

More About MND



A guide for people living with MND,
their family and friends



MND Australia has created this guide in collaboration with the State MND Associations.

MND Australia is the national peak body that supports people living with and impacted by motor neurone disease (MND). Our national and international networks help increase understanding of the disease and advocate for the needs of those affected. We fund world-class research for better treatments, improved care, and ultimately a cure.

MND Connect

For more information and resources about MND, or details about support services in your state, please contact the MND Info Line on **1800 777 175** or visit **mndconnect.org.au**

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How to use this guide

MND affects everyone differently. So not all the content in this guide will apply to everyone. You don't need to read it all at once. You may find it helpful to scan through and come back for more detailed information when you need it.

We developed content in this guide based on the latest evidence. Experts reviewed this guide to ensure its quality and accuracy at the time of publication. However, researchers and health professionals constantly update and revise MND information. You should consult your healthcare team regarding any specific health needs. MND Australia Inc. does not accept any liability to any person for the information or advice (or the use of such information or advice) provided in this guide or incorporated into it by reference.

Introduction

If you or someone close to you has been diagnosed with motor neurone disease (MND) you might have many confusing and confronting emotions. Working through these emotions may not be easy. But there are ways to help reduce some of your worries and manage what's going on.

More About MND follows on from our introductory guide **What Is MND?** We designed this guide to give more information about MND, including details about diagnosis, treatment and care. It also includes information about services offered through the State MND Associations and other organisations.

We've created this guide to help share quality information about MND, including an overview of MND and what to expect. This includes:

- key facts about MND
- information about how doctors diagnose and treat MND
- ways to manage symptoms and live better for longer with MND
- who to talk with, and what forms of support and services are available.

There is currently no cure for MND. But research has shown some treatments can help people with MND live better for longer.

How you deal with early symptoms of MND can affect how you manage symptoms that arise later. Talking about symptom management early helps you to plan ahead.

State MND Associations provide information, education, advice and support for people with MND, their families and carers.

Each state delivers their own range of services to people living in their locality. For MND Victoria this also includes Tasmania and for MND NSW this includes the ACT and the Northern Territory.

You can contact your local MND Association by calling the MND Info Line on **1800 777 175**. When you dial this number, you will be connected to your local MND Association.

“Resources like this are vital for people who have been impacted by MND, guiding us through the post-diagnosis fog and the journey ahead.”

What is motor neurone disease (MND)?

Motor neurone disease (MND) describes a group of diseases that affect nerve cells called motor neurons.

Motor neurons carry messages from the brain to the muscles via the spinal cord. They enable us to move, speak, breathe and swallow. With MND these nerves become damaged and die. When this happens the muscles they support start to weaken and waste away.

MND is a progressive, degenerative, neurological condition. This means symptoms will worsen over time. The average life expectancy is 2–3 years from diagnosis. It can be much shorter or longer depending on the type of MND.

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

Who does it affect?

Every day in Australia, two people learn they have MND, and two people die from the disease.

- In 2023, an estimated 2,300 people in Australia were living with MND*.
- Of those with MND, 60% are male and 40% are female.
- Around half of people with MND are diagnosed under the age of 65.
- MND is most common in the 65–74 age group.

What causes MND?

In most cases, the cause of MND is unknown. This is referred to as 'sporadic' MND. This means there is no family history of MND, no clear genetic mutation and no known cause.

Current thinking is that MND develops due to multiple complex interactions between genetic and environmental factors. These might include:

- MND-related genes that increase the likelihood of MND
- contact with environmental toxins
- ageing.

By themselves, these factors are not enough to trigger MND. However, repeated exposure to multiple factors over time might trigger MND.

It is thought that any of these factors may act alone or with others to cause MND. Recent research suggests a six-step process with genes, environment and ageing contributing to the development of MND.

The lifetime risk of developing MND is about 1 in 300 by the age of 85.

(*Deloitte figure of 8.7 per 100,000 adjusted for 2023 population)

Familial MND

Latest research suggests that in up to 15% of MND cases, a mutated or 'faulty' gene is present. You may hear this referred to as 'familial' MND as the mutated gene is inherited from a parent. Within the families affected, the disease may present at different ages. It can affect different parts of the body and progress at different rates. Some family members who carry the 'faulty' gene never actually develop the disease.

Ongoing research throughout the world is looking for causes, and potential treatments. Visit mndaustralia.org.au/research to find out more.

What does MND affect?

There are two main groups of motor neurons: upper motor neurons and lower motor neurons.

Upper motor neurons send messages from your brain to the lower motor neurons in the brain stem and spinal cord. They are responsible for the complex, high-level control and coordination of thoughts and movements.

Lower motor neurons begin in your spinal cord. These long nerve fibres connect the upper motor neurons to the muscles. They send messages from the brain and upper motor neurons, allowing you to use your muscles to move, walk, swallow, talk and breathe.

Both upper motor neurons and lower motor neurons are often affected in MND. However in less common types of MND only upper or lower motor neurons are affected.

Upper and lower motor neurons

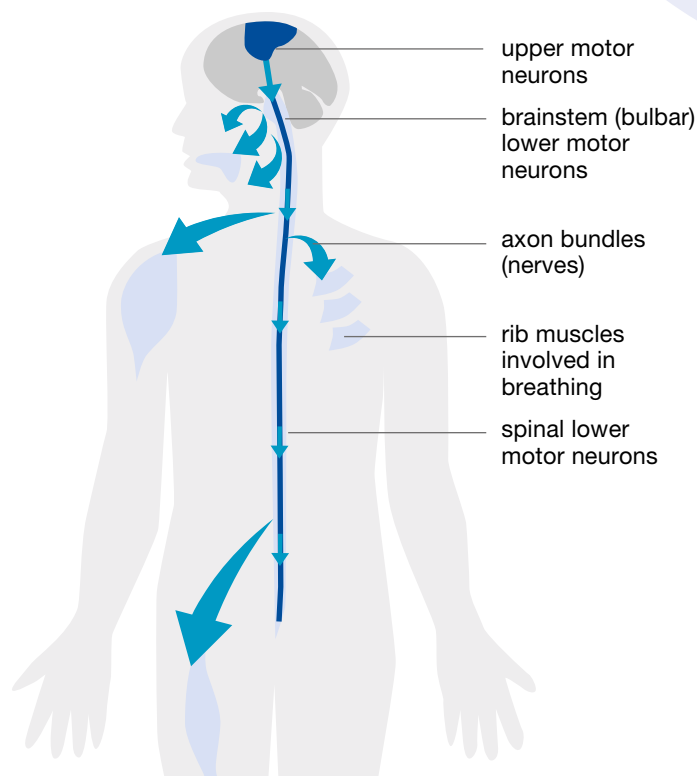


Diagram reproduced with permission from ALS Society of Canada

What are the signs of MND?

Early signs of MND may be mild, and symptoms vary from person to person. Symptoms also vary based on whether the upper or lower motor neurons, or both upper and lower motor neurons, are affected.

Early problems from MND include:

- stumbling or falls due to weakness of the leg muscles
- trouble doing up buttons and hooks or using cutlery due to weakness of the hand muscles
- slurring of speech or trouble swallowing due to weakness of mouth and throat muscles
- twitching (fasciculations) or cramping muscles.

In most cases, changes to thinking are subtle. Symptoms of cognitive and behaviour change in MND include trouble:

- concentrating
- finding the right words for conversations
- solving problems and learning new things.

Emotions may change when upper motor neurons are affected. For example, a person may laugh or cry for no real reason, or respond to something in a way that does not match how they actually feel. You may hear this referred to as pseudo-bulbar effect or emotional lability. Research suggests that around half of all people with MND are affected.

MND/FTD

A small number of people with MND (5–15%) will receive a diagnosis of 'motor neurone disease with fronto-temporal dementia'. Doctors call this MND/FTD. Often the symptoms of dementia precede the motor symptoms, sometimes by a number of years.

What remains the same with MND?

- Most of the time people with MND can hear, taste, smell and feel as usual. This is because the nerves that control the senses are not usually affected.
- MND does not directly impact the bowels and bladder. However, other symptoms like muscle weakness or swallowing difficulties may lead to changes to bladder control or constipation.
- MND has no direct impact on libido, sensation and sexual function. However, fatigue and other physical changes can create barriers to intimacy. It may also affect your confidence.

How is MND diagnosed?

It can be difficult to diagnose MND. Early symptoms are often subtle and hard to detect. There is no single test that can diagnose MND, and in the early stages symptoms can be similar to other neurological conditions.

If a general practitioner (GP) suspects a problem with the muscles, the brain, nervous system or other neurological issues they will organise referral to a neurologist (a doctor who specialises in disorders of the nervous system).

A neurologist will likely need to conduct a number of tests and watch a person for some time before confirming they have MND. Only a neurologist can diagnose MND.



Tests

As well as a clinical examination, a neurologist will likely conduct a range of tests, in particular:

- **nerve conduction studies (NCS)**, which involve figuring out how the nervous system is working by studying electrical stimulation of nerves and recording muscle activity, and
- **electromyography (EMG)**, a process of inserting a needle electrode into various muscles to measure their electrical activity.

Other tests may include:

- MRI scanning of the brain and spinal cord
- blood tests
- lumbar puncture
- muscle biopsy.

Getting a confirmed diagnosis for MND can take some time. As MND symptoms are similar to those seen in other conditions, tests are often needed to rule out other neurological conditions.

Waiting for a diagnosis

Waiting for test results can be stressful and frustrating. After diagnosis is confirmed, most people will experience a range of emotions. It can take time to accept what is happening, and to adjust.

For support and information, contact the MND Info Line 1800 777 175 or visit mndconnect.org.au

What are the different types of MND?

MND is often grouped into four main types. The groupings are mainly to do with how MND affects different parts of the body, and how fast the disease progresses.

The four main types of MND are described in the table below. Each type is not a completely different disease, but a different form.

Type	Features
Amyotrophic lateral sclerosis (ALS)	<ul style="list-style-type: none">• the most common type of MND (about 70% of cases)• involves both upper and lower motor neurons• stiff limbs, weak muscles, muscle twitches and overactive reflexes• usually starts in the arms, legs or throat• early signs are tripping, stumbling or dropping things• life limiting, with a life expectancy of 2 to 5 years from diagnosis
Progressive bulbar palsy (PBP)	<ul style="list-style-type: none">• less common than ALS (around 20% of cases)• starts in the bulbar region of the brain, which controls neck and face muscles• usually affects speech and swallowing muscles first• early signs include slurred or quiet speech, or trouble swallowing• life limiting with life expectancy between 6 months and 3 years• may progress to affect other parts of the body over time
Progressive muscular atrophy (PMA)	<ul style="list-style-type: none">• relatively rare form of MND (around 5% of cases)• only involves lower motor neurons• begins in either the arms or the legs• gradual loss of muscle mass (atrophy) leading to weakness• slower progression than other forms of MND, with longer life expectancy• many people diagnosed with PMA later develop upper motor neuron signs, and are reclassified as having ALS
Primary lateral sclerosis (PLS)	<ul style="list-style-type: none">• very rare (less than 3% of cases)• only involves upper motor neurons• symptoms vary but may include problems with balance, stiffness and weakness of muscles (particularly in the legs), slurred speech• typically progresses slowly, with life expectancy of 10–20 years

What is motor neurone disease (MND)?

Over time, as symptoms and the rate at which they progress become clearer, your diagnosis may be reviewed and changed to another type. In some cases, neurologists may not be able to establish which type of MND a person has at the time of diagnosis. They may need to observe a person's condition over time (months, or in some cases, years).

Kennedy's Disease

Kennedy's disease refers to Spinal and Bulbar Muscular Atrophy (SBMA). It is a rare inherited disease caused by a genetic mutation and affects men. It is not motor neurone disease but symptoms may be similar, so it might be mistaken for MND.

To find out more, see **Further information** on page 14.



Treatment and care

The rate at which MND progresses varies depending on the type, and from person to person. It is a degenerative condition, which means symptoms will worsen over time. However, support is available to help you live better for longer with MND.

MND Associations give information, support, education programs and a range of services and equipment for people with MND, their family and carers. To find out more, contact the MND Info Line **1800 777 175**.

Medication: Riluzole is used to treat amyotrophic lateral sclerosis (ALS) and progressive bulbar palsy (PBP) – the most common types of MND. Riluzole has been shown to slow progression of MND. See page 15 for more information.

Non-invasive ventilation (NIV): Also known as bi-level positive airway pressure (BiPAP), NIV helps people with MND to breathe better. Usually used at night, NIV involves wearing a mask over the nose and/or mouth.

The mask connects your airway to a small pump (bi-pap machine). The pump creates just the right amount of pressure to keep your airways open. This allows air to easily come in and out of your lungs when you breathe. Research has shown that using NIV can improve sleep quality, reduce breathlessness and help a person with MND live longer. See Breathing and ventilation on page 17 for more.

Gastrostomy or PEG: Some people with MND decide to have a PEG (Percutaneous Endoscopic Gastrostomy) inserted. A PEG is a short, fixed tube that is placed in the stomach through the abdominal wall. A PEG helps to improve nutrition and quality of life, and may help a person with MND live longer. See page 19 for more.

MND multidisciplinary care: Living with MND can be easier with the support of a diverse group of health professionals and service providers, also known as a multidisciplinary care team. See pages 11–13 for more.

Research and clinical trials

Many people with MND are interested in participating in MND research. This can be done in a number of ways. Clinical trials test new treatments and interventions in people to find out if they are safe and/or effective. If you would like to know more, talk to your neurologist or visit mndconnect.org.au

What is multidisciplinary care and how does it help?

MND is a complex condition. The needs of people with MND change over time, and rate of progression is different from one person to another.

Multidisciplinary care teams give people with MND access to a range of health professionals who work together to provide a coordinated response to care needs. A multidisciplinary care team may have doctors, nurses, allied health professionals, palliative care teams, psycho-social and community care workers. See the table on pages 12–13 for details.

MND clinics: These specialised clinics provide multidisciplinary treatment and support for people living with MND across Australia. The health professionals involved in these clinics and services are experienced in MND.

To find out about MND clinics in your area, contact the MND Info Line **1800 777 175** or visit mndaustralia.org.au/mnd-connect/mnd-clinics

Asking questions

Some people find it hard to ask questions. However, asking questions can help you find the treatment and support that is right for you. It can also help you to plan and make changes in your daily life. It is a good idea to prepare a list of questions to take to appointments. Keep a record of the answers. You can ask a family member, carer, or health professional to take notes if you need to.

Research indicates that multidisciplinary MND care can improve both quality and length of life. When someone with MND receives multidisciplinary care, they maintain function for longer and are admitted to hospital less often.



MND multidisciplinary care team

Your multidisciplinary care team may include the following:

General practitioner (GP) or local doctor	<ul style="list-style-type: none">• usually your first point of medical contact• liaises with the neurologist and other health and community service providers
Neurologist	<ul style="list-style-type: none">• specialises in conditions of the nervous system• coordinates tests and confirms diagnosis of MND• monitors disease progression and management of your symptoms
Occupational therapist	<ul style="list-style-type: none">• helps you to maintain mobility, function and independence• provides advice about home modification, different ways of performing tasks• helps with selecting, acquiring and adapting specialised equipment and technology
Physiotherapist	<ul style="list-style-type: none">• helps you maintain physical activity and mobility• shows your family or carer how to safely help you move from one position to another, e.g. from a chair to a bed• helps with techniques to support coughing and breathing
Orthotist	<ul style="list-style-type: none">• constructs and fits braces and splints that provide support and increase mobility
Respiratory specialist	<ul style="list-style-type: none">• provides information, advice and guidance about breathing
Speech pathologist	<ul style="list-style-type: none">• advises about communication aids and devices• helps with swallowing techniques and food consistency

Registered nurse/MND nurse	<ul style="list-style-type: none">• can include ongoing care and care coordination, often for people in their own homes• specialised MND nurses usually work in MND clinics and have expertise in MND symptom management
Social worker, psychologist or counsellor	<ul style="list-style-type: none">• gives counselling on the psychological and emotional aspects of living with MND• social workers can give information on community services that may assist you with accommodation, legal, financial and other issues
Palliative care team	<ul style="list-style-type: none">• can help to improve quality of life for people with life limiting conditions such as MND• gives expert symptom management and emotional support for people living with MND and their families• assists you to plan your future care
MND Association Advisor	<ul style="list-style-type: none">• helps connect you to the services you need• offers ongoing support and information to families and service providers as needs change
MND Support Coordinator	<ul style="list-style-type: none">• assists NDIS participants with putting their National Disability Insurance Scheme (NDIS) plan into action
Community service providers	<ul style="list-style-type: none">• include personal care workers who provide general household assistance such as showering and dressing, emotional support and care• may be funded and accessed via the National Disability Insurance Scheme (NDIS) or Aged Care system (My Aged Care)
Dietitian	<ul style="list-style-type: none">• helps with diet and MND as well as nutrition advice

Further information and key points

MiNDAUS Registry

The Australian Motor Neurone Disease Registry, known as MiNDAUS, is open to all people diagnosed with MND in Australia. It is free, and quick and easy to join. The MiNDAUS Registry collects health information during clinic visits as well as any information participants choose to enter. Joining helps researchers understand MND and develop better treatments. Participants can also receive emails about clinical trials. Learn more at mindaus.org

Key points

- MND affects the motor neurons which we use to control movement. It does not usually affect the senses.
- Early signs of MND vary from person to person. They may be mild and include things like stumbling or dropping things, or slurred speech.
- Diagnosing MND can take time. There is no single test for MND.
- MND is thought to be caused by a combination of factors. These include exposure to environmental toxins and chemicals, ageing and genetics.
- Riluzole is currently the only PBS-listed medication approved to treat MND in Australia.
- As a complex disease, MND treatment is best coordinated through a multidisciplinary healthcare team.
- Multidisciplinary care teams give people with MND access to a range of health professionals who work together to coordinate treatment and support.

Further information

From our range of fact sheets and publications:

- What is MND?
- Familial MND and genetic testing
- Kennedy's Disease
- Cognitive and behaviour change with MND
- Multidisciplinary care

Videos and animations

- Genetics and MND
- MND diagnosis
- Treatment for MND

From the MND Connect website:

- mndaustralia.org.au/mnd-connect/what-is-mnd
- mndaustralia.org.au/mnd-connect/types-of-mnd
- mndaustralia.org.au/mnd-connect/newly-diagnosed
- mndaustralia.org.au/mnd-connect/mnd-research
- mndaustralia.org.au/mnd-connect/mnd-clinics
- mndaustralia.org.au/mnd-connect/how-health-professionals-help

MND Info Line

1800 777 175

9am to 4.30pm Monday to Friday

mndconnect.org.au

Living better for longer with MND

It can be challenging to learn that you or someone close to you has MND. It will take some time to adjust. But with the right information, you can learn to live better for longer.

MND will change the way your body functions, and there is a wide range of possible symptoms.

Everyone experiences MND differently: symptoms may occur at a different rate, or in a different order. It is important to get advice from qualified health professionals that is tailored to suit your needs. However, there are common strategies you can use to help manage the day-to-day of living with MND.

This section provides an overview of ways to manage symptoms including mobility issues, fatigue, breathing, swallowing, and speech changes. Managing MND symptoms as they arise may help you to cope better with them. You may find that your ability to be involved in everyday life also improves.

What medication is available?

Riluzole is currently the only PBS-listed medication approved for treatment of MND in Australia. Riluzole is also sold as Rilutek™ or APO-Riluzole.

Riluzole comes in tablet and liquid form (Teglutik®). It can be bought from a pharmacy with an initial script from a neurologist and follow-up scripts from a GP. It is available on the Pharmaceutical Benefits Scheme (PBS) for people who meet defined eligibility criteria.

While Riluzole does not cure MND, recent research suggests it may prolong average survival by 6 to 19 months.

For most people living with MND it is best to start taking Riluzole soon after diagnosis in order to receive the greatest benefit.

See **Further information** on page 21 to find out more about Riluzole.

Other medications and therapies

People living with MND often ask what other drugs and treatments are available. Edaravone or RADICAVA is currently approved for use in countries including Japan, South Korea and the USA. Other drug treatments are currently being developed and studied through clinical trials around the world, including Australia.

When searching the internet, it can be hard to know the difference between reliable health information and paid advertising. ALSUntangled® is a reliable international source for reviews of alternative treatments, helping people with MND to make informed decisions. **alsuntangled.com**

Mobility

MND affects movement and mobility in most people. Daily activities may take more effort. You may need help to get around.

Some people tend to fall, which can lead to injury. It is important to consult health professionals to get the best advice to protect yourself from falling.

Aids and equipment can help with independence, communication, comfort, safety and participation in work and social activities. You may hear these referred to as assistive technology (AT).

Occupational therapists (OTs) or physiotherapists can give advice on strategies and equipment that can support you to stay mobile for longer, including:

- using mobility aids, such as walking frames or orthotics (e.g. a brace that holds your foot and ankle in the right position)
- wearing the right footwear
- strategies that prevent falls
- managing fatigue
- making your home environment safe.

Fatigue

Fatigue (tiredness) is a common symptom of MND. Even daily tasks like washing and dressing can be tiring. You may need to rest and take time to recover. Fatigue may also be due to depression, poor sleep, poor nutrition or weakened breathing muscles.

Learning what makes you tired, and how to conserve energy, can improve your quality of life.

Your healthcare team can advise you on ways to improve sleep and manage your fatigue.

Tips for managing fatigue include:

- plan harder tasks or outings for times when you usually have more energy
- rest when you need to
- be flexible with routines
- listen to your body and don't push yourself too hard
- use aids and equipment to make tasks easier
- make your personal environment safe and easy to move around
- take shortcuts where possible (e.g. sit rather than stand, get dropped off at the doctor's door rather than walk from the car park).

Getting a good night's sleep

Sleep plays a vital role in feeling good day to day. Many people with MND have problems that disrupt their sleep. Talk to your care team about what is available to help support you getting a good night's sleep. If breathing is the issue, non-invasive ventilation (NIV) might help. Aids and equipment are also available to support comfort and movement in bed. To find out more visit mndconnect.org.au

Breathing and ventilation

MND causes weakness in most muscles in the body, including the breathing (respiratory) muscles. Breathing muscle weakness usually develops gradually, but in some people it can happen quickly. Sometimes it is the first sign of MND. Most people first notice breathing problems when they lie flat, or at night during sleep.

Some signs of respiratory muscle weakness include:

- shallow breathing
- breathlessness when lying flat
- disturbed sleep
- waking up with a headache
- daytime sleepiness
- weak cough or sneeze.

If you experience changes to your breathing, let your GP, neurologist, respiratory specialist or clinic know. They can provide specific advice and instruction on what strategies might be best for you.

Respiratory care may include:

Respiratory assessment: Regular breathing checks can help guide your care. Tests measure breathing symptoms, breathing muscle strength and lung volume (vital capacity). Strategies are available to help with the feeling of breathlessness, difficulty coughing and clearing mucus, as well as sleep-related breathing problems.

Non-invasive ventilation (NIV): Involves wearing a mask over the nose and/or mouth. The mask connects you to a small pump (also known as a BiPAP machine). The machine creates just the right amount of pressure to keep your airways open. This helps move the air easily in and out of your lungs when you breathe. The NIV machine is usually used at night. As respiratory muscles weaken you might use it at times during the day as well. Portable NIV can be arranged.

See **Further information** on page 21 to find out more about Breathing and ventilation.

Research has confirmed that using non-invasive ventilation (NIV) can increase survival time, in some cases by up to 13 months.



Eating, drinking and swallowing

Some people with MND will experience problems with eating, drinking and swallowing. As the nerves and muscles weaken, basic functions like opening and closing the mouth and chewing and swallowing food may become harder.

Being unable to eat can not only affect you physically, it can reduce your enjoyment of life. You may feel like you're missing out or not able to catch up with others like you normally would.

Both a speech pathologist and dietitian can provide important support and guidance for eating, drinking and swallowing problems. Drawing on support will make it easier to deal with problems. You can also come up with strategies to enjoy socialising and spending time with others.

Let your GP, neurologist or healthcare team know if you notice any of the following:

- having the feeling that food is stuck in your throat
- difficulty swallowing or chewing
- coughing or choking when eating
- dribbling saliva
- thick saliva
- taking a long time to chew and swallow.

A speech pathologist can advise you on tips and tricks around food and drink consistency to help with swallowing. The following suggestions might also be useful:

- puréed (vitamised or blended) foods flow more slowly and are usually easier to swallow
- eat from shallow spoons and take small mouthfuls
- sip drinks slowly – this reduces the risk of fluids going down your windpipe
- eat foods you like – taste stimulates the swallow reflex
- sit as straight as possible with your head upright
- use specialised eating utensils, such as spouted cups and syringes.

Visit mndconnect.org.au to find out more about eating, drinking and swallowing, including tips for saliva management.



Tube feeding

If swallowing becomes too tiring, or too hard, gastrostomy (also known as PEG or RIG) may be an option. It may be possible to have most food and medication via the tube and still eat more enjoyable food by mouth.

With PEG:

- a short, fixed tube is surgically inserted into the stomach through the upper abdominal wall
- nutrition, fluids and medications are delivered directly into the stomach via the tube.

For some people, getting a feeding tube inserted can be a difficult decision. However it is discrete and can be covered by clothing. Some of the benefits include:

- may help you maintain your weight
- improves hydration and nutrition
- can reduce fatigue, hunger and constipation
- makes taking medication easier.

See **Further information** on page 21 to find out more.



Pain

Not everyone with MND will experience pain, but if you do, getting help early can make a difference.

MND itself does not cause pain. However, progressive muscle weakness and wasting, immobility, muscle cramps, stiffness and changes to posture can lead to pain and discomfort. In addition, muscle wasting can make pre-existing conditions like arthritis worse.

Pain may come and go at all stages of the disease. It can interfere with daily activities, how you feel, your sleep, relationships and general enjoyment of life.

It is important to discuss your needs and preferences with your healthcare team. This will ensure you are able to manage pain in a way that works for you and your carers.

A physiotherapist or occupational therapist can advise on strategies to help manage pain and reduce the risk of injury. These might include:

- careful positioning to support head, trunk and weight of limbs
- regular repositioning by a carer if you are unable to reposition yourself
- passive limb movements to relieve muscle and joint stiffness
- aids, transferring techniques and pressure relieving equipment.

A GP, neurologist or palliative care specialist can prescribe a range of medications for pain.

Some people also find massage, warm packs and relaxation activities helpful.

Speech and communication

Speech and communication are an important part of daily life. Being able to express your views can assist you make decisions about MND and your quality of life.

Some people with MND experience changes to speech or voice early, while for others it can happen much later. As MND progresses, however, most people (around 80%) will experience some problems with their speech. This is because MND can cause weakness in the tongue, lips, vocal cords and breathing muscles.

Speech changes usually include:

- slurred speech
- hoarseness or a weak voice
- lower volume or difficulty projecting voice
- in some cases, complete loss of speech.

Losing the ability to speak can lead to frustration, feelings of isolation and loss of control. However, speech pathologists and occupational therapists can provide you with great tips and strategies to support communication. These tips can also help you to interact with those around you.

Simple communication strategies include:

- take your time and don't rush
- be prepared – write down key or difficult words
- communicate face to face so the listener can watch lips, eyes and gestures

- if possible, find a quiet space
- carry a card that lets people know that you can hear and understand.

It is a good idea to talk with a speech pathologist about technology early, even before speech problems develop. One type of technology called voice banking involves recording your voice while it is still clear for use later on.

Other types of technology include eye gaze devices, tablets and other light weight devices, and accessibility features on smartphones. Technology can help with recreation activities like reading, watching film and television, playing games and chatting with others online.

Assistive technology (AT)

Aids and equipment, usually referred to as assistive technology (AT), can help with maintaining independence, communication, comfort, safety and participation in work and social activities. Common forms of AT include power wheelchairs, hoists, ramps and special cushions and mattresses.

Home modifications are also important to consider. Exactly which type of AT or home modifications are needed, and when, depends on a person's physical needs and how quickly their MND progresses. Communication technology can make it easier to stay in touch with family and friends and have a positive impact on your wellbeing. See mndconnect.org.au for more.

Further information and key points

Planning ahead/end of life care

When you have MND, talking about the future can be hard. But it does help to plan ahead. There are ways to make it easier, and feel less worried about what lies ahead. Planning ahead includes making decisions about financial, legal and medical needs. It may also include having difficult conversations with family and friends, connecting you with local services, and ensuring your needs are met.

See our **End of Life Care** guide for more.

Key points

- Motor neurone disease is a complex, challenging condition. Getting the right information, education and support can help you learn to live better for longer.
- There is a wide range of possible MND symptoms. Symptoms may occur at a different rate, or in a different order.
- Riluzole (also Rilutek™ or APO-Riluzole) is currently the only PBS-listed medication approved for treatment of MND in Australia.
- MND affects movement and mobility in most people. You may need help to get around and prevent falls.
- Learning how to conserve energy and manage fatigue can improve your quality of life.
- Breathing can become difficult as MND progresses. Non-invasive ventilation (NIV) is an option as the respiratory muscles weaken.
- A speech pathologist and dietitian can provide support and guidance for eating, drinking and swallowing.
- Progressive muscle weakness can cause cramps and spasms, which may be painful. Getting help early is key.
- Most people with MND will experience some problems with their speech. There are a range of strategies and technological devices to assist.

Further information

From our range of fact sheets and publications:

- MND evidence-based treatments and support: an overview
- Riluzole
- Pain management with MND
- Breathing and MND: an introduction
- Breathing and MND: what you can do
- Breathing and MND: medications and non-invasive ventilation
- Considering gastrostomy: PEG and RIG
- Maintaining weight for health with MND
- Planning ahead

Videos and animations:

- Treatment for MND
- Non-invasive ventilation and MND
- Living with MND
- Maintaining independence at home with MND

Trusted information

MND Australia is recognised as a trusted source of information about MND and is a healthdirect partner. References for this guide are available on request. Please send your request by email to info@mndaustralia.org.au

Services and support

How we can support you

MND Australia is the national peak body for people living with MND, their loved ones and carers.

Through our research arm, MND Research Australia, we support high-quality MND research to discover the causes, improve care and find treatments and ultimately a cure for MND. Through the MND Info Line, MND Connect, and the network of State MND Associations, we provide MND specific information, education and support.

MND Connect

Visit **mndconnect.org.au** for resources and information about diagnosis, treatment and how to live better for longer with MND. This includes written web content, videos and animations, downloadable fact sheets, booklets and more. You can also learn about information sessions, specialist MND clinics near you, and links to services and support for people with MND, family and carers.



MND Connect

Connecting people
to MND information,
services & support

MND Info Line

1800 777 175

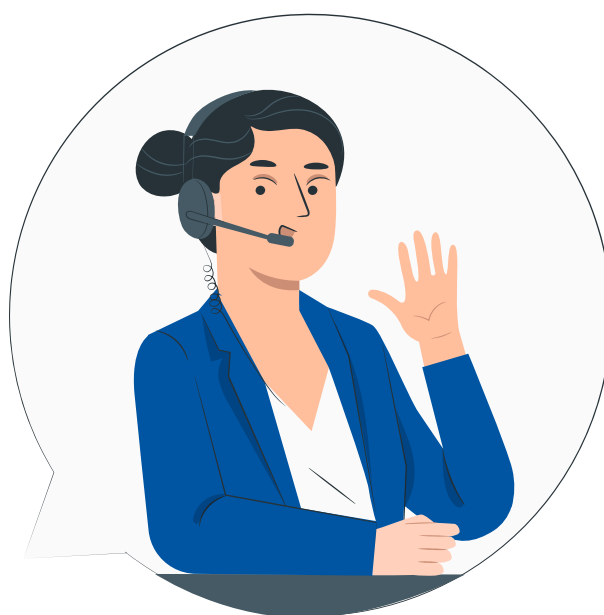
9am to 4.30pm Monday to Friday

mndconnect.org.au

MND Associations

The MND Association in your state or territory provides a range of supports and services. Some of these include:

- information
- ongoing support and guidance
- linking you with MND clinics and other specialist services
- advice for navigating My Aged Care and NDIS plans
- MND Advisors, who connect you with services and offer direct support
- NDIS Support Coordination
- MND education and information sessions, held throughout the year
- access to assistive technology (AT) and equipment
- peer support sessions and support groups
- support for carers
- allied health
- volunteer programs.



Other useful organisations

Health information

- **healthdirect** provides free virtual health information from trusted sources, as well as advice and referral **healthdirect.gov.au**
- **ALS Untangled®** reviews alternative and off label treatments, with the goal of helping people with ALS (MND) make more informed decisions **alsuntangled.com**

Disability and aged care

- **National Disability Insurance Scheme (NDIS)** provides support, information and connections to services for people with a disability who become participants before the age of 65 **ndis.gov.au 1800 800 110**
- **My Aged Care** is the starting point for accessing Australian Government funded aged care services **myagedcare.gov.au 1800 200 422**
- **Disability Gateway** assists all people with disability, their families and carers to locate and access services across Australia **disabilitygateway.gov.au 1800 643 787**

Support for people from Aboriginal and Torres Strait Island communities

- **Australian Indigenous HealthInfoNet** is closing the gap by providing the evidence base to inform practice and policy in Aboriginal and Torres Strait Islander health **healthinfonet.ecu.edu.au**

Advance care planning and palliative care

- **Advance Care Planning Australia** helps prepare people and those supporting them to plan for future health care needs **advancecareplanning.org.au 1300 208 582**
- **National Palliative Care Service Directory** is an initiative of Palliative Care Australia, which allows you to search for palliative care services in your area **palliativecare.org.au/directory-of-services**

Carer support

- **Carer Gateway** connects carers with services and support across Australia **carergateway.gov.au 1800 422 737**
- **Carer Help** provides online information and resources for carers to help support loved ones at end of life **carerhelp.com.au**

Communication support

- **Translating and Interpreting Service (TIS)** provides phone and on-site interpreting for people who do not speak English, and organisations communicating with them. **tisnational.gov.au 131 450**
- **National Relay Service** helps people who are deaf, hard of hearing and/or have a speech impairment to make and receive phone calls.
P 1800 555 660 TTY 1800 555 630
F 1800 555 690 SMS 0416 001 350
E helpdesk@relayservice.com.au



until there's a cure, there's care

MND Australia

mndaustralia.org.au
info@mndaustralia.org.au
(02) 8287 4980

Member Organisations

To contact the MND Association in your state call the MND Info Line 1800 777 175

MND New South Wales

mndnsw.org.au
admin@mndnsw.org.au

MND Tasmania

mndatas.asn.au
info@mndatas.asn.au

MND Queensland

mndaq.org.au
info@mndaq.org.au

MND Victoria

mnd.org.au
info@mnd.org.au

MND South Australia

mndsa.org.au
admin@mndsa.org.au

MND Western Australia

mndawa.asn.au
admin@mndawa.asn.au

ACT and NT contact:

mndnsw.org.au
admin@mndnsw.org.au

What do you think?

Let us know what you think of this More About MND guide. We'd love to hear what you think we did well and where we can improve the content for people with or affected by MND.



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