End of life care: A guide for people living with MND

mnd
Australia

End of life care:
A guide for people living with MND

Version: 1. Next revision: 12/24.

ISSN: 2653-0155 (Print)
Published by MND Australia
MND Australia Inc.
ABN 52 650 269 176
ARBN 609 051 792

Ph: 02 8287 4980
info@mndaustralia.org.au
mndaustralia.org.au

Designed by Michels Warren / ChinaShop

Contents

Foreword

Most of us avoid talking about death and dying, and find these kinds of conversations uncomfortable or upsetting. We put off making a will, appointing a power of attorney or talking about our wishes at end of life. It is not until you, or someone close to you, receives a diagnosis of a life limiting condition such as motor neurone disease that these conversations come to the fore and the need for trusted information on end of life becomes important.

A diagnosis of motor neurone disease can be devastating and it may take some time to adjust and take in the news that you have a life limiting condition. At some point you will want to plan ahead and consider how you would like to be cared for as you approach the end of your life. End of life care encompasses making decisions about financial, legal and medical needs, having difficult conversations with family and friends about death and dying, connecting with services and support in your local community and ensuring you are as comfortable as possible.

MND Associations identified the need for practical information on planning ahead and end of life care for people living with MND, their carers and family members in an easily accessible and friendly format. This guide has been developed to help address that need and to pull together relevant information including who to talk with to ensure that your needs and wishes for end of life care are acknowledged and respected. The aim of the guide is to help make sensitive and important conversations easier. Our hope is that the guide will help more people with MND be able to achieve a dignified death.

The guide is made up of five colour coded parts that cover a range of topics, some of which may be confronting to read and think about. The guide is not designed to be read in one go. We recommend that you dip in and out of the guide and read parts or topics when you feel ready or to find answers to specific questions or concerns.

You may wish to read the guide with the support of those close to you, your MND Advisor or a member of your health care team. MND is a very individual disease with each person experiencing different rates and patterns of progression. Try to discuss your future needs and wishes as early as you can. We hope that by reading and sharing the guide you will be able to begin conversations to help you feel less worried about the future, feel more in control and more able to focus on getting on with living.

There were many people involved in developing this guide that I would like to acknowledge, and give special thanks to the MND Association of England, Wales and Northern Ireland for giving us permission to adapt their award winning End of Life: A Guide for People with Motor Neurone Disease. We have also engaged widely to ensure this guide reflects the needs of Australians living with MND and their carers and families, changing laws and current models of disability support and health, aged and palliative care.

I would like to personally thank the members of the MND Australia team and the MND Association Information Shared Service group who worked diligently throughout 2020 to develop the guide.

And I would like to especially thank all those involved in reviewing, checking the accuracy and relevance of the information and contributing images and quotes, especially our review group of health professionals, people living with MND, carers and past carers.

Carol Birks, CEO MND Australia

How to use this guide

This guide explains treatments, who to talk with about sensitive topics, creating a legacy, how to address your wishes and ways of getting help and support.

Please be aware: the guide refers to death and dying. Should anything you read cause you distress be sure to seek out someone to talk to and come back to the guide when you feel ready.

> *"When I was diagnosed with MND I was a chaotic mess of emotions, full of fears and questions. This guide provides practical advice and gentle reassurance for people at any stage of their MND journey. It would have calmed some of my fears, and answered many of my questions, as well as questions I hadn't thought to ask."*

The guide is made up of 5 parts, which are numbered and colour coded.

Part 1: **What do I need to know?**

Part 2: **Things I'm likely to experience**

Part 3: **What my family, friends and others close to me need to know**

Part 4: **What else might I need to consider?**

Part 5: **How do I get more help?**

In each part, there are individual sections that provide specific information and advice on a common theme.

We recommend sharing this guide with your carer, family and others supporting you. Sharing the guide can make it easier to gather information, and help others to respect your needs and wishes.

In this guide "carer" refers to the significant person in your life who supports you. A carer may be your spouse, partner, mother, father, son, daughter or a trusted friend or relative.

Please also be aware that some words and terms (e.g. advance decision to refuse treatment, ADRT, hospice, palliative care unit) vary across states and territories. Check with your MND Advisor or health professional team about terms that are used where you live.

We would like to advise Aboriginal and Torres Strait Islander readers that this publication may contain images or names of deceased persons.

We trust this guide will help more people with MND, their families and carers, to feel informed and empowered to better navigate and manage their care.

Who you can talk to about this guide

MND Associations where you live:

- MND New South Wales
  (ACT, Northern Territory)
- MND Victoria
- MND Tasmania
- MND Queensland
- MND South Australia
- MND Western Australia

MND Info Line
(Free call): 1800 777 175

You can also contact MND Clinics in your state or territory.

MND Australia can help with further questions about this guide or for access to other information via:

P 02 8287 4980
E info@mndaustralia.org.au
W mndaustralia.org.au

What do I need to know?

Section 1: Planning ahead and why it helps

Section 2: Managing emotions

Section 3: Having difficult conversations

When you know more about planning ahead, it can help reduce worry about the future, and start the process of finding the end of life care that you want.

1: Planning ahead and why it helps

Planning ahead is about being prepared. Preparation normally involves sorting out your medical, financial, legal and other needs.

What are the benefits of planning ahead?

- an opportunity to think about, discuss and plan for your daily life and end of life care
- more likely to have your needs met
- feel more comfortable talking with family and friends
- having peace of mind.

Examples of plans:

- medical (advance care, treatment)
- financial (income, expenses, life insurance, superannuation)
- legal (writing a will, Enduring Power Of Attorney)
- place of care (home modifications, aids and equipment)
- family
- spiritual, religious.

While planning ahead helps, you may find your wishes about end of life may change during your MND journey. Planning ahead does not have to lock you in to your decisions and you can change your mind at any time.

Planning ahead isn't about giving up – it's about achieving a better quality of life, and getting on with living and the time you have.

When is a good time to start talking about end of life?

- when you feel ready
- it can be hard, but talking about it as early as possible does help
- early discussion can make it easier as speech and communication or other parts of your health can be affected by MND
- when you may want to consider who you'd like to act on your behalf for medical and financial needs
- early discussion is also important because a slower progressing form of MND can develop into a faster form.

Who can I talk with?

If you feel ready and want to start conversations about end of life early you may want to discuss it as part of making decisions about managing symptoms. You can talk with qualified staff and others who are sensitive to your needs, including:

- staff at MND Clinics
- MND Advisor from your MND Association (MND Advisor)
- Palliative Care specialist
- GP
- family and friends.

See Section 3 for who else you can talk with, and tips for helping conversations.

See also MND Australia's fact sheet Planning Ahead for more information.

Are end of life care and palliative care the same?

You will often hear the terms palliative care and end of life care when talking about end of life. The terms are used throughout this guide. By understanding the differences between the terms, it can help you make more informed decisions.

Palliative care

Palliative care is support for the health, wellbeing, safety and other needs of a person with life-limiting illness to help them maintain their quality of life. Palliative care is a family-centred model of care, meaning that family and carers can also receive practical and emotional support.

Palliative care is provided by a range of people. The care may be provided by your GP, community nurse, neurologist and other members of your health care team, supported if and when necessary by a specialist palliative care service. Care may be referred to as a palliative or neuropalliative approach to your care. For people living with MND, a palliative care approach is beneficial from the time of diagnosis.

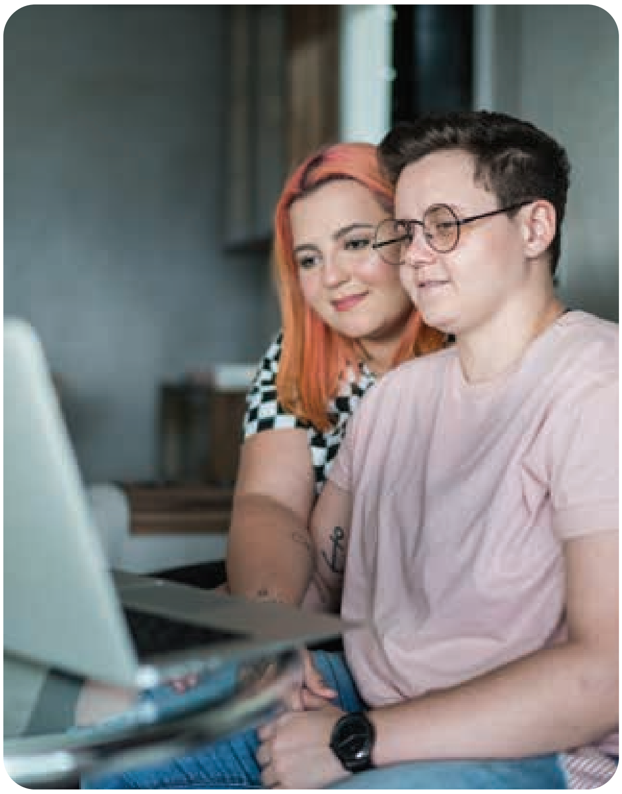
Care might involve helping you with sleeping better, symptom management, dealing with stress and anxiety, medications for managing pain and any social, spiritual, religious and other needs. Palliative care is available at home, in hospital or wherever else you may need or want it, wherever possible.

End of life care

End of life care is support that aims to provide you with more help during the last few weeks of life when the needs of you, your carer and family may be higher.

A specialist palliative care team may become more involved in your care and in supporting your carer and health and community care team at this time. Increased services and support are very important in the last few weeks.

With greater support, it is possible to make sure that your care is of a high quality and that your needs and wishes are respected.



2: Managing Emotions

Learning to manage emotions as you approach or think about end of life care involves developing an understanding of:

- practical ways you can deal with the different kinds of emotions related to MND and end of life care
- anticipatory grief
- spiritual and religious support
- changes to personality, behaviour and emotion
- types of professional help available to you.

It's okay if you feel emotional about end of life care. But you can use advice, tools and approaches here in this guide to help reduce stress, worry and other difficult emotions to make things easier.

A sensitive time

Making decisions about end of life care may be a particularly sensitive time for you. Every person has a different set of circumstances and needs. You are likely to experience a range of emotions. You may feel overwhelmed, fearful or worried about:

- the future, what may happen to you and your family and friends
- how you will die
- a loss of control over your life
- how complex end of life decisions can be.

It's also normal for you to feel:

- anger at the medical profession, family and others if you feel your wishes aren't being met
- isolation from those not in your position
- sadness at your loss and for your family
- guilt that you may cause stress and worry for others
- stress from changes in relationships between you and your family and friends.

You may find relief

It's important to remember that you can also feel relief that you finally know what options are available to you and can express your wishes. You may also feel resignation, denial or acceptance or a mixture of feelings that may change often.

Grief and loss

During this time, you may feel pressure to discuss sensitive issues. You, your partner, carer, children, relations and friends may all experience what is known as ‘anticipatory grief’. Anticipatory grief is where you begin to grieve for the loss to come. With that loss, you may feel a sense of impending dread.

There will be grief for losses along the way, too. The progressive nature of MND means that physical independence, facial expression, communication and activity may all be affected.

Not only are you likely to feel grief about dying, but about each limitation that MND may bring.

The feelings that you, your carer and family experience may be different at different times. Feelings may change rapidly, too. You may feel frustration and anger at certain points, while your carer might feel more accepting of the situation.

But you can make feelings of grief easier by talking openly about the experience. Talking openly can help you reduce the anxiety that anticipatory grief may cause.

Talking openly:

- helps everyone because the grieving process can affect all who are close to you
- could be important for your carer.

Your carer, who may be providing both emotional and physical support to you, may find the experience particularly intense. Sharing feelings and experiences is important for carers to help reduce any intense feelings that may occur from time to time.

Coping with intense emotions

You're likely to find various ways of coping with intense emotions. If you find emotions difficult, try to allow yourself to express anger, irritation, tears – even laughter. Expressing feelings helps release tension.

Taking positive actions helps you feel more in control and reduces frustration and sadness. Positive actions build confidence. Staying active for as long as possible can help you too, and you may like to try:

- catching up with a friend or loved one
- doing physical activities, like gardening or spending time outdoors
- planning a trip, event or holiday
- seeking out experiences with family and friends for lasting memories
- participating in music therapy
- doing stretches and exercises with the guidance of a physiotherapist with understanding of MND
- hydrotherapy with a qualified professional with understanding of MND
- spending time at local clubs whose activities support those with disabilities, like swimming, sailing and horse-riding.

Making decisions or talking about home modifications and assistive technology may be a particularly sensitive and emotional time for you and your carer. See if you can focus on the positive outcomes of adapting your home environment and using assistive technology to make it easier for you to maintain your quality of life and to support your mobility and communication with others. Talking with the occupational therapist and speech pathologist from your MND Clinic or health care team about your concerns may help to reduce these feelings and support you to plan ahead.

Counselling and psychological support

Your GP can offer a referral to a counsellor, psychologist or other kinds of support workers to help work through emotions and other difficulties. Some services may be subsidised and available at a lower cost, while others may charge more. You can talk to your GP if you're worried about the cost and about what other options are possible.

If you have not yet been referred to a palliative care team or service try to talk with your GP or MND Clinic about palliative care and a referral.

Planning ahead with a palliative care team can also provide you with a wider range of services and support, including practical options. A palliative care team is there to support your comfort, wellbeing and quality of life. The team can help manage any physical or emotional difficulties you have and are best involved soon after the diagnosis as part of your wider multidisciplinary care team.

With more services, you and others close to you can better manage end of life decisions and the emotional impact. A MND Association Advisor or representative from a MND Association, MND Clinic or similar in your state or territory can also help advise and connect you with support.

Depending on your needs, services could include:

- counselling or psychological support
- spiritual or religious guidance
- access to complementary therapies
- family discussion of sensitive subjects, with professional support.

Other support

At times, you may need to speak with a good listener outside of your immediate circle of support.

The MND Association in your state or territory is available to help you in any way they can. MND Associations can help with:

- accessing information, support and services through the MND Info Line
- MND education and information sessions, held throughout the year
- MND Advisors to support you and your family from the time of diagnosis
- accessing aids and equipment – such as a MND Association loan or rental service
- support coordination for those who are NDIS participants
- staying connected socially via support groups and coffee mornings
- support for carers
- educating service providers involved in your care about MND.

Membership of a MND Association offers many benefits to people living with MND, including more affordable access to MND education, information, aids and equipment and other sources of support. Others you know that don't have MND can also be members. Check with your MND Association for more information about membership.

Spirituality and religious concerns

You may find yourself thinking more about spirituality when approaching end of life. Spirituality, its link to faith, meaning, culture and related ideas, is often part of making sense of life and death.

You, and those close to you, may want spiritual guidance and support from:

- palliative care services
- hospice services
- community faith leaders
- hospital chaplains and spiritual care workers
- representatives of other beliefs (e.g. those not religious or faith based)
- social workers
- counsellors.

There is no guarantee that spiritual support will bring you resolution, or heal psychological, emotional or spiritual pain. But guidance may give you an opportunity to talk about your concerns at a detailed level and invite a wider view.

You may have religious or spiritual requirements that you want observed during or following your death. You may not want to leave the organisation of all requirements, such as a funeral service, to those close to you.

Help with the process

Talking to funeral directors will help you plan any service or ceremony held after your death, and how your wishes can be best met.

Or you can compile a list of what you would like for a funeral service (e.g. music, location of service, dress code). Making your own list might help you feel in control. You might feel better knowing that you have helped your partner and family navigate this process.

Palliative care staff can also help with spiritual or religious concerns that may impact your decisions on medical care and treatment.

Behaviour changes

Some people with MND experience changes in how they normally act and behave. Changes can include restlessness, a lack of drive, acting impulsively, eating more sweet foods, fixating on one activity or routine, or lacking empathy for others.

If you have noticed any similiar changes, there may be a variety of causes:

- the emotional impact of the diagnosis
- personality, mood and behaviour changes due to MND (called cognitive change), may affect some people
- breathing and respiratory problems, which can make it difficult to sleep well and cause fatigue
- general tiredness from the extra effort required if movement and mobility have been affected
- frustration and anger, as symptoms and disability increase
- infections, such as chest or urinary infections, which can lead to confusion
- a symptom called emotional lability, which affects some people with MND, is where you may laugh or cry at inappropriate times.

Emotional lability

If you experience emotional lability, it may leave you feeling out of control. Emotional lability can also be distressing for those close to you, who may not understand. Your responses may not match how you feel. Knowing that this is a symptom of MND may help you and those close to you. In many cases emotional lability is a temporary symptom that reduces over time. You can discuss this with your GP or a health professional with MND experience. Medication or other assistance can help.

3: Having difficult conversations

Talking about end of life care can be hard, but you can make it easier by learning about:

- how you can start conversations about end of life care
- who you're likely to meet when organising medical and other care and support
- what you can talk about
- questions you can ask
- what else might help you.

Like most people, many health professionals find end of life care difficult to discuss. But you can make difficult conversations easier with strategies and tips for how to manage them.

Talking with health professionals

It is recommended that professionals talk about end of life care when you or your family ask them to do so. Palliative care service staff are trained to talk with you about end of life care. Palliative care staff are more likely to open conversations with you about planning ahead, and death and dying.

Other members of your health and community care team may not bring up the topic unless they feel you are happy to talk about it with them.

It's okay to bring it up

You can help start conversations about end of life by:

- asking direct questions
- opening conversations, which gives professionals 'permission' to explore the topic with you.

Most health services are initially accessed through your general practitioner (GP) or specialist MND Clinic. Throughout the course of the disease you're likely to meet a number of health professionals with varying degrees of skill and understanding in working with MND.

Health professionals

Health professionals who you're likely to meet include some or all of the following:

- consultant neurologist
- specialist palliative care team members
- neurology or MND specialist nurse
- MND advisor
- MND support coordinator
- community nurse
- respiratory specialist
- gastroenterologist
- speech pathologist (SP)
- dietitian
- physiotherapist
- occupational therapist (OT)
- counsellor
- psychologist or neuro-psychologist
- pharmacist
- complementary therapist (e.g. art, music, massage therapy)
- support worker/personal care worker
- social worker
- GP.

Asking questions

It's okay to ask any question you would like answered. Try to steer conversations to things you feel comfortable with and are ready to address, or would like to consider.

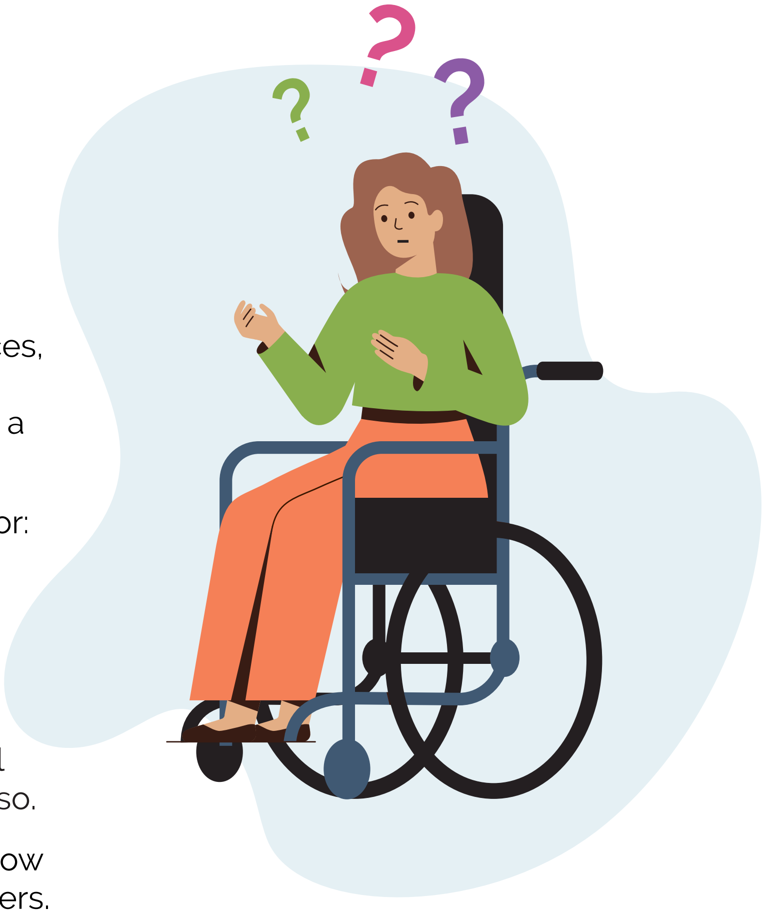
It is your right to have your preferences, wishes and needs considered, and respected. You may also like to have a family member or friend with you.

You may need to ask professionals for:

- plain, truthful responses to help make the best decisions you can
- conversations that work for you – if you feel the conversation is going too fast, or the professional becomes too abrupt, always say so.

It may take a little time to work out how best to manage questions and answers.

Preparing a list of questions, taking them to an appointment and writing down answers can help. A health professional is able to ask questions or write things down for you if communication is difficult. Keeping a record may help conversations flow and make sure you don't miss anything.



General questions you can ask:

‘I’m thinking about what I might need in the future, can you help me plan ahead?’

‘I’m frightened about something, can you help?’

‘What would you recommend to a loved one in my situation?’

Questions on treatment or other medical procedures:

‘Can this treatment be stopped at a later stage if I don’t want it anymore? How would that be managed?’

‘Will this treatment extend life?’

‘Can I ensure I’m not given treatments if I don’t wish to receive them?

‘Can I not be resuscitated, if that’s what I want?’

For matters about family and others close to you:

‘Is there anything my family and friends need to know about this treatment?’

‘How do I talk to my family about the future?’

A response may not answer your question. If you receive a response like, ‘Don’t worry, we’ll look after you,’ ask more questions to get the information or level of detail you need.

Other resources that may help

MND Australia develops and publishes a range of evidence based and best practice information for those impacted by MND.

MND Australia has been funded by the Australian Government Department of Social Services through an Information, Linkages and Capacity Building (ILC) Grant to improve access to a range of information and education resources for people living with MND, their family and friends and the health professionals and service providers involved in their care. Visit mndconnect.org.au to access the following resources:

Visit mndconnect.org.au to access the following resources:

- More Facts about MND
- Cognitive and behaviour change in MND
- Families and young people (booklet series)
- Multidisciplinary care
- Planning ahead.

Other organisations

Advance Care Planning
advancecareplanning.org.au

ALS Association
als.org

MND Association of England, Wales and Northern Ireland
mndassociation.org

Discussion starter resources

dyingtotalk.org.au

What matters to me conversation guide –health.gov.au/publications/what-matters-to-me-conversation-guide

Things to remember

Planning ahead with your medical, legal, financial, housing, family and other needs can reduce worry and improve quality of life.

Even if you find it hard to talk about end of life, try to have these conversations as early as possible. If MND affects your speech and communication, discussion may become more difficult over time.

You cannot change the diagnosis or prevent what will happen, but you can help to ensure your needs and wishes are respected.

If you do feel overwhelmed, find someone you can talk with about it. It can be a family member, a friend, a health professional, someone at your state or territory MND Association, or members at a support group meeting or online forum.

Personality, mood and behaviour changes due to MND (called cognitive change), may affect some people.

Things I'm likely to experience

Section 4:
What I can expect as MND progresses

Section 5:
How will I die?

Section 6:
Care and support available for me

Please be aware that the following pages contain sensitive information about MND and its treatment for end of life care.

4: What I can expect as MND progresses

How you walk, talk, hold onto things, eat, drink, swallow, breathe and think may become hard with MND, and may get worse over time. Each person experiences the disease differently, and the speed at which it progresses for you may not be like others, but it can be fast.

Managing MND symptoms

Some things you may need to deal with as part of managing MND as it progresses are:

- mobility and movement
- speech and communication
- swallowing and saliva
- breathing
- tiredness and low energy
- changes to personality, mood and behaviour (known as cognitive change).

Managing MND symptoms early helps you to cope better with them and have the best quality of life. You can have a greater say over managing end of life care, too.

Movement and mobility

Increasing muscle weakness is likely to affect the use of your arms, hands and your ability to grip, as well as your legs and movement and mobility.

You may find it harder to feed yourself, get yourself dressed, perform daily routines or transfer your body weight (e.g. from bed to chair).

Plan ahead

Planning ahead as soon as possible can help you deal with mobility and movement issues, as well as help you feel more prepared and in control.

It helps to talk with your care team about:

- assessments of your general and future needs, and those of your carer
- assessments by a physiotherapist and/or occupational therapist for aids and equipment, such as an appropriate wheelchair
- home adaptations (e.g. wheelchair ramps and doorway widening, shower and bathroom modifications so they're easier for you to move around in)
- home and personal care
- respite care so your carer can rest or have time away
- residential, hospital or hospice care should you develop high and complex needs that can't be managed at home (e.g. when there are safety concerns or complex symptoms to manage).

Speech

If your speech is affected, it is likely to get worse over time. Problems with speech may be due to breathing difficulties, which can reduce the volume of your voice. Your face, throat and tongue muscles may also weaken, which can change how you speak and sound.

Tools for communication

Tools to help you communicate include:

- notepad and pen, if your grip is not affected
- simple printed word or image cards
- alphabet board
- adapted ways to use your computers, tablet or phone. The devices can be used with on-screen keyboards, various mouses or switches to scan and select items you would usually use.
- software or apps that enable speech-to-text, text-to-speech or symbol-to-speech output (i.e. typing options with voice generation)
- 'Voice banking' technology
- eye gaze technology
- audio or video recordings for the future.

A speech pathologist with knowledge of MND is able to assess your needs. You may find inexpensive and simple solutions. Some tools will be more useful than others to you at different stages.

You may also wish to put advance care plans and advance decisions in place before your speech and communication get worse.

Swallowing

If you find swallowing difficult, it may lead to:

- changes in how you eat, drink and take medications
- loss of weight
- too much saliva and drooling
- more risk of food and drink entering the lungs and setting off infections
- mild choking, or in rare cases, severe choking.

What helps

Add thickeners to any liquid you drink. These are available in pharmacies. Most people find they cope better over time with soft foods (adding gravy to meat and chicken, soups, yoghurt, ice cream etc.). Eventually you may need pureed foods.

You could also:

- talk with your doctor about using prescribed medication or over-the-counter remedies to relieve thin saliva, thick saliva or a dry mouth
- talk with a speech pathologist and/or your health care team to help find solutions for managing saliva problems
- have your swallowing assessed by a speech pathologist if you are coughing and/or choking on food/fluid or medications
- have a dietitian advise on safer food and drink options for you
- ask your health care team about having a feeding tube placed into the stomach for liquid food, medications and fluids (known as a gastrostomy, PEG or RIG).

Maintaining nutrition with tube feeding

Tube feeding helps maintain nutrition, reduces potential problems with the lungs and reduces the stress and time taken to eat and receive medication.

A tube doesn't need to be used immediately. A tube can be inserted so it is ready to use when you need it. You can still eat and drink, as long as you feel safe and comfortable.

What should I think about when planning ahead?

If you want to learn more about tube feeding, talk with your doctor, a dietitian and a speech pathologist to help make the right choice for you.

Remember that:

- timing is important
- tube feeding requires a hospital procedure
- there may come a point when it's not possible for a tube to be inserted due to issues like breathing problems
- if tube feeding feels like it's no longer helping, you can stop it at any time.

When nearing the end of life, the body usually needs less food, and eating less may not feel as worrying. Others may be concerned but there is no need for them to encourage more eating in the final stages.

Water

You can continue to receive water by the tube to prevent dehydration if you wish, which may help you remain comfortable. If you have never had a tube fitted and can no longer swallow fluids, it can be helpful to keep the mouth and lips moist. Ask the professionals supporting you for advice.

For example, your team can advise you on whether mouth-swabs vs sips of water could help with keeping the mouth and lips moist.

If you have concerns about swallowing and safety, speak with your health care team about nutrition and hydration, which can also impact weight, energy and bowel functions.

Saliva changes

Some of the changes that might be hard for you to accept are changes in saliva. Fortunately, there are some simple things that can help.

Saliva changes include:

- excess saliva and drooling
- very thick saliva, like string
- very dry mouth.

You can manage saliva changes with treatments:

- excess saliva: use of prescribed medications to help dry the mouth
- thick, stringy saliva: use natural remedies that contain a substance that breaks up thick saliva, including dark grape, papaya or pineapple juice (best frozen into ice cubes then broken into ice chips to suck on)
- very dry mouth: use Aquaspray or dry mouth products from the chemist, or citrus lollies to stimulate saliva.

It's best to talk with your speech pathologist and team of health professionals about how to manage saliva and related problems.

Breathing difficulties

The muscles you use to breathe may weaken as MND progresses. Breathing may become much harder for you and lead to other problems.

Signs of problems with breathing you might notice include:

- disturbed or non-refreshing sleep
- daytime sleepiness and feeling very tired
- shallow breathing, even when at rest
- difficulty breathing when lying flat
- repeated chest infections
- a weak cough or sniff
- morning headaches
- waking up tired.

You may also experience:

- confusion, poor concentration and/or memory
- poor speech volume
- irritability and anxiety
- excessive use of muscles in the upper chest and neck – this may feel like a need to use the muscles in the chest and neck to help draw breath in.

A specialist respiratory nurse, respiratory consultant, neurologist, physiotherapist or specialist palliative care professional can advise on helping you with breathing.

Ways to breathe easier

You can make breathing easier with:

- assisted coughing techniques
- breathing exercises
- finding ways to relax
- body positioning to ease breathing
- making changes to a room's air flow and temperature
- saving your energy to make the most of the way you breathe, and
- mechanical breathing support.

You can help reduce feeling anxious from any difficulty you may have with breathing by talking to your GP or specialist about using medications to help with breathing and anxiety.

A riser/recliner chair, wheelchair, powered bed or other assistive technology could help relieve pressure on your breathing.

You can also try increasing the number of pillows you normally use, so that you don't lie flat at night.

If you find that breathing problems increase, you may need to consider:

- medical and nursing review
- mechanical breathing support
- support for weak cough
- risks with use of oxygen
- flu vaccination.

Mechanical support

Mechanical support is when a machine either supports or takes over your breathing.

There are two main forms of support you can use:

- non-invasive ventilation (NIV), where a portable "Bi-PAP machine" supports your own breathing by providing extra air through a mask over your nose, or over your nose and mouth
- invasive ventilation (tracheostomy), where a machine takes over your breathing through a tube inserted into the windpipe through the neck.

In Australia, evidence suggests that NIV is more commonly used for support.

Risk with use of oxygen

In most cases, ventilation for MND uses normal air to help you breathe. Extra oxygen is not usually recommended with MND, as it can upset the balance in your body between oxygen and carbon dioxide. However, if your oxygen levels are low or you have other underlying conditions that affect breathing, oxygen should be used with caution. Your team is best to advise on use of extra oxygen.

Weak cough

If your cough weakens, support can be given. Support might include ways to increase the amount of air you take in, with a technique called "breath stacking" and the use of lung volume recruitment bags. You may also be offered a machine or medication to assist your cough and help you clear mucus.

Flu vaccination

Chest infections can make breathing difficulties worse and increase mucus. Try to avoid contact with people with colds or flu and request a flu vaccination from your GP. A vaccination won't stop colds, but does reduce the risk of flu. The flu vaccination is usually available around early April and you need it every year. Your doctor will check if it's suitable for you. You may feel slightly unwell after the vaccine, but it won't give you flu. Ask your GP if your family can also have the vaccine to help protect you.

What should I think about when planning ahead?

- an assessment to see if non-invasive ventilation (NIV - Bi-PAP) is suitable
- breathing support reduces some of the problems with breathing, but will not stop the muscle weakness in your body from getting worse
- if there comes a time when you feel that breathing support is not helping, consider whether you'd like it withdrawn, even though it may shorten your life
- talking to your doctor about how withdrawal of mechanical ventilation would be managed and the medications they would give to help you relax
- an Advance Care Plan.

Advance Care Planning

An Advance Care Plan helps to make sure any treatments and other care represent what you want – your goals, values, beliefs and preferences.

The plan records which treatments to withdraw and precise circumstances in which you want withdrawal to take place.

A plan helps deal with decision making during emergencies and at other times if you are no longer able to communicate.

A common example is whether or not an emergency team should use invasive ventilation (tracheostomy) to revive someone who is unconscious. It can be difficult to stop using this type of ventilation once started if the person has weak breathing muscles.

In an emergency, you may or may not want certain treatments.

Remember

Advance care planning can help make sure your wishes are respected, including not receiving treatment.

Each state and territory has their own legal framework for the use of advance care plans, and they may become legally binding.

See Section 9 for more information about advance care planning.

Changes to personality, moods and behaviour

Some people with MND may have some changes to personality, moods and behaviour as part of the disease, and you may notice similar changes. Generally, the changes are mild, but if more serious, making decisions may become difficult for you.

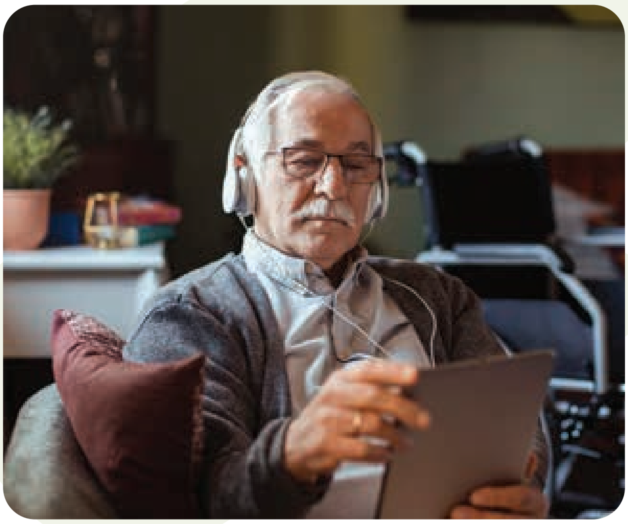
If you don't notice any changes, your carer, family or service provider may notice you having different moods and emotions.

Changes may also occur due to poor sleep, depression and your feelings about having MND.

You may also experience unexpected emotional reactions, where you find yourself laughing or crying for no particular reason. Unexpected emotions are more common if thinking and reasoning have been affected, but can still happen when simply dealing with MND. Unexpected emotional reactions are also known as emotional lability.

A small number of people develop a type of dementia called frontotemporal dementia (FTD), which is likely to involve more severe changes to reasoning and behaviour. Additional care is likely to be needed.

See Part 1 for more information.



Your neurologist and/or others in your health care team can advise on how to deal with changes to personality, moods and behaviour. You may be referred to a specialist neuropsychologist who can advise on managing the impact on you and your family.

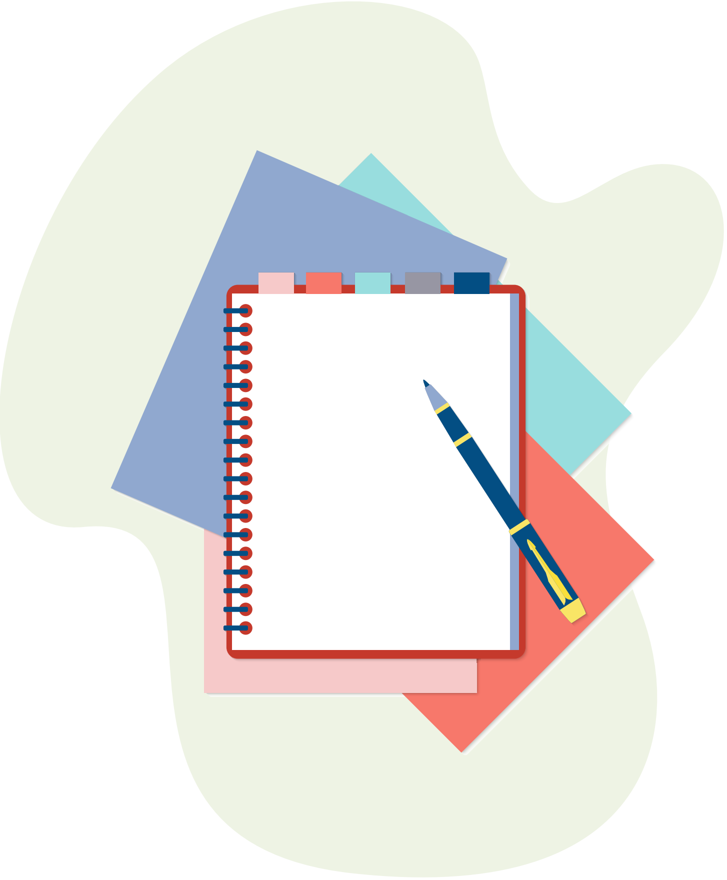
When talking with health professionals, try to make sure that you:

- have plenty of time to ask questions and record answers
- check to see if any problems are caused by things like tiredness or difficulty breathing
- ask a MND Advisor about the services available to your carer so they have time to rest
- consider whether a NDIS plan review can help in accessing additional services, if you have a plan.

You might want to explore ways of feeling calm and relaxed, including the use of medication and complementary therapies like music therapy.

What should I think about when planning ahead?

- discussing your needs, wishes and preferences as early as possible, if you feel they may become difficult to talk about
- writing down how you would like to be cared for in the future to help ensure your wishes are respected
- organising your personal affairs, such as making a will.



Other concerns you may have

Pain:

You may experience pain due to:

- stiff muscles and cramps
- immobility and weakness.

Talk to your health care team about:

- medications and physiotherapy for managing pain and discomfort
- pressure relieving mattresses and positioning your body differently to improve comfort.

Incontinence and constipation:

- you may not be able to visit the toilet easily if your mobility is severely affected
- aids such as an incontinence pad, catheter or urinary sheath may help
- try to avoid cutting down on fluid or not visiting the toilet regularly – this can lead to dehydration and constipation, and more pain and discomfort
- problems with the bowel can sometimes be managed with changes to diet, having enough fluids and in some cases medications
- your health care team is an important source of advice for pain management, incontinence and constipation
- talk to your palliative care team about managing symptoms at home, including use of the Caring at Home resources: caringathomeproject.com.au/
- see mndconnect.org.au for more information on managing symptoms.

5: How will I die?

Learning more about what may happen to you at end of life means that you can better:

- deal with worries you may have about difficulty breathing, communicating and other end of life symptoms
- understand causes of death
- know how specialist palliative care services and other professionals can help you with quality of life and help you achieve a dignified death in the place of your choosing, with your needs and wishes respected
- know who can support you and your family.

What happens

Mild or severe choking can be stressful for you and your carer at the time, but it is extremely rare for this to be a direct cause of death.

In reality, most people with MND do not die from a frightening event, but have a peaceful death.

As MND progresses, it usually causes further weakening of the breathing muscles which leads to increasing sleepiness.

These generally are the cause of death, either because of an infection (e.g. pneumonia) or because the muscles stop working.

Palliative care helps

Specialist palliative care services help you and your family deal with end of life through:

- managing the symptoms
- psychological, social, spiritual and practical support
- use of medication and pain relief
- meeting your needs as a person, and holistically, i.e. what helps you feel relaxed, able to spend time with others and enjoy your hobbies and passions.

When breathing becomes weaker, you may feel breathless and this can be distressing.

Your doctor, MND Clinic, community nurse, members of the specialist palliative care team or other health professionals can help you to manage breathlessness and anxiety.

Talk with your health care team

Try talking openly with your health care team so that you can:

- receive medication to help reduce symptoms as they become more severe, not just in the last stages of life
- know how medication will affect you
- adjust medication dosage in consultation with your health practitioner to find a level that works best for you.

If talking openly about your worries becomes hard, your carer or family can ask health professionals what is happening, so they know what to expect. Medication to manage symptoms in later stages may make you feel sleepy and not fully aware of people and events. It helps if your family are prepared for this.

Changes to breathing

Further weakening of the muscles involved in breathing will cause tiredness and increasing sleepiness.

Over a period of time, which can be hours, days or weeks, your breathing is likely to become shallower. Shallow breathing usually leads to reduced consciousness, so that death comes peacefully as breathing slowly reduces and eventually stops.

Sometimes the breathing pattern can change just before death. Previously deeper breaths become much shallower.

For people using mechanical ventilation, the palliative care team will be able to offer advice about when it might be best to discontinue its use.

Finding help

You might find talking or thinking about death difficult. Some people find the grief and sadness overwhelming.

Your GP, specialist palliative care professionals, another health care professional or MND Advisor can listen and offer you, your family and carer support and advice as you progress towards the end of life.

You can also contact the MND Info Line for emotional support and if you have any questions.

6: Care and support available for me

You may wish to die at home, or in a hospital or hospice. You can also be supported at home and then move to a hospital or hospice for the last few weeks, days or hours.

You may move to a residential aged care facility during the course of your disease. You will be cared for at end of life by the staff in the facility and supported by your GP, and if needed and available, specialist palliative care services.

End of life care

The aim of care and support at end of life is to meet the needs of you and your family in the setting of your choice.

Generally with end of life care you will continue to receive the health and home care services already in place, as well as specialist palliative care services. Your team will provide you and your loved ones with help up to, during and after death.

There are two main types of care that you are likely to use when approaching end of life:

- specialist palliative and nursing care services
- support from your existing health and home care services, MND Clinic, and MND Association.

Make sure to ask for a referral from your GP to your local palliative care team as soon as possible – it helps build a relationship with them and makes planning for your needs easier as MND progresses.

Palliative care staff will also be able to work alongside your existing health care team or MND Clinic to support a palliative approach to your care.

Specialist palliative care services may not be available in your area. You may instead be referred to a community nursing service to provide additional support as you approach end of life.

Specialist palliative and nursing care services:

- have staff with extra training and expertise to support end of life care
- aim to help you live as fully and comfortably as possible
- where possible, offer care that suits you and your family's needs, in your preferred place of care: including in your home, hospital, day hospice, residential aged care, palliative care unit, outpatient clinics and community health centres.

Remember:

No matter who you are or where you live in Australia, your MND Association team can answer questions, provide advice and tips and help you to access the right service at the right time for end of life care.

Palliative care

Palliative care staff provide you with a more focused approach to end of life care. Staff aim to consider your needs as a whole.

Palliative care includes:

- clinical care and symptom management
- nursing care and medical advice
- counselling and spiritual support
- relief from pain
- use of allied health professionals and complementary therapies
- help for people close to you
- guidance on financial support.

When or how can I be referred?

Referral to palliative care services is usually from your GP, neurologist or MND Clinic, but other health professionals can also refer. Specialist palliative and nursing care services can be provided where needed.

Depending on your progression, you may have to wait if services in your area are busy. However, the earlier you can build a relationship with a hospice or specialist palliative care service, the more benefits you are likely to receive.

Most palliative care services are free, but there may be some costs associated with hospice and hospital care.

Medicare will generally cover your palliative care costs. Private health insurance may also cover some costs. Carers may be eligible for carer payments.

See Section 8 for more information on carer payments.

Your team can help

Your GP, neurologist, MND Association and others from your health and home care team can all help with end of life care, including advice on other forms of support that may be available.

You can also talk through how those close to you could be supported or find help.

Your team can help you with:

- NDIS planning
- navigating My Aged Care
- finding access to education, advice, counselling and other support for family and carers.

Check to see what else you might need

If you're receiving support from the NDIS, check what other forms of assistance you will require as your needs change over time and with end of life care.

Additional assistance may include help with:

- transport to hospices, hospitals, allied health, respite or other sites for palliative care
- increased personal care
- assistive technology to support your comfort and communication and carer safety.

Speak with your MND Association about who may be able to support you with your NDIS plan, or setting up a plan review.

My Aged Care

My Aged Care is generally available to you if you are aged 65 or over and may be able to help with:

- transport
- meals and dietary needs
- personal care
- household chores
- personal care assistance
- allied health, including speech pathology, physiotherapy, dietitian
- respite
- counselling
- access to home care packages and residential aged care.

If you are already receiving a Home Care Package you may need to be reassessed to help you access a higher level and more support.

Your health care team and MND Association have a good understanding of what support may be best to suit the needs of those close to you, and in your local area.

COVID-19

We encourage you to talk to a doctor about COVID-19 to understand what the virus means for MND and your unique circumstances. You may have concerns about the virus and people coming into your home and protecting yourself from infection, including use of vaccines.

For more information:
National Coronavirus Helpline
1800 020 080
mndconnect.org.au

Help for others

There are a range of options available to help your family, loved ones and carers during end of life care:

- counselling
- support groups
- respite care
- advice and information about dealing with grief
- online support and information.

Your health care team and MND Association have a good understanding of what local support may best suit the needs of you and those close to you.

See Part 5: How do I get more help? for more information.

Further information

MND Australia resources

Breathing and motor neurone disease: medication and non-invasive ventilation

Breathing and motor neurone disease: what you can do to be more comfortable

Cognitive and behavioural change

Talking about MND with families and young people

Considering gastrostomy

More facts about MND

Multidisciplinary care

Planning ahead

Further information on End of Life Care from other organisations

Advance Care Planning Australia

National Palliative Care Service Directory

Palliative Care Australia

Help for carers, families and friends

Carers Australia

Carer Gateway Community Forum

Carer Gateway Counselling Service

Carer Gateway: How to get respite

CarerHelp

What my family, friends and others close to me need to know

Section 7:
Talking with family and children

Section 8:
Organising financial, legal and other personal affairs

Section 9:
Advance care planning and decisions

Section 10:
What happens after I die?

Please be aware that the following pages contain sensitive information about MND and its treatment for end of life care.

7: Talking with family and children

Talking about end of life care with your loved ones can be hard. You may not want to upset those close to you, face up to difficult changes or be worried about feeling sad. It's normal to have concerns about end of life.

Talking can help you release tension and work through emotions. Others will know what you want, which is important if it becomes hard to talk as end of life approaches and MND progresses. MND may:

- affect your ability to speak and communicate, including loss of gestures and facial expressions
- cause you extreme fatigue, which may make it difficult to concentrate
- change your thinking, reasoning, moods and emotions.

Your family can feel more relaxed knowing what you want. Putting all your financial and legal affairs in order will make it easier following your death. Those close to you may feel more supported and comfortable about sharing their feelings, too.

Starting a conversation

When you feel ready, you may want to think about how to start a conversation with your family or friends about end of life care. You might like to try talking in a way that makes you and others feel comfortable. It might help you to focus on one part of your care or your financial affairs at first. Then, consider how you could bring up the topic in a gentle way.

For example, you might like to talk about a favourite song, and how you'd like it played at your funeral. Then, see how your conversation goes. Asking questions may also give your family permission to open up about their thoughts.

After your first conversation, you may find it easier to focus on one topic, and raise other concerns another time.

It may also help for you to keep your early conversations short. Shorter conversations can help everyone feel more comfortable, without being overwhelmed.

It might also help you to try:

- setting a time when it's quiet to talk so everyone feels ready and focused
- sharing this guide first to help others and better prepare them
- concentrating on just one area at a time, such as making a will, then deal with something else
- asking a palliative care specialist to help when cultural beliefs and attitudes make it difficult to discuss end of life.

Topics you could talk about:

- your future care needs and care planning
- what to do if you need emergency care or treatment
- contingency planning (for example, what to do if your carer is unable to support you for any reason)
- options for supportive treatment and their withdrawal
- how to record your wish to refuse treatment, such as completing an Advance Decision to Refuse Treatment (ADRT) (legislation is different in each state and territory)
- putting your affairs in order
- organ and tissue donation
- what happens when you die
- funeral planning.

This guide can help you consider and talk about end of life care.

What you choose to prioritise will depend on your own views and family circumstances.

People who can help

It takes a team of people, providing the right help at the right time, to best support someone with MND and their loved ones and deal with end of life care.

You might find it helps to map out the people who may be able to support you as you approach end of life. For example:

- who already supports you and is part of your network of family and friends?
- what ways are they supporting you?

There may be others who share your interests, and who could help. You might want to consider those who:

- can entertain or look after your children
- look after pets (e.g. dog walking)
- have similar hobbies and interests
- watch movies and sports
- bake and cook meals to share
- help with organising bill payments
- do gardening and other work around the house.

Tools for communication and organising support

- What's App
- gathermycrew.org
- Hub family organiser: hubapp.com
- cozi.com
- Facebook Messenger

Your carer

Your needs will increase as MND progresses. The demands will grow for your carer and others involved in your care, too. It is important that your carer considers their own health and well-being.

There is a range of people who could be your carer, including a parent, child, sibling, neighbour or friend. Being a carer can affect your relationship, in rewarding and challenging ways. External support (paid workers who provide care for you) helps give your carer a break from stress and worry. Some rest and respite for your carer can improve their wellbeing, and make your close relationships easier and more like they were before MND.

Relationship changes

Your carer may be your partner. You might find your relationship becomes stronger as a result, but there may be changes, including:

- your roles in the relationship
- your partner having to take on more of the physical tasks around the home
- having to leave work as needs increase, if either of you are employed
- your sense of purpose
- experiencing concern about intimacy
- having less contact with some friends and social groups, meaning you rely more on your carer or those supporting you.

Your carer may sometimes try to hide their feelings to protect you and not look after their own needs enough. Hiding feelings can make it difficult to develop open communication.

"I'm as prepared as I can be, but I'll never be ready."

Talking through feelings

It can be important for you and your carer to be open with your feelings because:

- it may help you both to work better together as a team
- you can address your carer's needs and fears as well as your own
- shared understanding helps everyone to cope better as a team.

If you can, try to notice when people close to you need to share their feelings and encourage this to help with open conversations.

Your carer may find it helps to talk through any concerns with their GP or another health professional. Talking things through can help carers feel more prepared for the challenges ahead.

Carers may wish to talk things through without you, which is normal. Talking openly may be easier without the worry of causing you more distress.

Talking with children and young people

Talking about death can be even more difficult if you have children and young people in your life.

It's normal to try to protect children and young people from distress, but they notice far more than we realise. If children and young people are left without clear explanations, their own imagination may fill in the gaps. Children and young people may think that they are to blame or become isolated and frightened.

What helps

You may find it helps to:

- share your emotions with children and young people – this shows them that it's okay to release some of their own emotions
- give them the right amount of information at the right time (depending on their age, and how fast MND is progressing)
- be clear when giving information and try to avoid misunderstanding.

If possible see if you can avoid protecting children from bad news, making promises that cannot be kept or 'sugar coating' the reality of end of life.

Ways to talk

While every child and family are different, some techniques to help talk about end of life are:

- talking in a safe place with no distractions
- telling them how daily life will change
- letting the child know that it's okay for them and other family members to cry and ask questions
- giving children time to process what's going on
- being accurate and clear.

For example, a parent explaining that MND is a terminal illness and how long they may live, might say:

"Many people will live for a long time, but not everyone does. Having MND means I won't live as long as some other people, but I will be here for as long as I can with you."

Children think differently

Children think differently, and they behave and react in very different ways to adults. Children may show these differences. Children may seem as if they don't understand the enormity of what is happening to you or that they don't even care, but this is not necessarily true.

Children:

- may think and act very differently to adults
- tend to absorb information in bite-size pieces, then go back to what they were doing before the conversation started
- may need to talk repeatedly about what has happened for understanding and comfort
- ask questions about what is happening at inappropriate times.

You may feel affected by their behaviour, which is normal. It is just a child's way of dealing with what's going on.

> *"Our precious daughter was nearly seven years old when I was diagnosed, and of course one of my biggest concerns was what it would mean for her. We have tried hard to answer her questions gently and honestly, reassure her of our love and create beautiful memories. I'm so grateful for the time we've had together and proud of the gorgeous, resilient, kind, empathetic person she has become."*

How you can respond

You can change your use of words and language to help children understand. When talking about sensitive things with children, you may find it helps to use language they understand. Words that we use as adults may have a different meaning to a child.

When talking about MND with children, it can help to:

- explain that muscles aren't working properly, so that children understand why someone is changing and growing weaker
- talk about things the child will already have noticed.

For example, if your leg muscles are affected, explain how this will make it more difficult to walk. If your facial muscles have been affected, explain how it may be difficult to smile, but this does not mean you are angry.

It can help if you are as clear as possible. Call MND by its name rather than saying that a person is generally sick or unwell. Telling a child that their loved one "is not going to get better" can be hard, but they will want to understand what is happening to you and to feel included.

Be honest

Try to be honest with children. Answer any questions that a child asks you as truthfully as possible for their age and level of understanding. If you skirt around an issue it may confuse and cause anxiety for the child later on.

See if you can think about special activities to make memories for children and other loved ones. Activities might include recording videos and photos, sharing stories or writing letters. You might like to consider whether you would like to choose gifts or write cards for special future occasions.

When talking with children, it may help if you try to:

- explain what is happening as the disease progresses, so the child does not feel isolated
- allow them to say and do the things they need to as part of their own grieving
- create a memory book or box to capture moments that will provide comfort to the child in the future.

Memory book or box

A memory book or box filled with special things can help your children or other loved ones to remember times that you spent together – such as photos, letters, cards, t-shirts, toys and music.

You may also want to think about recording conversations, your history or special memories with recordmenow.org **(see Section 16).**

Children change

Children think in a more mature way as they get older and will:

- seek information on their own
- know more than you realise, but still need to talk to you
- look up information on the internet and worry, as this is not always correct or relevant
- carry a heavy responsibility as a young carer
- feel torn between home and student life.

Help from others

You may want to explore counselling and other support services for children and young people to help with difficult conversations. Encouraging young people to stay connected with their friends, hobbies and other interests in the outside world is important and helps them have a balanced life.

You can get help from others. Family members, teachers, friends and other people who are close to the child or children need to be told what is happening as soon as possible, so they can also offer support if needed. Teachers may be a great source of support, especially in the later stages. You might want to share MND information with teachers, too.

You can explore your concerns with others by:

- joining your MND Association for group meetings and informal sessions with others going through similar experiences
- speaking with a MND Advisor from your MND Association.

You may also like to visit:

- mndconnect.org.au
- hopelovescompany.org/resources

for more information for children, family and teachers.

8: Organising financial, legal and other personal affairs

Getting organised, by collecting records and documents, making a will, managing your finances and banking accounts and setting up an Advance Care Plan reinforces the finality of what lies ahead.

But getting organised helps you receive end of life care that meets your needs and wishes. You can also make sure your preferences are met after you die.

Please note: the information in this section does not represent legal advice. The information is best used as an overview of what to consider.

Records and documents

Helping others find your records and documents makes it easier for them to work on your health, financial and legal matters after you die.

Gather all important records and documents: keep these in one secure place for ease of access during your care and in the event of your death. Important records and documents include:

- birth, marriage, divorce and citizenship certificates
- bank and credit card information
- tax information
- investment details (e.g. shares, funds)
- Centrelink and Medicare details
- a list of social media and other online accounts and their passwords
- loan details and property title/lease documents
- will
- passport
- passwords
- superannuation and insurance information
- Advance Care Directive
- contact details of professionals, family and friends
- funeral information.

Make a list of all main contacts and passwords

Important contact details will be needed after your death. For example, for your bank, superannuation and insurance companies and so on. Add passwords and filenames for computer access if relevant, but make sure these notes are kept secure.

Provide written permission

Your carer will find it easier to talk to health professionals and service providers on your behalf if they have your written consent to discuss your medical records.

Your Will

Making a will

A will is a legal document that lets you leave clear instructions about what will happen to your money, property and belongings (known as your estate), in the event of your death. If you have children, you can also provide instructions in a will for appointing their guardian, their education and wellbeing.

A simple will is not usually expensive and could save your family costs in legal fees.

Dying without a will

If you die without a will (called 'dying intestate'), the law decides what happens to your estate and those close to you may not receive the share you would have wished. Laws differ between states and territories across Australia, and may impact on how your estate is distributed.

For example, you may want your estate to pass to close friends or charities, but without a will it could pass to distant relatives instead.

Can I write my own will?

You can write your own will, but this is a legal document and needs to be worded correctly to be valid. We recommend that you work with a qualified solicitor.

Working with a qualified solicitor or similar professional may be important if you:

- have complex finances, including self-managed superannuation
- need to provide for someone who is unable to make decisions (known as lacking mental capacity)
- need to provide for someone under 18 years of age
- have your own business
- have overseas finance or property
- share a property with someone who is not your husband, wife or civil partner
- have family members who may challenge your will (e.g. children from another marriage).

Public Trustees in your state or territory can also help.

What goes in your will

Your will needs to include:

- who you want to benefit (known as beneficiaries) and the specific items or amounts you want them to receive
- who gets anything else that is left
- who should benefit if the people you have named to receive items or amounts die before you do
- who you wish to appoint as guardians for any children under 18
- who is going to sort out your estate and carry out your wishes after your death, known as your executor (you can have more than one executor if required).

When making your will, you should follow standard legal requirements. Your will must be signed and dated by two witnesses to your own signature (witnesses cannot benefit from the will and must not be related to you or anyone else who benefits).

Your executor can be a relative or friend. An executor will have a legal responsibility to ensure your estate is distributed as instructed in your will. This can take a long time, particularly if property needs to be sold, so you must ask first if they are prepared to accept this task. The executor will only be able to claim direct expenses from your estate, unless you leave them items or amounts in the will.

You can update your existing will, with an official alteration, or you can change your will at any time by making a new one. The new will should state that it revokes (officially cancels) all previous wills and you should destroy your old will.

If you marry or enter a civil partnership, this makes any existing will invalid unless the will has been written to take the new relationship into account. A divorce does not invalidate a will, but following the decree absolute, a divorced partner cannot act as executor or benefit in any way. Should you wish to leave them something, you need to write a new will.

Can my will be challenged?

Your will can be challenged after you die, usually because:

- someone feels they have the right to make a claim, or a larger claim, against your estate
- someone thinks you lacked the ability to make decisions when it was written (known as mental capacity). For example, they believe that you had dementia or that medication was affecting your ability to make reasoned choices.

Laws across states and territories of Australia may differ and/or change over time. Make sure to seek legal advice about organising your will.

Financial planning

Starting financial planning early will help you to better manage end of life financial support. Planning can also help to ensure that all your financial affairs can be easily dealt with following your death.

You don't need to work through your finances alone. Getting help from a financial advisor, or a trusted friend or family member acting as your financial power of attorney, can make dealing with finances much easier.

To help with organising your superannuation, insurance and other financial matters, a professional advisor can help you understand your options, including those offering free advice:

- Money Smart Hotline (1800 007 007)
- Australian Investment and Securities Commission (ASIC)
- your MND Association
- accredited Financial Counsellor
- social worker.

Financial Power of Attorney

Appointing someone to make decisions on your behalf means that they can make financial decisions for you when the progression of MND or related problems mean you cannot participate in decision making.

A person who is appointed to make financial decisions on your behalf using a legal document is called an 'Enduring Power of Attorney (financial)'. The meaning and use of the terms, 'power of attorney' and 'enduring power of attorney' vary across Australia.

You may want to think about the person you would like to appoint and speak with them to see if they'd like to take on the role. The person should be someone you know very well and who you can trust with sensitive issues. You will trust this person with your finances, so they should understand your needs, and be able to fully act on your wishes.

You can learn more about appointing an Enduring Power of Attorney at the Australian Government – Wills and Power of Attorney.

Insurance

When managing your superannuation account, check to see if:

- it includes life insurance
- it includes total and permanent disability and income protection insurance
- you can access your superannuation funds earlier than usual
- Centrelink will provide an early release of your superannuation on ‘specified compassionate grounds’ (e.g. palliative care, funeral expenses, living expenses)
- the Australian Tax Office can also help you access your superannuation funds earlier.

Contact Centrelink, the Australian Tax Office or your financial advisor or social worker for more information.

If you have insurance, your provider will be able to advise on options that may be able to help, like the release of a lump sum to you given MND is a terminal illness.

The early release of life insurance and income protection may also be possible to help with living and funeral costs.

ASIC’s Money Smart provides information about prepaid funerals. You may be able to arrange and purchase your funeral in advance for an agreed price.

Medicare

Medicare may provide cover for:

- consultations with palliative care specialists and case conferences
- ongoing care from a multidisciplinary team, and
- other health care needs you have.

You can speak with your doctor about a Management Plan and document the Team Care Arrangements. Medicare rebates require the plans to be in place.

The Medicare general enquiries help line and your MND Association may also be able to help better understand rebates that are available and how to access them.

Financial support for carers

Financial support for carers is a critical part of their role supporting you, and could make a big and positive difference to their work.

The Australian Federal Government provides financial support to people caring for those living with MND, including: a carer allowance, carer supplement and payment schemes. The Continence Aids Payment Scheme and Essential Medical Equipment Payment Scheme may be relevant. Income tests and other eligibility criteria may apply.

Services Australia, Carers Australia, Carer Gateway and Care Search can provide you and your carer with more information.

Advice for specific issues

You might find it helps to speak with a professional financial advisor about a number of more specific and personal financial issues such as:

- access to bank accounts (e.g. use of joint accounts)
- transferring benefits to another account so others can access money for you
- making gifts to people before death
- managing debts
- daily or regular financial details (e.g. income and tax records, benefits or pensions, household or expensive items, mortgages, stocks and shares, telephone and other regular bills, trust funds)
- early retirement.

You may worry more about how your children, family or others that depend on you will cope as you approach end of life. It's important to talk through with your dependents the options for managing their needs. You can also talk about options with social workers and other health professionals, and legal representatives.

Services Australia and your local social work and community services centre and MND Association can also advise on what can help.

Guardians

If you have children, think about and try to decide on who you would like as their guardians. You may want to ask a potential guardian if they are prepared to accept this important responsibility. If a person accepts, they can be named as a guardian in your will.

A guardian could also help if the other parent is going to continue looking after your children in the event of your death - in case the other parent dies before the children reach 18 years old. Without a guardian appointed, the legal system will decide who looks after the children.

Pets

You may need to plan for pets too, if you have them. A family member or friend may be willing to take over pet care, but this needs to be discussed in advance. The Royal Society for the Prevention of Cruelty to Animals (RSPCA) and your local council can advise on what agencies may be able to help with pets and with:

- arranging care for a temporary period in case you need to go into hospital
- or finding a new home, if you feel this is needed.

Finding the best possible care for you can help

It's important to discuss how you'd like to be supported with health professionals and service providers, ask searching questions and try to find the best possible care that feels right for you. You can make others more aware of your values, needs and preferences with:

- an Advance Care Directive, which is a record of your values, life goals and preferred outcomes, or directions about care and treatments
- a Substitute Decision Maker, who tries to make the decision the person with MND would have made if they had been able to (i.e. "standing in their shoes").

You need to tell everyone involved, including close family and friends, health professionals and service providers about an Advance Care Directive or Substitute Decision-Maker. Also, make sure that an Advance Care Directive and related documents are accessible if you are admitted to hospital in an emergency or your preferences may not be met.

Other things to think about

You may also want to think about:

- whether you would like to donate your organs or tissue for transplant or research purposes
- a funeral savings plan or pre-paid funeral
- what you would like to happen at your funeral.

Relationship roles

Roles in your relationships change when dealing with a progressive illness like MND. Your partner's role may involve taking on tasks that are unfamiliar. It can help if you:

- speak with your partner about everyday activities you have always taken responsibility for, such as cooking, how appliances and the heating or cooling system work, dates for family birthdays or seasonal gardening tasks
- try to resolve any difficulties in family relationships and think about how you would like to be remembered
- talk face-to-face about how you'd like to be remembered, or try using letters, audio and video recordings, scrapbooks, memory boxes and sentimental items.

Memories

Memories are also about the time you have now. Your life will continue to change as you adjust to the progression of the disease. Many people find that it helps to spend time with an immediate circle of family and friends.

Your digital legacy

Thinking about your digital legacy can help, too. Your digital legacy refers to any online records you leave in your name – banking, photos, email accounts, Facebook and other social media.

You might want to plan how your digital legacy is managed and organised after your death, including whether:

- online access to banking or financial accounts will need cancelling or administration and how to inform the executors of your will about this
- any digital items with financial value need to be included in your will, such as ebooks you have authored
- your right to pass on anything you 'own' online depends on the terms and conditions of the organisation where it was sourced or is now stored
- any digital records that have emotional value rather than financial worth, such as photographs
- any passwords for your social media and email accounts may need to be given to someone you trust for guardianship, as the content may be comforting for family and friends.

Summary of things to consider

	Things to consider	Useful sections
Legal	Select a legal professional for assistance with legal documents, such as your will. Make a will. Keep all important documents, certificates and records in one safe place. Note where to find important documents, with a list of key contacts. Give these instructions to your carer, partner, relative or friend. If required, arrange for Power of Attorney or Enduring Power of Attorney for your chosen representative.	Section 9: Advance Care Planning and Advance Directives
Care	Provide written consent for health professionals to discuss your medical history with your carer, partner, relative or friend. Ensure you have your wishes, needs and preferences for future care recorded on an Advance Care Plan (ACP). Record any advance decisions about refusal or withdrawal of treatments on an Advance Decision to Refuse Treatment (ADRT) form. Talk through end of life planning with your health care team. Make any arrangements for organ or tissue donation, if wished.	Section 3: Difficult conversations with professionals Section 4: What I can expect as MND progresses Section 16: Other useful organisations Section 9: Advance care planning and advance decisions Section 12: Organ and tissue donation Section 15: Help from the MND Network
Dependents	Arrange care services for adult dependents, if they need support during your end of life care or after your death. Make arrangements for guardianship for children under 18 (even if you have a partner, in case both of you die before the child/children become adult).	Section 7: Talking with family and children Section 11: Inherited MND and genetic counselling

Summary of things to consider

	Things to consider	Useful sections
Financial	Consider who will help manage your bank account, credit cards or safety deposit box, if needed, and how this will be done. Find out what will happen to any outstanding mortgage on your home or to any debts that you owe when you die. Keep all financial and tax records in one safe place, including sources of income such as pensions, shares, superannuation, insurance and benefits. Note where to find important documents, with a list of key contacts. Give these instructions to your main carer, partner, relative or friend.	Section 10: What happens after I die? Section 15: Help from the MND Network Section 16: Other useful organisations
Personal	If you wish, decide how you would like to be remembered, through letters, recordings, video or keepsakes. Discuss any wishes you may have about your funeral with family and friends. Gather contact details for wider family and friends who you would like to be informed about your death. Let people know about any arrangements for organ or tissue donation, if planned.	Section 7: Talking with family and children Section 9: Advance care planning and decisions Section 10: What happens after I die? Section 12: Organ and tissue donation
General	Leave instructions about how and when to do tasks that have always been your responsibility, e.g. car services, insurance renewals or how to operate household appliances. Inform anyone who needs to help manage your digital legacy - in other words, any records, documents, resources, media or presence you have online (see earlier text in this section for details).	Section 15: Help from the MND Network Section 16: Other useful organisations

9: Advance care planning and decisions

Planning for emergencies and future medical care and support, and setting up Advance Care Directives, helps make sure you know what your choices are with end of life.

Please be aware that the following pages contain sensitive information about MND and its treatment for end of life care.

Planning for emergencies

No matter what happens with your future care, it can help for you to think about emergency situations and:

- what will happen if my carer is unable to support me for any reason?
- where can I find appropriate care and support if my carer needs a break (usually called respite care)?
- how do we access emergency treatment out of hours or when we need it?

You will need to find out about how you get out-of-hours assistance for care or where to get urgent help in an emergency. You can find out the best options by speaking with your:

- GP, neurologist and health and community care team
- local hospital or hospice
- palliative care team and NDIS or Aged Care service providers about what they can do to help you in emergency situations, and
- your MND Association.

You can store information online in a MyHealth record. Your family and trusted friends are able to access this information by making them a nominated representative. Learn more at myhealthrecord.gov.au

Keep any of your contact details for out-of-hours or emergency help where they can be easily found if needed.

Other things you can do

There are other important things you can do to help with emergency situations.

Keep your essential personal and medical information in a safe, easy to access place. Include a list with your medicines, instructions about oxygen, respiratory support, PEG, allergies, your specialists and other essential information that could help paramedics and other health professionals in an emergency. Make sure the list is stored in one spot that is easy to find, e.g. on the fridge door.

A Carer's Emergency Card can be carried by a carer to alert someone to your care, in case they are away from home and unable to support you. These cards are available from carergateway.gov.au

You may also want to make important documents easy to find. If you make advance care plans or an Advance Care Directive, keep them in place that is easily accessible for paramedics and others in an emergency (e.g. not a safe).

Advance care planning

Advance care planning can help you make sure that family, friends, carers, health professionals, service providers and others close to you know what your values, goals and preferences are for health and personal care needs.

When others understand what you want, they can make choices for you, if you cannot make decisions or communicate.

Advance care planning is also important for meeting your practical needs in daily routines (e.g. looking after pets).

Advance care planning can help you with almost every part of your care, including your preferences for:

- location of care (e.g., at home, in hospital, in residential aged care or a hospice)
- religious or spiritual beliefs that impact your care
- how specific parts of care are to be delivered (e.g., whether you prefer a bath or a shower)
- who provides care
- decisions about the type of treatment you do or do not want
- how you would prefer to be cared for in an emergency if you are unable to communicate for any reason.

A preferred place

You may have a preferred place for end of life care or death. A preferred place may be very important to you.

You may want to:

- be in a hospital or hospice
- stay at home, unless you need emergency treatment.

Talking about what you want

Whatever your choices may be, they will be respected where possible. It's important to remember though that your preferred locations cannot be guaranteed as:

- your care needs may be too complex to handle in your home or you may be admitted to hospital in an emergency
- there may not be any available beds at the time needed (e.g. in a local hospice with limited capacity)
- Advance care planning with MND can be straightforward, but it's important to try to be open, feel ready and have others listen to you.

You may need to start some hard conversations with family and close friends.

When starting advance care planning, it can help if you have a good understanding of your own beliefs, goals and preferences.

It might help to think about what would happen if:

- your family and friends found it hard to understand you because your thinking, moods and emotions were affected, or your speech was unintelligible
- you lost all independence and needed help from others to do everything
- you were no longer able to eat or drink.

You may also need to consider:

- any past experiences of health care that may influence your views on future care, that may be positive or negative, and happened to you or others
- things that you enjoy about your life, such as talking with family and friends
- what you want to do with your time as end of life approaches and time runs short
- things that are important to you to help maintain your dignity and quality of life.

Options for care at home

If you have not already done so, you may want to explore options for care at home. Paid carers can provide the help you need and reduce the pressure and stress on you, your carer, family and other loved ones (e.g. help with showering, dressing).

You may be receiving support with informal care. Informal care generally means things like help from family and friends with household chores, transport to doctors, social visits or arranging health care.

A lot of informal care is provided to someone who depends on a partner, parent, child, neighbour or friend, including people living with MND. Not everyone is aware that other options for care exist, and which might better suit their needs.

Talk with your doctor and others close to you about how paid carers may be able to help.

Your MND Association and **Sections 6, 15 and 16** can provide more information about ways to access care.

Substitute decision-maker

You may want to think about who could be a substitute decision-maker, too. The person will make medical and other important decisions on your behalf, if you are not able to do so. You might like to consider someone who:

- is close to you
- knows clearly your wishes, and whom you trust to follow those wishes and act in your best interests
- can be a strong advocate for you
- is 18 years of age or over
- is willing to take on the role
- is not a paid carer
- is not a healthcare practitioner who is responsible for your health care.

Formalising your choice

You will need to formalise your choice of substitute decision-maker with a relevant form used in your state or territory. The form must be witnessed by a person who can authorise a statutory declaration (e.g. medical or legal practitioner). Guides for a substitute decision-maker and advance care planning are available at advancecareplanning.org.au

Advance Care Directive

When you feel ready, you can speak with your family, others close to you and your doctor about what you want for medical treatment and care. You can speak with others to help:

- make sure those close to you know or understand what you want
- make it easier for others to guide your medical treatment
- reduce the worry about future care for you and those close to you.

MND can affect your speech and communication, and, in some cases, your ability to reason. You may feel anxious about the possible lack of personal control over treatments as the disease progresses. You may worry that your preferences are not followed.

Recording your preferences

Recording your preferences in an Advance Care Directive can help to make sure that they are followed.

An Advance Care Directive is a record of your:

- preferences for future care
- values and life goals
- directions about care and treatment.

An Advance Care Directive covers your decisions about the kinds of treatment you do and don't want. Decisions include the withdrawal of life-sustaining treatment and the precise circumstances in which you want this to happen.

Withdrawal of life-sustaining treatment might mean stopping something that is no longer helping or has become a burden. A natural death may follow, although not always straight away. Symptoms can be eased with medication to reduce anxiety, pain or discomfort.

A useful example is future breathing support. You may want breathing support to be withdrawn at a particular point. You would need to be specific about the circumstances for the withdrawal, so that your carer, family and health professionals know when to act, should you be unable to communicate this yourself.

Of course, you do not have to complete specific directives about whether you do, or do not, want certain kinds of treatment when making your Advance Care Directive.

Your Advance Care Directive:

- can formally appoint a substitute decision-maker
- is a legal document and must be considered by health practitioners and your substitute-decision maker
- can differ between states and territories (see more information at the end of this section)
- should be completed with your doctor.

Your Advance Care Directive only takes effect (can only be used) if you are unable to make your own decisions, whether temporarily or permanently.

Make it easy to find

You should make your Advance Care Directive easy to find and therefore easy to follow.

You can give copies of your Directive to:

- family
- carer
- GP, neurologist and other health professionals and service providers
- substitute decision-maker, and
- hospital.

You can make sure that the Directive is given to the ambulance service where you live, or is easily available to them, and others you feel are appropriate.

You can also complete the MyHealth record online so that you can upload all your advance care planning documents, and make it easier for others to find them.

You can change it at any time

You can also change your Advance Care Directive at any time if your:

- preferences for care or any part of the Directive change
- substitute decision-maker changes
- medical condition changes.

Make sure that all people with a copy of the Advance Care Directive have the most recent version of it. The most recent version of the Directive will be followed.

What is cardiopulmonary resuscitation (CPR)?

CPR is a medical procedure that combines mouth-to-mouth resuscitation and cardiac compressions. The procedure helps circulate blood so it can provide oxygen to the body, and the brain and other organs stay alive while waiting for an ambulance and medical help.

CPR is used when the heart stops beating and breathing stops.

The decision to attempt CPR is made by the clinical team in charge of your care if you suffer cardiopulmonary arrest. There may be a reason why CPR is unlikely to work depending on your condition and circumstances, in which case it may not be attempted.

Your Advance Care Directive can specify the circumstances in which CPR may or may not be used. A clinical team must involve you in any decisions about resuscitation, unless there is good reason not to. You or your substitute decision-maker cannot demand treatment.

Doctors will consider which treatments may potentially offer benefit to the person in terms of prolonging life, improving or restoring function or treating symptoms.

However, you have the right to ask for, and expect to receive, the best possible medical and nursing care to ensure your comfort and the best quality of life possible.

Communicating your wishes

If you need someone to act on your behalf, it should be in your best interests. However, all efforts should be made to help you communicate your own wishes, with the use of communication aids if required. Even if you have problems making complex decisions, you may still be able to make certain choices, such as what you want to do during the day.

An Advance Care Directive can help guide most parts of end of life care, and is legally binding, if valid and applicable. The Directive helps ensure your wishes for treatment are respected, if you become unable to make or communicate your decisions.

You can also legally appoint one or more representatives (whether a family member, friend or professional) to make financial or healthcare decisions on your behalf through an Enduring Power of Attorney.

Medical Enduring Power of Attorney

An Enduring Power of Attorney for medical treatment is a legal document where you appoint someone to make medical treatment decisions for you – such as agreeing to medication or surgery. “Enduring” means it continues (endures) when you are unable to make medical decisions for yourself.

Your new Advance Care Directive Form will replace all other documents you may have completed previously, for example an Enduring Power of Guardianship, Medical Power of Attorney or Anticipatory Direction.

Speak with a legal professional about what you need to consider when completing an Enduring Power of Attorney for medical treatment.

See Section 8: Organising financial, legal and other personal affairs or Australian Government Information and Services info.australia.gov.au

10: What happens after I die?

Letting others know what should happen after you die, making funeral arrangements, organising your estate and thinking about bereavement support for family and friends can help deal with the reality of end of life.

Your family, carer, close friends or executors of your will may also find this section helpful for dealing with things after your death.

What happens immediately after you die depends on place of death.

At home

If you die at home it is likely that your carer, and maybe members of your family and special friends, will be with you. They will be able to stay with you for as long as they like.

Your family or carer should contact your GP as soon as they feel ready, and it is practical to do so. Your GP will need to verify your death. Your family or carer will then be able to contact the funeral director who will collect your body.

In hospital or other facilities

If you die in a hospital, residential aged care facility or hospice, then staff will give your family time alone with you. Staff may be able to help with contacting the funeral director who will collect your body.

Who should be informed?

There are three main groups of people who should be informed when you die:

- family and friends
- work colleagues (if you were still employed or had been recently employed)
- relevant organisations.

You can help make this easier for those close to you by listing who should be informed, with contact details from your address book, computer or telephone.

People close to you may find it hard to tell wider family and friends that you have died. See if you can ask trusted people to assist, when the time comes, and later to help send funeral details. They may help inform relevant organisations, too.

Contacts

Health care: your GP, your MND Association, your dentist and any specialists that you may have seen on a regular basis for MND. If you die in hospital or a hospice, they may be informed through their systems.

Government and service providers: to stop any benefits, pension payments and/or care and support services that you may have received.

Financial: such as your bank, or insurance or investment companies. It is important for your executor or family to inform these contacts as soon as possible, as this can help prevent someone using your stolen identity. Once these organisations know that you have died, they will usually give your executors or relatives time to sort out your affairs, even if debts are involved.

Legal: such as your solicitor, who may be familiar with your estate. However, unless you have stated that you want your executor or family to use a preferred legal professional (perhaps where your estate is complex), they may find it worthwhile to compare costs, as legal fees can vary widely.

Service contacts: where personal and household payments may need to be cancelled or amended. For example, house insurance may need to be transferred to another name or it may no longer be valid.

Tissue and organ donation: see Section 12.

Funeral arrangements

Attending a funeral provides an opportunity for those close to you to acknowledge what has happened. A funeral can help others say goodbye and begin to adjust. A funeral is also about celebrating you and the life you lived. People are allowed to reflect on how you will still remain a part of their lives.

You may wish to leave instructions about the way you want your funeral to be arranged, such as:

- cultural requirements, where religious rites or other rituals need to be observed
- strong beliefs or views about what you would or would not want to happen at your funeral
- a wish for particular songs, memories and messages to be shared.

But you may prefer not to be involved in funeral arrangements. If you don't want a funeral, you can have a direct committal. A direct committal is when your body is immediately taken from the mortuary or place you died and cremated or buried without any service.

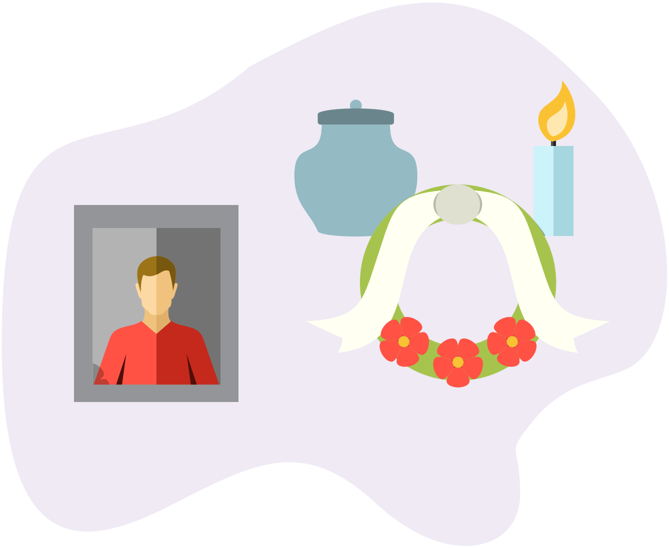
The choice is yours and this should be respected, but it can help to let those close to you know your main preferences, which may be influenced by your religion, culture or beliefs.

You may want to think about:

- if you wish to be cremated or buried (and if so, where)
- if you want a religious ceremony or not
- if you do want to provide specific instructions, you may find that your family and friends find this difficult to discuss.

Having open discussions with your family about your funeral can be very positive, so they know your wishes. Open discussions can be difficult, though. You can instruct a funeral director in advance who will help guide your family and friends when the time comes.

You can also add funeral instructions in your will. Your will can guide how your remains are to be handled and the funeral costs paid from your estate, if you choose not to prepay for the arrangements. Executors are responsible, however, for seeing that the instructions in your will are carried out, as far as is reasonably possible.



Clear details about your wishes can help

There may be a financial limitation or another reason why something cannot be carried out. Leaving clear details about your wishes may help though in relieving other people of some of the decision-making.

The Australian Government does provide some payments and support for funerals. See the end of this section for where to find more information about support for funerals.

You can hold a home funeral, have a service on a beach, in an office, at a church or just about anywhere. A funeral can also be as formal and traditional as you like.

Some common types of funerals are:

- a traditional religious ceremony according to your faith, usually conducted by a local faith leader
- a civil funeral (which may include some religious content, such as hymns and prayers), usually conducted by a civil celebrant
- a funeral with no religious content, usually conducted by a humanist celebrant.

A funeral director or specialist can help with arrangements if you'd like particular cultural or religious rites to be observed, or to look after yours and your family's wishes. Try to select a funeral director who belongs to a professional association. The Australian Funeral Directors Association (AFDA) has member firms in every state and territory.

Costs

Essential funeral costs can be charged to your estate. But if the proceeds from your estate do not meet the costs of a funeral, whoever arranges the funeral is still expected to pay the final bill.

Funerals can cost from $4,000 for a basic cremation to around $15,000 or more for a more elaborate burial. Funeral costs vary across different states and territories of Australia.

Your bank account is likely to be frozen after your death (until your estate has been sorted). Most banks will release money to cover funeral costs though, as long as there is enough in the account.

If your family needs financial help with the funeral, benefit payments may be available. Payments are available to:

- single income support recipients, pensioners
- carers, and
- members of a couple who are receiving a pension (e.g. if you're married, in a registered relationship or in a de facto relationship).

Those receiving ABSTUDY, Farm Household, Youth or Partner allowances may also be entitled to payments. Counselling and other support services are also available for dealing with grief.

Financial planning

Savings plans and pre-paid funeral plans are available, which can help reduce costs of funerals. A funeral director and the Australian government's MoneySmart and Services Australia (Death and Bereavement) can help with advice and information. See the end of this section for where to find more information.

Your family or executors should not sign any paperwork with a funeral director until they are sure they want to employ their services – otherwise they will be liable for payment.

Your estate

If you have any bank accounts, savings, property or other assets when you die, this is known as your estate. Your estate needs to be administered, which means giving items or amounts from your estate to those who are entitled (your beneficiaries). Beneficiaries are decided in your will or, in the absence of a will, by law.

A Probate is required to administer your estate. A Probate is a court order that proves your will is reliable and allows your executor or executors to administer your estate according to your will.

The administration of an estate depends on your estate and the instructions you leave in your will. Your executor or personal representative should seek legal advice if in any doubt.

Informing others

Whoever administers your estate will need to inform the people about your death and those who:

- hold any of your assets
- you may owe money to (known as creditors).

Estate administrators are required to perform budgeting and payments, such as:

- work out how much your estate is worth at the date of your death
- pay inheritance, capital gains or other tax if applicable
- apply for the grant of representation
- gather all funds and items to be distributed, including the sale of property and other assets if required (known as collecting assets)
- manage or pay any debts
- prepare a set of accounts for the estate
- complete outstanding tax returns
- distribute the estate to beneficiaries (those named in your will or, if there is no will, as decided by law).

Statutory notices

Estate administrators can also place statutory notices (usually small newspaper adverts) to inform any unknown creditors, should they need to make a claim against your estate. Ask a legal professional for more advice about notices.

Your executor or representative may want to contact the Australian Tax Office helpline with any queries, including property sales, addressing debts and other issues: 13 28 61.

Grief

Grief can involve many feelings and may sometimes feel irrational, but grief is a very personal and individual experience. There is no right or wrong way to experience grief. You may worry about how your family and friends will cope with their grief when you die, which is normal. With an incurable and life-shortening illness like MND, the grieving process usually starts before you die. This is known as 'anticipatory grief'.

Anticipatory grief may be experienced by you and your loved ones from time to time, or with each progressive loss, and can take its toll on health and wellbeing. **(see Section 2: Managing emotions)**.

Bereavement

Those close to you who grieve for you after your death are going through what's called 'bereavement'.

Bereavement can be very distressing and isolating. With bereavement and dealing with the consequences of your death, others may find the experience very tough. The progressive nature of the condition means that your carer and family probably had to provide increasing support during the course of the disease and may have experienced multiple and difficult emotions throughout that period. Services and support are available for your carer and family to help them cope with bereavement.

Counselling and support

If you feel counselling would help you or your family, ask your doctor for advice on services. Sometimes a local palliative care service can provide this type of support. Your MND Advisor can also help link you and your carer and family with professional support and peer support groups.

Thinking ahead

It's important for you and your carer to try and maintain health and wellbeing. Be sure to keep up your usual dental and other health check-ups. Mental and physical health check-ups could be useful for carers to support them with the physical and emotional challenges of their caring role.

Sometimes, a life-shortening condition can bring people closer together, providing time for reflection. It can help families to make up for past quarrels and opens up opportunities for everyone to share their feelings. Carers and those close to you may also find it helpful to talk to someone else in confidence.

The MND Info Line can provide a listening ear and guidance: 1800 777 175

Summary of tasks

The following table provides a checklist of what needs to happen following your death, when this needs to happen and who needs to do each task.

Task	When	Who
Death is confirmed or 'verified'	As soon as practicable after death. In hospital, staff may give your family time alone with you first. Should you die at home, your family or main carer should contact your doctor as soon as they feel ready to do so. They do not have to tell the doctor or anyone else, until they want to. An ambulance does not need to be called.	A doctor can verify a death. A registered nurse with relevant training can also verify a death, where this was expected. To keep this as simple as possible, the doctor should have seen you within 14 days of death, so keeping in touch with your doctor at end of life is important. The person who verifies death will usually disconnect any medical equipment.
Organ and tissue donation	It needs to happen as soon as possible after death, should circumstances allow. This may only be possible if you die in hospital.	If you have made arrangements for organ for tissue donation, those close to you need to know in advance, as well as relevant health professionals. See Section 12.
Your body is moved to a mortuary or a funeral director's premises (there may be cultural or religious requirements that influence this, particularly if you die at home or your body needs to remain at home for a period of time before the funeral).	After death is confirmed and as soon as arrangements can be made. If your death has happened at the time expected, a doctor may authorise a funeral director to move your body and visit to confirm death at the funeral director's premises.	By mortuary or funeral director staff. If at home, a member of your family will usually need to inform the funeral director. If your body is held in a hospital mortuary first, your family will be asked to appoint a funeral director and make arrangements for them to transfer your body to their chapel of rest.

Summary of tasks

Task	When	Who
Either the Medical Certificate of Cause of Death is provided, or the coroner investigates the death (depending on the circumstances).	After death has been confirmed.	A doctor gives the completed certificate to your family or representative, or arrangements are made for investigation by the coroner. Please note: other arrangements may be necessary if a coroner is involved for any reason, or an inquest is needed.
Registration of death	Registration must be done with the Births, Deaths and Marriages registry in your state or territory. If you're having a funeral, the funeral director will usually do this on your behalf.	A death certificate will be issued by the Births, Deaths and Marriages registry in your state or territory. It's important to make multiple copies of the death certificate, have it certified by a Justice of the Peace and provide a certified copy to all people and organisations that have requested it.
Arranging and holding the funeral	Usually within two weeks of death, but this may be influenced by cultural requirements or the need for investigation by the coroner (if necessary).	Family and friends may wish to make their own arrangements, but this is usually done with the assistance of a funeral director.
Informing health, government, financial, legal and service organisations	As soon as possible to avoid problems with overpayment on bills or receiving income that may need to be repaid, e.g. stopping benefits and pensions that you were receiving.	This can be done by family or friends, or executors of your will. Some of these contacts may need to be made during the administration of your estate.
Claiming funeral and bereavement benefits	The type and amount of benefits and support will depend on your individual circumstances, your relationships to those close to you and the time when Services Australia is notified of your death.	If eligible, funeral and bereavement benefits are available to single income support recipients, pensioners, carers and members of a couple who are receiving a pension (e.g. if you're married, in a registered relationship or in a de facto relationship).
Administering the estate	This usually begins after the funeral, but can take time depending on the complexity of your affairs.	Where you have a will, this will be done by your executors. Where there is no will, the law decides what happens to your estate.

Further information

Advance Care Planning Australia

Australian Centre for Grief and Bereavement

Australian Funeral Director's Association

Australian Government – Wills and Power of Attorney

Australian Tax Office – Deceased estate checklist

Carer Gateway

CarerHelp

Healthdirect

MND Associations

Money Smart

National Carer Counselling Programme

National Centre for Childhood Grief

National Palliative Care Service Directory

Palliative Care Australia – The Dying Process

Services Australia

What else might I need to consider?

Please be aware that the following pages contain sensitive information about MND and how it may impact on blood relatives.

11: Inherited MND and genetic counselling

The causes of most cases of MND are unknown, and this is referred to as ‘sporadic’ MND. But around 1 in 10 people (10%) with MND have a type of the disease that is familial (inherited).

People with a familial form of MND can pass the genetic mutations onto their children. Scientists have found the genetic fault of about 60% of these familial cases in Australian families.

Family history

If you are concerned about the possibility of a family history of MND and what this could mean for your blood relatives, you may wish to seek genetic counselling.

Genetic counselling is sensitive to the emotional aspects of the situation but it is not psychological help. A genetic counsellor will:

- explain the facts as clearly as possible
- explain the implications for your family, and
- provide options, such as genetic testing if this is a path you choose to take.

Genetic counselling and testing

You can speak with a neurologist experienced in MND about genetic counselling if you want to learn about familial MND. That way you can better manage any potential impacts on you and your family.

You may also want to learn about genetic testing. Testing for familial MND can affect the wider family and their decisions about health. Testing must be voluntary and is generally done with a blood sample. It is important to think about the reasons for testing, and speak with a neurologist or genetic counsellor about its benefits and challenges.

You can learn more about familial MND, genetic counselling and testing from:

- your neurologist
- the MND Australia fact sheet: Familial MND and Genetic Testing, or
- MND Decision Tools - Predictive Genetic Testing: mnddecisiontools.com

12: Organ and tissue donation

Many people are interested in donating parts of their body after their death to help others.

Donation for transplant

Donation for transplant means that organs or tissues are donated to directly help another individual, by transplant into the other person's body.

It may be possible for you to make an organ and tissue donation. The biggest factors to think about are where and how death occurs and the condition of your organs and tissue. Your age and medical history will be considered. However, you shouldn't assume you're too young, too old or that MND may prevent you from becoming a donor.

Tissue donations include:

- heart valves and other heart tissue
- bone
- tendons
- ligaments
- skin
- parts of the eye.

Organ donations include:

- heart
- lungs
- liver
- kidneys
- pancreas.

Tissue donation

Tissue donation is not the same as organ donation.

With tissue, the donor's death does not have to occur under the same circumstances as organ donation. For tissue donation, death does not need to occur within a hospital setting.

Unlike organs, tissue can be stored for varying periods of time. Organs such as the heart and lungs can only be stored for a short amount of time.

Eye and tissue donations can be made up to 24 hours after death, regardless of where death occurs.

Organ donation

Deceased organ donation can only happen after a person has died, usually in an intensive care unit and under strict conditions. How donation then occurs depends on whether death was due to 'brain death' (the brain stops working and this is irreversible) or 'circulatory death' (blood stops circulating through the body and this is irreversible).

Talking about your wishes

It can help for you to discuss any donation wishes you may have with your family. Donor families:

- do not have to pay any financial costs after death has been certified and donation is made
- can change their minds about donation at any point up to the time when the patient is taken to the operating room.

By joining the Australian Government's Organ Donor Register, you can find out more, and what may need to be considered with MND. Each state or territory has its own DonateLife agency with more information: donatelife.gov.au

Donations for research: various types of organ and tissue can be donated for research, but MND research tends to focus on tissue from the brain and spinal cord. People with MND can contribute by donating their brain and spinal cord tissue after their death.

In Australia, there are generally a variety of MND research studies underway at any one time. The studies need people with MND to participate. Talk with your neurologist about the best ways of getting involved.

You can also contact a MND clinic. MND Australia has a full list of MND clinics at mndconnect.org.au

Or call the MND Info Line 1800 777 175

After arranging to donate tissue for MND research, make sure that you:

- discuss your wishes with family, those close to you and relevant health professionals
- complete and sign any necessary consent forms
- tell everyone the procedure required, so that necessary arrangements happen as quickly as possible after death.

Donations to help MND research

Brain banks are organisations in Australia that care for brains and related samples donated by individuals who have had neurological disorders or issues, including MND and Parkinson's disease. 'Healthy' donations are also collected.

Brain banks help researchers to understand how brain diseases occur. The research aims to improve diagnosis, develop effective treatments, and hopefully, cures.

A brain or spinal cord tissue donation is made when someone decides to donate their brain for medical research following death. Speaking with your neurologist can help you to learn more about what you need to do to organise brain or spinal cord tissue donation. Brain donations are organised by state based brain banks. A list of state based brain banks can be found on the Brain Foundation website - brainfoundation.org.au/support-us/donate-your-brain

13: Choice and control at end of life

Towards end of life, there are valuable sources of information and support that can help if you feel distressed, and enable you to make choices about being as comfortable as possible, according to the law in your state or territory.

Palliative care professionals are specially trained to help you and your family and loved ones work through the final stages of life.

Please note: the information in this section does not represent legal advice. The information is best used as an overview of what to consider.

We recommend talking with a qualified legal representative, your neurologist and palliative care professional should you be worried about any part of control over when you die.

Choices and control

Living with MND can create fear for you about what may happen as it gets worse. You may start thinking about having control over when you die. But many people with MND find that they get better at dealing with the disease. Your views may change over time.

Sometimes, you may feel distressed and find MND hard to cope with. Negative feelings can come from the challenges and pressures of living with MND. For some, there is a fear of being a burden to others. Talking with others can help you solve or reduce many problems. You may feel calmer and consider other ways to manage the disease.

If living with MND is hard, you can try to talk with:

- a friend, family member, neurologist, GP, palliative care professional, other health care professionals in your team or someone you trust
- your MND Association Advisor
- the MND Info Line: 1800 777 175
- 24-hour helplines like:
  Beyond Blue on 1300 22 4636
  Lifeline on 13 11 14
  Men's Line on 1300 78 99 78
- a religious or spiritual leader.

There are a number of ways that you can have choices and control towards the end of life. Many ways such as advance care planning, decision making and choices for managing MND have been outlined previously in this guide. But having control also raises questions about suicide and voluntary assisted dying and what is possible in the law.

The benefits of palliative care

Speaking with a palliative care professional or other trusted health care professional can help you to answer any questions you may have about dying, what it means in law, and ways of maintaining control that work best for you.

A palliative care professional can advise on:

- how you can best use medications to remain as comfortable as possible, such as those used for pain relief and reducing anxiety
- staying close to family and ways they can find help and support
- advance care planning to make sure your needs and wishes are respected
- assistive technology to maintain your comfort and safety at end of life
- when and how mechanical breathing support or use of a feeding tube can be stopped or withdrawn
- making sure the right medical professional is available at the right time to manage your symptoms as they arise.

Laws differ across Australia

Laws for suicide and assisted dying differ between states and territories across Australia and may change over time. For more information about the law and end of life:

Department of Health

See the publication 'What do you want for your end of life care' at health.gov.au

Victoria Statewide Voluntary Assisted Dying Care Navigator Service

P (03) 8559 5823
M 0436 848 344

Advance care planning

1300 208 582
advancecareplanning.org.au

> *"When you have MND it can be really confronting to think about the future. However, I have found that where loved ones and I have been able to prepare for major transitions they have been easier to cope with."*

14: What people living with MND have said about end of life

Your experience of MND is unique to you.

But the reflections and stories from others living with MND about their fears and concerns for end of life can help make sense of what you might be going through, for you, and your family and loved ones.

MND Associations, Palliative Care Australia and other recognised organisations with Facebook and other social media accounts could be useful places to learn more from others.

Group meetings, online videos, books and other sources of information from people living with MND can also help deal with end of life.

"Every day we were a day closer to saying goodbye forever, so we made every day count."

"Thank you for putting together such a wonderful guide of what to expect, the emotional part is great as people do behave differently, so we need to be understanding, to be gentle even when it's hard."

Facebook:

- MND Associations
- Palliative Care Australia
- Carers Australia
- MND Genies

Videos:

- MND Association of England, Wales and Northern Ireland 'Palliative and End of Life Care'
- Palliative Care Australia 'Busting Myths about Palliative Care'
- The Man Who Learned to Fall, documentary

Books:

- *Lap of Honour: A No Fear Guide to Living Well with Dying*, Gaby Eirew and Dr. Pippa Hawley
- *Tuesdays with Morrie*, Mitch Albom
- *The Best of the Worst News: Tales of Inspiration from Around the World and My Life with ALS*, Norman MacIsaac

Group meetings:

Contact your MND Association to find out more about group get-togethers for people affected by MND and their carers in your region

Spotlight on MND blog:

- 'Lasting Memories' provides ideas to capture memories for your friends and family
- 'Making a Difficult Time Easier with the MND Decision Tools'
- 'MND Genies: Advocating and Raising Awareness of Familial MND'

More MND Australia resources available at mndconnect.org.au:

- Planning Ahead
- Cognitive and Behavioural Changes in MND
- Familial MND and Genetic Testing

This guide was based on information prepared by MND Association England, Wales and Northern Ireland, feedback from people living with MND in Australia and studies of what helps support end of life care for MND.

In this guide, we have tried to make it easy to find options for end of life care and help you and others feel more confident in dealing with challenges that lie ahead.

How do I get more help?

Section 15: Help from the MND Network

Section 16: Other useful organisations

15: Help from the MND Network

Sometimes, you may feel isolated, but you are not alone. The network of MND Clinics and MND Associations across Australia are a great source of trustworthy information, advice and support.

MND Associations can also help you find other sources of support in your area, including financial, home care, funeral arrangements, managing stress, translation, help for families and bereavement. You're likely to be referred to people and services who have an understanding of what it feels like to live with MND.

MND Clinics

Multidisciplinary MND Clinics or services are available across Australia to provide ongoing and coordinated MND care from a team of health care professionals experienced in MND.

Your neurologist and the team at your MND clinic or service are important for assessing and managing your MND symptoms, learning about research and latest interventions, discussing how you can be best supported, and where to find more help.

A multidisciplinary approach to your care may also be provided by your neurologist, GP and local health and palliative care team if accessing a specialist clinic is difficult.

Where to find MND clinics:
mndconnect.org.au

MND Associations

There are six MND Associations across Australia that provide individualised support to people living with motor neurone disease (MND). The associations provide a range of services that may include all or some of the following:

- information
- ongoing support and guidance
- home visits, whenever possible
- advice for navigating MyAgedCare
- help with NDIS plans
- assistance in accessing MND Clinics, local services, NDIS and aged care services
- NDIS support coordination
- provision of equipment or assistance in accessing equipment from government agencies
- information and education programs
- carer workshops and programs
- peer support sessions and support groups
- occupational therapists.

Learn more about the MND Association in your state or territory by calling the MND Info Line 1800 777 175.

MND Advisors

MND Advisors help people with MND connect to the services they need.

MND Advisors also:

- offer ongoing information and support to families, health professionals and service providers
- advise about how you can access government services and support
- support people who are eligible for the National Disability Insurance Scheme (the NDIS) and MyAgedCare.

When a MND Advisor supports you with the NDIS, they prepare you to enter the scheme, and guide you through the planning process.

Having help with NDIS planning can be a major benefit for getting access to what you need.

You can organise to speak with a MND Advisor by:

- calling the MND Info Line 1800 777 175
- or contacting your MND Association.

NDIS support coordination helps people who access the NDIS to enact their plans.

MND Coordinators of Support:

- make sure the details of an NDIS plan are put into action
- help with setting up home and community supports, funded by a NDIS plan
- can provide ongoing advocacy to the NDIS for making sure all reasonable and necessary support needs are included in a person's plan.

You can learn more about MND Coordinators of Support by:

- calling the MND Info Line 1800 777 175
- or contacting your MND Association.

Equipment loans

Equipment loans and other support in accessing assistive technology (AT) are provided by MND Associations, when and if you need it.

Tried and tested AT may be available for loan at low or no cost to a person with MND. If you have a NDIS plan, AT can be loaned or rented from the MND Association and funded through the plan.

Assistive technology available from MND Associations may include:

- electric wheelchairs
- hoists
- voice amplifiers
- shower chairs
- walkers
- beds
- raiser/recliner chairs
- computer systems and other devices for communication purposes (e.g. voice output devices) and/or controlling your environment (e.g.tablet computers).

Assistive technology

Assistive technology (AT) can help you to better manage MND as well as improve quality of life, carer safety and independence.

NDIS plans can provide funding for rental of AT from MND Associations or for the purchase of specialised items of equipment. People accessing MyAgedCare may be able to purchase low cost items through their Home Care Package (HCP) funds. As the HCP funds are capped, older people will need to access AT through state government equipment services or from their MND Association. Local palliative care services may also have AT available to people to support comfort as they approach end of life.

You can learn more about equipment loans and other support by:

- calling the MND Info Line 1800 777 175
- or contacting your MND Association

Membership

Membership of a MND Association is available at low or no cost for people with motor neurone disease. If others you know not living with MND want to join an Association, the cost is a small membership fee, renewable annually.

16: Other useful organisations

There are useful services and support available from other organisations across Australia, in addition to the MND Associations and clinics.

Government, health, non-profit and similar organisations can help with:

- disability aged, nursing and palliative care services
- tax and financial needs
- advance care planning
- support for carers
- mental health and emergency services
- funeral arrangements
- advocacy, consumer rights and community and language support.

We are not responsible for the organisations listed here or anything stated on their website or supplied as a service or product.

We keep this information updated, but the contact details may be subject to change before the next revision. If you need help locating an organisation, please call 1800 777 175.

Disability and aged care services

National Disability Insurance Scheme (NDIS)

The NDIS provides support, information and connections to services for people in their communities. Services include allied health, personal care, assistance to access day-to-day activities, work, school, hobbies, support groups as well as information about what support is provided by each state and territory government. People with a permanent disability under 65 years of age are entitled to receive reasonable and necessary supports to meet their assessed needs funded by the NDIS.

The NDIS is generally available to people with MND aged under 65 years old.

NDIS: 1800 800 110
ndis.gov.au

My Aged Care

My Aged Care is the entry point to services to help older people with everyday tasks and personal care. There is an assessment process to access the Community Home Support Program, Home Care Packages or residential aged care depending on the care and support the person needs.

My Aged Care is for people who are 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people).

My Aged Care: 1800 200 422
myagedcare.gov.au

Support for people from Aboriginal and Torres Straight Island communities

Aboriginal and Torres Strait Islander Health and Medical services are run across Australia, providing culturally appropriate health services for the Aboriginal population. Find a service:

National Aboriginal Community Controlled Health Organisation:
naccho.org.au

Australian Indigenous HealthInfoNet:
healthinfonet.ecu.edu.au

Translating and Interpreting Service (TIS)

TIS is provided by the Department of Home Affairs for people who do not speak English, and organisations communicating with them. It is available 24 hours a day, every day of the year and provides:

- immediate phone interpreting
- ATIS automated voice-prompted immediate phone interpreting
- pre-booked phone interpreting
- on-site interpreting.
- The service is the cost of a local call for anyone who needs an interpreter.

TIS National: 131 450
tisnational.gov.au

Tax and financial needs

Australian Investment and Securities Commission (ASIC)

ASIC regulates financial services and products and provides information and advice on what to do when you have a problem with your finances.

Customer contact centre: 1300 300 630
asic.gov.au

Australian Tax Office – Deceased estate checklist

The Australian Tax Office can help with managing estates, tax and financial matters relating to end of life, including providing advice and tools like the Deceased Estate Checklist.

Individual info line: 13 28 61
ato.gov.au

Money Smart

Money Smart is an Australian government program that helps people to better manage their money with free tools, tips and guidance. The program can advise you on insurance income protection and costs associated with funerals.

Money Smart Hotline: 1800 007 007
moneysmart.gov.au

Services Australia

Services Australia provides government payments and services, including Centrelink, Medicare and Child Support.

Call Centrelink to see what payments you may be eligible for, such as carer payments for palliative care or early release of superannuation on 'compassionate' grounds.

Services Australia manages Medicare payments and payments to support carers. Medicare may provide cover for the health services that help manage your medical condition. Services Australia also provides information and advice about Wills and Power of Attorney.

136 240
servicesaustralia.gov.au

Advance care planning and palliative care

Advance Care Planning Australia

Advance Care Planning Australia works to help prepare people and those supporting them to plan for future health care, and for a time when someone may no longer be able to communicate those decisions themselves.

Advice Line: 1300 208 582
advancecareplanning.org.au

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care. Palliative Care Australia represents people working towards high quality palliative care for all Australians.

02 6232 0700
palliativecare.org.au

Palliative Care Service Directory

You can search the Palliative Care Service Directory for information about services that provide specialist palliative care and general palliative care (e.g. general practices and allied health organisations and community support agencies). The Directory provides name and type of service, location, contact details and availability of after-hours support.

palliativecare.org.au/directory-of-services

End-of-Life-Care, MyAgedCare

End-of-life-care is information provided as part of the Australian government's MyAgedCare. The resource can help you learn about ways to stay comfortable during the last stages of life. The resource also helps with finding aged care providers who can help you access specialist palliative care services.

My Aged Care: 1800 200 422
myagedcare.gov.au/end-life-care

CareSearch

CareSearch palliative care knowledge network provides online access to evidence and information about palliative and end of life care for patients, families, carers and health professionals.

caresearch.com.au

CarerHelp

Carer Help provides online information and resources for carers to help with supporting loved ones at end of life.

carerhelp.com.au

Support for carers

Carer Gateway

Carer Gateway helps connect carers with with services and support across Australia, including phone counselling, other carers, skills development opportunities and coaching.

Carer Gateway Information Line
1800 422 737
carergateway.gov.au

Mental health or emergency services

Australian Centre for Grief and Bereavement

The Australian Centre for Grief and Bereavement aims to help individuals and families who need help after the death of someone close to them. The Centre is based in Victoria and provides a range of bereavement support programs for both children and adults, including face to face, telephone or counselling and support groups. There may be a cost for those accessing support from the Centre outside Victoria.

1800 642 066
grief.org.au

Bereavement counselling is also available through palliative care services

Beyond Blue

Beyond Blue provides information and support for managing stress, anxiety, depression and other mental health conditions to people across Australia.

1300 22 4636
beyondblue.org.au

KidsHelpLine

Kids Helpline is a free, confidential 24/7 online and phone counselling service for young people aged 5 to 25.

1800 55 1800
kidshelpline.com.au

Lifeline

Lifeline provides national 24 hour crisis support and suicide prevention services. Lifeline is also a source of information, tools and resources for suicide prevention.

Lifeline: 13 11 14
lifeline.org.au

MensLine Australia

MensLine Australia provides telephone and online counselling service for men to better manage emotional health and relationship concerns.

MenLine: 1300 78 99 78
mensline.org.au

ReachOut

ReachOut is an online mental health organisation for young people and their parents. ReachOut provides practical support, tools and tips to help young people deal with everyday issues and tough times, and information for parents so they can support their teenagers, too.

about.au.reachout.com

Funeral arrangements, organ and tissue donations

Australian Funeral Directors' Association

The Australian Funeral Directors Association aims to enhance and promote professional funeral standards within the funeral industry.

03 9859 9966
afda.org.au

Donate Life

The Australian government's DonateLife provides information and support about organ and tissue donation and can help you find support in your state or territory.

Donate Life Network:
donatelife.gov.au
Organ and Tissue Authority:
02 6198 9800
Services Australia:
1800 777 203

Brain Banks

The Brain Foundation provides information and contact details for the state based brain banks

brainfoundation.org.au/support-us/donate-your-brain/

Advocacy and technology agencies

Australian Consumers Communication Action Network (ACCAN)

The Australian Communications Consumer Action Network (ACCAN) is Australia's peak communications consumer organisation representing individuals, small businesses and not-for-profit groups as consumers of communications products and services. ACCAN aims to help empower consumers to make good choices about products and services, including the use of internet platforms and mobile phones.

02 9288 4000
accan.org.au

Record Me Now

A downloadable free app to leave video messages for family and children, so you can provide love and guidance after death.

E director@recordmenow.org
recordmenow.org

National Relay Service

For people who are deaf, hard of hearing and/or have a speech impairment, the National Relay Service helps to make and receive phone calls.

There are a number of relay call options (connections) that can be accessed by phone, web or teletypewriter (TTY). There may be more than one relay call option that suits you, depending on your needs and situation.

P	**1800 555 660**
TTY	**1800 555 630**
F	**1800 555 690**
SMS	**0416 001 350**
E	**helpdesk@relayservice.com.au**

MND Associations

MND New South Wales

Gladesville Hospital
Victoria Road
Gladesville NSW 2111
(Locked Bag 5005
Gladesville NSW 1675)

P 02 8877 0999
F 02 9816 2077
E admin@mndnsw.asn.au
mndnsw.asn.au

MND Queensland

1/89 Factory Road
Oxley QLD 4075
(PO Box 470
Inala QLD 4077)

P 07 3372 9004
F 07 3278 9871
E info@mndaq.org.au
mndaq.org.au

MND South Australia

66 Hughes Street
Mile End, SA, 5031
(PO Box 2087 Hilton Plaza)
Hilton SA 5033

P 08 8234 8448
F 08 8351 9524
E admin@mndsa.org.au
mndsa.org.au

MND Tasmania

PO Box 379
Sandy Bay TAS 7006

P 1800 806 632
E info@mndatas.asn.au
mndatas.asn.au

MND Victoria

265 Canterbury Road
(PO Box 23)
Canterbury Vic 3126

P 03 9830 2122
F 03 9830 2228
E info@mnd.asn.au
mnd.asn.au

MND Western Australia

1/184 Raleigh Street
Carlisle WA 6101

P 08 6186 4133
E admin@mndawa.asn.au
mndawa.asn.au

ACT and NT contact:

Locked Bag 5005
Gladesville NSW 1675

P 02 8877 0999
F 02 9816 2077
E admin@mndnsw.asn.au
mndnsw.asn.au

MND Association of New Zealand

PO Box 24-036
Royal Oak, Auckland 1345
New Zealand

P 09 624 2148
F 09 624 2148
E admin@mnda.org.nz
mnd.org.nz

Freecall MND Info Line 1800 777 175 to contact the MND Association in your state or territory

MND Associations, MND Australia and MND Research Australia

MND Australia, its research arm, MND Research Australia, and members, the MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND.

MND Australia works on:

- advocacy to improve access to quality needs based government funded supports for all people living with MND
- developing high quality and trusted information resources for all those impacted by MND
- connecting the MND community and increasing awareness and understanding of MND
- investing in the best research for bringing us closer to understanding the causes of MND, effective MND treatments, better care and a cure.

MND Australia represents members and the Australian MND community internationally as a member of the International Alliance of ALS/MND Associations

MND Australia

Unit 6, 2 Phipps Close
Deakin, ACT 2600
PO Box 117, Deakin West ACT 2600

P 02 8287 4980
E info@mndaust.asn.au
mndaustralia.org.au

facebook.com/mndaustralia
twitter.com/mndaustralia
mnd_australia on Instagram

MND Connect

MND Info Line
1800 777 175
9am to 4.30pm Monday to Friday
mndconnect.org.au

Acknowledgements

This guide was made possible by many people who shared their experiences and views on MND and end of life care. We would like to thank:

- all those living with MND and their families who have contributed to our surveys, studies and/or provided feedback
- our review group of people living with MND, carers and past-carers
- MND experts, health professionals and others who reviewed and checked guide information
- MND Associations across Australia.

MND Australia is indebted to the MND Association of England, Wales and Northern Ireland for permission to adapt their 'End of life: A guide for people with motor neurone disease'.©

Funding

The development of this resource was partly supported with funding from the Australian Government Department of Social Services. Visit dss.gov.au for more information.

Trusted information

MND Australia is recognised as a trusted source of information about MND and is an information partner of Healthdirect Australia. References for this guide can be provided on request.

Feedback

Your feedback is really important to us to help improve the way we develop information resources. If you would like to provide feedback on this guide, please email:

info@mndaustralia.org.au

Or write to MND Australia at
PO Box 117, Deakin West ACT 2600

Disclaimer

The content of this guide is for information purposes only. The content was reviewed to support its accuracy by appropriately qualified and experienced people. 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 booklet or incorporated into it by reference.

The information in this booklet is provided on the basis that all people accessing this resource undertake responsibility for assessing the relevance and accuracy of its content for their own purposes. 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 condition of the patient.

Index

t: 02 8287 4980 | e: info@mndaustralia.org.au | w: mndaustralia.org.au