, acquisition and adaptation of disability aids. Occupational therapists can visit private homes to advise on equipment or home alterations.

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.

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-synthesising computers that can be operated from a single soft-touch switch.

Speech pathologists can assess and advise on different swallowing techniques, food preparation and selection. This may be done in collaboration with a dietitian who can provide dietary and nutritional advice.

A community or district nurse can provide a range of nursing and ancillary services to people in their own homes. Services are usually obtained by referral from a health professional such as a GP. Provision of services varies from state to state so check with a GP or the Motor Neurone Disease Association.

A social worker, psychologist, or accredited counsellor provides counselling on the psychological and emotional aspects of MND. In addition, a social worker offers 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 emotional support and advance care planning. They can also advise about medications to manage breathing difficulties and pain.

As the progression and symptoms vary it is important that individual differences are noted and catered for. It is important to check major questions with the treating neurologist.

It is possible that some health professionals may not have had previous experience with MND. The MND Association can provide printed and online information for health professionals on the management of MND and the support available locally.

Most MND Associations offer support and advice from professional staff and experienced volunteers. These people work together with those who have personal experience of living with MND and their carers, to provide support and advice based on a wide understanding of the issues associated with the disease.

Are there multidisciplinary MND Clinics and Services?

There are now 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 regional/care advisors also attend these clinics to provide information and support.

Additional information about motor neurone disease, support services and research can be found on the websites of MND Australia and state MND Associations (see back cover).

Using the Internet to access health information

The Internet can be a valuable source of health information that can help you understand your health issues as well as those of your friends or families.

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 should 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, such as medical terms.

You should also 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 Health Insite, the Australian Government gateway to reliable health information at www.healthinsite.gov.au

Is motor neurone disease painful?

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 unaffected.

However, while most people experience little or no pain at any stage of the illness, others may experience some pain or 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
- » carers need to know how and when to assist the person with MND to readjust their position in order to minimise this problem. Electrically operated beds and chairs and special cushioning can assist the person with MND improve their mobility and comfort

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.

Relaxation therapy can be of great value especially if breathing or swallowing problems are also being experienced. It is possible that someone from the health or palliative care team may be able to teach a few simple relaxation techniques. Some people find commercially available relaxation tapes helpful. Others may find acupuncture useful in the treatment of pain. People are encouraged to check with their doctor before embarking on additional treatments to those being given already.

Mobility

Most people with MND develop mobility problems to a greater or lesser extent.

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 aids and equipment, 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
- » 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.

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:

- » if possible, try not to remain in the same position in bed for too long
- » satin or silk sheets may help moving about in bed
- » 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 allow easier movement in bed
 - » impaired swallowing reflexes may cause a build up 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, if present.
- ### Breathing difficulties
- Many people with MND have decreased lung capacity because of muscle weakness, making any activity that requires increased respiratory effort harder.
- Respiratory 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.

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 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 required during the day as MND progresses.

NIV has been shown to improve quality of life for people living with MND. NIV is suitable for many people with MND but it will not be suitable for everyone. 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.

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
- » 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
- » thickened drinks flow more slowly and are thus easier to control
- » 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

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

An excellent video/dvd regarding swallowing difficulties, produced by MND Victoria, 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 eat. 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.

Obtaining aids and equipment

A Federal Government funded program provides free disability aids to permanently disabled people living at home who are not eligible for help under other government services. The name of this fund varies from state to state. An occupational therapist can advise on how to access this fund.

Provision of equipment can be arranged by physiotherapists and occupational therapists, who assess needs and make application for provision of the aid. The Independent Living Centre (ILC) is a useful place for viewing equipment. Some ILCs have trained health professional staff to assist in selection and provide limited trialing of equipment at the Centre. For more information ph. 1300 885 886 or see www.ilcaustralia.org

Aids and equipment are also available from other sources including most MND Associations. Contact your state MND Association for details.

Financial assistance and advice

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 are available from some state MND Associations.

There are a number of pensions, allowances and benefits available from the Federal Government for people who are aged or disabled. Financial help is also available for carers.

Centrelink

Some payments may be subject to an income and asset test.

Age Pension - Must meet Australian residency requirements. Available to men 65 years and over and women aged from 60.5 years to 65 years depending on date of birth.

Disability Support Pension - Available to people aged 16 or over and under age pension age who are unable to work for a prolonged period because of a disability.

Health Concession Cards - Three health concession cards are currently available through Centrelink. These are a Commonwealth Senior Health Card, Pensioner Concession Card and a Health Care Card. All cards provide concessions on pharmaceutical prescriptions. Some state, territory and local government services will provide other discounts on services to holders of these cards.

Carer Payment - An income support payment for people who cannot support themselves through participation in the workforce while caring for someone with MND. Contact Centrelink for information about conditions which may apply.

Mobility Allowance - Mobility allowance helps meet the extra cost of travel for disabled workers. If the person is still working the mobility allowance can be used to purchase a modified vehicle or access subsidised mobility costs to remain employed.

Carer Allowance - A person may be able to claim carer allowance if they live with and look after an adult who requires a lot of additional care because of their MND.

Further information on pensions and benefits ph. 132 717. Information is available in languages other than English ph. 131 202. Centrelink employs Indigenous Customer Service Officers to provide for the needs of people of Aboriginal or Torres Strait Islander descent. See www.centrelink.gov.au

Veterans

Other benefits may be available to veterans and their widows. Contact the Department of Veterans' Affairs ph. 133 254 or see www.dva.gov.au.

Commonwealth Respite and Carelink Centres

Commonwealth Respite and Carelink Centres are information centres for older people, people with disabilities and those who provide care and services. Centres provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia. Centres can also assist carers with options to take a break through short-term and emergency respite services. Ph. 1800 052 222 or see <http://www9.health.gov.au/ccsd/>

Carer Support

As most people with MND remain at home, the needs of the primary caregiver 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 the various Motor Neurone Disease 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 shed some tears together. For more information contact your state MND Association.

The National Respite for Carers Program

This program is one of several 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. More information on this program is available from the Commonwealth Respite and Carelink Centre ph. 1800 052 222 (bh) or, for emergency respite support outside standard business hours, free call 1800 059 059. They can give advice about respite services and also arrange 24 hour emergency respite care.

National Carer Counselling Program (NCCP)

The National Carer Counselling Program provides short-term counselling and emotional and psychological support services for carers. Contact your local state Carer Association ph. 1800 242 636. Fees may be charged for this service.

Motor Neurone Disease Associations

MND Australia is the national peak body for MND care and research in Australia.

MND Australia:

- » comprises six not-for-profit state associations and its research arm, the MND Research Institute of Australia (MNDRIA)
- » brings together people concerned with MND including those living with MND, their carers, families, volunteers and health professionals

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

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

- » providing ongoing information, education, advice and support to people with MND, their families, carers and health and community professionals
- » providing equipment on loan - the range of equipment available from state associations varies
- » supporting research into the disease and its management

MND Associations offer services in all states and territories. MND Australia is an active member of The International Alliance of ALS/MND Associations, which represents ALS/MND Associations around the world.

www.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. It:

- » 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
- » assists Australian health professionals and community care workers to help people living with motor neurone disease to live better for longer

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