



Understanding **MOTOR NEURONE DISEASE**

A guide for newly diagnosed people and their families





The Motor Neurone Disease New Zealand Charitable Trust (MND New Zealand) is a small not-for-profit organisation. Our main purpose is to ensure that people living with MND have the **best quality of life** possible.

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Disclaimer

This booklet provides information only. Content should not be taken as a recommendation for any individual, or as an endorsement by MND New Zealand. We strongly advise you to discuss options with those who know you best before making any changes to your routines.

How we can support you

Welcome to New Zealand's MND community. It may be the 'worst club in the world' to join, but it is filled with determined, kind and helpful people. Our services will wrap around you and your family as you come to terms with the diagnosis.

Our MND Support Service

A **Support Advisor** can provide free, direct, personal support to you by phone, email, text, video call and occasional visits. We will be there as you navigate challenges and identify services you need. We have experience supporting many others living with MND, we share reliable information, and we help you connect to local services when the need arises.

With your permission we can liaise with the services involved with your care to help them anticipate and provide for your needs.

Our website

At **www.mnd.org.nz** you'll find reliable information along with helpful links and research updates.

Our newsletter

We produce a newsletter, **MND News**, to inform and connect us. Subscribe at **<https://mnd.org.nz/about-us/our-newsletters>**.

Our Facebook page

At **www.facebook.com/mndanz** you can join our active page to keep informed, supported and connected day by day.

Our Instagram page

At **www.instagram.com/mnd_nz** you can follow our page dedicated to MND stories from people in our community.

Our Walk 2 D'Feet MND

Our annual **Walk 2 D'Feet MND** events are held in towns and cities all over New Zealand every summer. The walks show families affected by MND they aren't alone and create hope for others.

Our regional groups

Some regions have local MND community groups that meet up occasionally. Ask your Support Advisor if there is one near you.

“**MND is extremely scary and confusing. You need professional support as early as possible to get all your choices in order. It helps to have these difficult conversations early, so you can get on with enjoying life.**

“**Simply knowing that MND New Zealand can help us when we need them is hugely reassuring. We are very grateful for their support workers.**”

– Kevin Manning (MND client)



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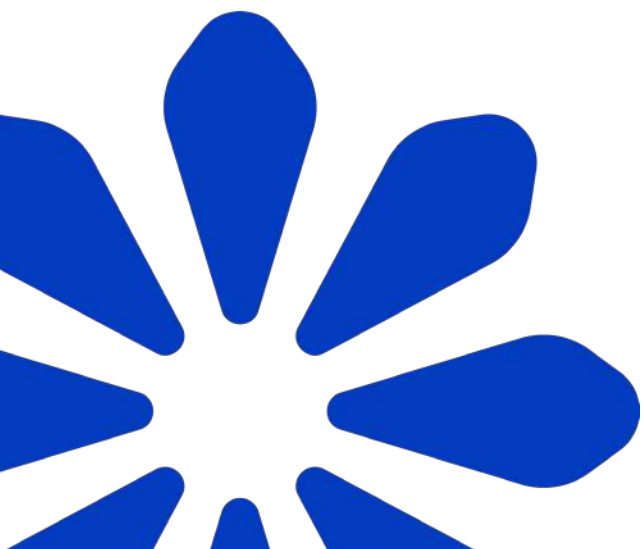
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**“It’s really important to stress this
– there is life after diagnosis.”**

**“One of the ways I have navigated
my way through the year and
dealing with the MND is by setting
short term goals and focus on the
good things and good times that
were coming.”**

– David Seymour (MND client)



Introduction

Most people reading this booklet will have experienced a recent diagnosis of motor neurone disease (MND) for themselves, a relative or friend. We understand the challenge and confusion experienced at this time and we hope this booklet answers some initial questions.

The information in this booklet is general and details will not apply to everyone.

Coping with the implications of the diagnosis is most likely your biggest challenge at this moment. Adjusting psychologically and emotionally takes time. We each have different needs as we go through this process. Most people need time, some need information, some need activity and distraction, some need to talk, some need to ignore until they are ready.

Telling others may be difficult. Some people share their diagnosis immediately with family and friends, others prefer to wait. Telling others can be more challenging than dealing with your own responses, so you may want some support. For guidance about how to approach conversations about MND with children, please see 'Information for Children' at <https://mnd.org.nz/about-mnd/newly-diagnosed/>

Confusion and grief are a natural part of this process, and identifying a support network may help. It can help to speak with a counsellor.

While no cure has been identified for MND as yet, **connecting to appropriate services early has been proven to make a significant difference to quality of life.**

Your individual symptoms and needs will vary, as will options for care and management, so keep in close contact with local specialists and service providers who know you best.

If you are reading this as a health professional or service provider working to provide care to people living with MND, we can also support you with information and networking to achieve co-ordination of care across the multidisciplinary team.



We didn't see the support worker until a few months after Edward's diagnosis. It took a few months for it to sink in – I think we were both in denial. Now, I find that it is good to have someone to talk to who understands what you are going through.

For anyone newly diagnosed with MND, I would say to just pace yourself, and take things a day at a time. Ask questions when you feel ready.

– Kay Raynor (wife of MND client)

What is Motor Neurone Disease?

Motor neurone disease (MND) is the name given to a group of diseases in which the nerve cells (neurons) controlling muscle movement progressively deteriorate and die.

With no nerves to activate them, muscles gradually weaken and waste away, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing.

Initial symptoms, rate and pattern of progression, and survival time after diagnosis vary significantly from person to person.

The term motor neurone disease (MND) covers several sub-types with similar characteristics (see page 8).

ALS (amyotrophic lateral sclerosis) is the most common sub-type of MND. MND is known as ALS in some countries.

MND occurs at similar rates across all cultures around the world. We expect over 300 people to be living with MND in New Zealand at any one time. MND is most common in 50 to 70-year-olds, with more men diagnosed than women. However it may be diagnosed in adults at any age.

Movement (motor function) is controlled by messages that travel from the brain via the upper motor neurones (UMN) descending through the spinal cord. The message is then conveyed via the lower motor neurones (LMN) from the spinal cord to directly activate muscles.

References to 'upper' and 'lower' in this context are related to the nerve system, NOT upper and lower limbs.

As nerves along this pathway degenerate, there is no message conveyed to activate muscles, so they gradually weaken and waste.

What are the symptoms?

Symptoms vary between individuals. Common symptoms can indicate a range of other conditions that need to be eliminated before a diagnosis of MND is considered.

Initial symptoms, rate and pattern of progression and survival time after diagnosis vary significantly from person to person.

Early symptoms are mild and may include:

- Stumbling due to weakness of the leg muscles
- Dropping or difficulty holding objects due to weakness of the hand muscles
- Hoarse voice or slurred speech particularly when tired
- Swallowing difficulties due to weakness of the tongue and throat muscles.
- Emotional responses triggered easily – laughing or crying more than previously
- Muscle cramps, weakness
- Muscle twitching (fasciculation)
- Fatigue
- Intellect is unaffected for many, but subtle cognitive and behaviour changes can occur. Family and friends may notice changes in thinking, attitude, problem solving, language, behaviour and personality.

A very small proportion of people show the more significant cognitive changes associated frontotemporal dementia (FTD).

What remains unaffected by MND?

For most people with MND the following are **not** directly affected:

- Senses of sight, hearing, taste, smell and touch.
- Bladder and bowel are not directly involved in nerve degeneration. However, toileting and bladder and bowel control can be affected by muscle weakness and general mobility issues. Constipation can occur when people become less mobile, change their diet or reduce liquid intake due to swallowing difficulties and as a result of certain medications.
- Sexual function. MND does not directly impair sexual functioning but for some people medications, immobility, respiratory problems, fatigue, and body image factors may have an impact.

How is MND diagnosed?

Diagnosing motor neurone disease can be clinically challenging and may take months or even years if symptoms evolve slowly.

A general practitioner (GP) may refer to various specialists in the early stages to address presenting symptoms. Over time they may come to suspect a neurological problem and refer to a neurologist. It may then be necessary for the neurologist to review an individual several times before the diagnosis becomes clear. Several other neurological conditions resemble MND, especially in the early stages, and need careful exclusion.

Various tests may be necessary to eliminate other conditions and to identify nerve problems:

- Nerve Conduction Studies (NCS) involves electrodes on the skin to stimulate the nerve and identify damage.
- Electromyography (EMG) consists of inserting electrodes into a muscle to measure their electrical activity.

What are the different types of MND?

Motor neurone disease is classified into four main sub-types depending on the pattern of motor neurone involvement and the part of the body where symptoms begin.

The neurologist will test for signs that show whether UMN¹ or LMN² pathways are involved. This may help determine which type of MND is present.

At diagnosis the neurologist may be unable to provide a definitive sub-type, but this may become clear over time.

As symptoms evolve and progress the classification may be adjusted. You may only ever be given a generic diagnosis of motor neurone disease.

Amyotrophic Lateral Sclerosis (ALS)

Both UMN¹ and LMN² are affected

ALS is the most common type of MND, characterised by muscle weakness and stiffness, over-active reflexes and, in some cases, rapidly

¹UMN – upper motor neurones are the nerves that run from the brain to the spinal cord.

²LMN – lower motor neurones are the nerves that run from the spinal column to the muscle.

changing emotions. Initial symptoms are limb weakness and the muscles of speech, swallowing and breathing are usually affected to some degree later.

ALS is used as the generic term for MND in some parts of the world.

Progressive Bulbar Palsy (PBP)

Both UMN and LMN are affected

Early symptoms present in the muscles of speech and swallowing. Limb muscles may become affected, with weakness and wasting to some extent over time.

Progressive Muscular Atrophy (PMA)

LMN signs initially but may subsequently develop UMN signs (diagnosis then changes to ALS)

PMA can be the hardest form of MND to diagnose accurately. It has a slower rate of progression and significantly longer survival compared to ALS and PBP.

Early symptoms can occur in the arms (flail arm type) or the legs (flail leg type). Muscle wasting and weakness, absent reflexes, loss of weight and muscle twitching are common.

Primary Lateral Sclerosis (PLS)

UMN only affected

PLS is very rare and diagnosis is often provisional until progression can be tracked.

MND with Frontotemporal Dementia (MND/FTD)

A very small proportion of people show significant cognitive changes. Symptoms of cognitive change often precede any physical symptoms, sometimes by many years.

¹UMN – upper motor neurones are the nerves that run from the brain to the spinal cord.

²LMN – lower motor neurones are the nerves that run from the spinal column to the muscle.

What about the research?

Research is ongoing, with worldwide collaboration and drug trials aimed at slowing down the progression of the disease.

Research is increasingly encouraging and there is a realistic hope for prevention of the development of MND in future. Scientists have in recent years become increasingly excited by the progress in understanding MND and remain very positive that significant progress will be made in the next two decades.

MND New Zealand fosters and encourages research into all aspects of MND, its causes, treatment, management and its impact on those affected by it. Visit **mnd.org.nz** for the latest updates.

In 2017, we created a national MND Registry, a database of people with MND in New Zealand specifically for research purposes. You can join by downloading the forms from **<https://mnd.org.nz/research/take-part-in-research/mnd-registry/>**

What causes MND?

In most cases, MND occurs in an individual with no known family history. Most cases of MND are sporadic, meaning they occur in an individual without any clearly identifiable causes or family history.

There are many theories about the potential causes of MND. These include:

- exposure to environmental toxins and chemicals
- infection by viral agents
- immune mediated damage
- premature ageing of motor neurones
- loss of growth factors required to maintain motor neurone survival
- genetic susceptibility

Increasingly the thinking is that several factors contribute to MND developing in any one individual.

Is MND hereditary?

In a small amount of cases (5–10%) there is known family history of MND or frontotemporal dementia (FTD), which can be genetically connected to MND.

Mistakes in the code of some genes have been linked to the development of MND.

Research continues into understanding how these genetic mistakes cause damage to motor neurones and what might be done to stop that.

Genetic tests exist for four of the genes that have been identified. If members of your family have had a form of MND or FTD, you might ask your specialist if a referral to the Genetic Health Service is appropriate. Genetic testing has implications and is not suitable for everyone. For more information see:

- 'Inherited MND' at mnd.org.nz/research/what-causes-mnd
- www.genetichealthservice.org.nz

Is MND contagious?

MND is not infectious. You cannot 'catch' it. There is no evidence that MND is transmittable from person to person.

Is there a cure for MND?

Research is ongoing worldwide with encouraging reports of new findings – but as yet there is no proven cure.

Riluzole (sold as Rilutek™) is the only drug available in New Zealand that is proven to slow the progression of symptoms in some people.

Riluzole is funded for people with MND who fit certain criteria and needs to be prescribed by a specialist, usually a neurologist.

Riluzole in trials has prolonged median survival by two to three months. Research indicates that people who start taking Riluzole early in their disease progression are more likely to remain in the milder stages of the disease for longer (Miller, 2012) **but it is not suitable for everyone.**

In May 2017, the US Food and Drug Administration announced its approval of the drug Edaravone (sold as Radicava™ and Radicut™) for the treatment of MND.

The evidence for this medication is so far fairly modest. It is not available on prescription in New Zealand, and the manufacturer does not currently (February 2018) plan to seek approval of Edaravone here.

Some ALS clinics in the United States of America are undertaking their own reviews and research as more patients are treated with Edaravone. MND New Zealand will continue to monitor the situation in the U.S.A and other countries.

Alternative therapies.

Many people with MND find treatment with complementary therapies helpful. Treatments such as aromatherapy, therapeutic massage, Indian head massage, reiki or reflexology may assist with stress management, pain relief, muscle cramps or relaxation.

Complementary therapies will complement existing medical care and should not be seen as a replacement to current prescribed medication.

Costly and unproven treatments are sometimes recommended by well-meaning people. Professional advice should be sought before embarking on unproven therapies.

It is important to discuss the likely benefits of unproven therapy, including the risk of side effects and costs involved.

The specialists involved with your care and reputable internet resources may be able provide background information.

Using the internet

The internet can be a valuable source of health information. However health information on websites should not take the place of discussions with health providers familiar with your individual needs.

Management of MND symptoms cannot be generalised across all sub-types or across individuals. There are many factors to be considered in relation to your personal best management.

Claims of cures come from various sources and should always be viewed with extreme caution and checked against reputable advice.

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

Always check the background to any information source, confirm facts and claims through more than one reputable source, and discuss with the specialists involved with your care.

See the back of this booklet for some website suggestions.

What help is available?

Everyone with MND experiences their own unique combination of symptoms and will benefit from different combinations of care.

A range of services, equipment and support are available to address many of the effects of MND. The aim is to help you remain as independent as possible so that your quality of life and control is maintained. You may not need all services listed below.

Our team of Support Advisors are experienced in making sure our MND clients have access to the right services at the right time.

Please contact your MND Support Advisor if you feel you have needs that are not being covered.

MND care and management

A variety of health professionals may become involved in your care. Some will become involved with you more than others.

Professionals providing your care may be from the same organisation or from a range of organisations.

Research indicates that co-ordination of services (through regular communication, liaison, and networking) contributes significantly to improving quality of life of people with MND.

This extended team is often referred to as the

multi-disciplinary team (MDT) or the primary health care team. It will include some of the following:

The General Practitioner

The general practitioner (GP) is usually the first contact for a person with MND. GPs recognise symptoms which indicate the need for referral to a neurologist. The GP will then liaise with the neurologist, other specialists and allied health care providers and make referrals as necessary.

The Neurologist

The neurologist assesses and diagnoses MND, and excludes other conditions.

The neurologist will monitor the progress of the disease, refer to appropriate services and review you at intervals.

The Occupational Therapist

An occupational therapist (OT) helps to maintain mobility, function and independence. OTs can advise on different ways of performing tasks and identify appropriate equipment. Large equipment (walking frames, wheelchairs etc) is government funded. Occupational therapists can visit private homes to advise on housing needs (e.g. ramps, bathroom modifications) and will be aware of what government funding is available.

The Physiotherapist

A physiotherapist helps maintain physical activity and mobility. Physiotherapists can instruct carers in the techniques of positioning and transfer to avoid injury to themselves or the person with MND. Ask for referral to a physiotherapist to learn strategies to help with respiratory difficulties and coughing to clear mucus.

The Speech-Language Therapist

The speech-language therapist helps in the management of communication and swallowing. They can advise on strategies and devices to maintain communication, and can help you manage your eating, drinking and taking medications if your swallowing skills change. They may suggest modifying the texture

of meals to make them easier to swallow, and alternative options if swallowing deteriorates.

The Dietitian

A dietitian provides dietary advice to help you maintain adequate nutrition and hydration, at all stages of the disease.

The Respiratory Specialist and Gastroenterologist

Some people will benefit from a referral to specialists involved with respiratory and nutrition issues for assessment and advice on interventions that might help.

The District Nurse

A community or district nurse can provide a range of nursing and ancillary services to people in their own homes. Services are usually obtained by referral from a health professional such as a GP.

The Social Worker

A social worker can provide advice on financial matters, benefits available through WINZ, legal and accommodation options in the local community.

The Counsellor

Psychologists and accredited counsellors provide support around the psychological and emotional aspects of living with MND. Sessions for the person with MND and their family members may be available through the GP or local Hospice in addition to private service providers.

The Palliative Care Team and Hospice Services

The palliative care team specialises in supporting quality of life for people with life-limiting conditions. The team is often based at a local hospice and may include medical specialists, nurses, social workers and counsellors. They can help with emotional support, advance care planning, and advise about medications. Community teams support people to remain at home. Some local Hospices also offer in-patient respite beds for short term

stays.

MND Clinic

Co-ordination of care is recognised as a significant factor that improves quality of life with MND. Across New Zealand this co-ordination is achieved in different ways. Areas with higher populations may offer specialist MND clinics, MND Nurse Specialists or Co-ordinators. Smaller communities will look to a local physician and community health team to work together to co-ordinate care. Local networks of service providers liaise with each other to support best practice. Our regional MND Support Advisors liaise with the local network and can represent your needs.

Ministry of Health services are available through local DHBs, both hospital based and in the community. Your GP/Specialist can refer you to the services you need.

Financial help

Needs Assessment and Service Co-ordination (NASC) Agencies

Some government funded support is available to enable people with limited mobility to live at home. Help with personal care and some household tasks can be arranged following a visit from a NASC needs assessor. A referral to a NASC provider can be made by your GP or another member of the team involved with your care.

Once your needs have been identified and funding approved, carers are usually employed by local agencies. You may be eligible for an Individualised Funding option which means you may manage your own fund and employ carers directly.

Work and Income New Zealand (WINZ)

WINZ advise on entitlements to financial support as individual circumstances vary. Ask your GP/Specialist to refer you to a social worker to support you with this process.

www.workandincome.govt.nz

Life Insurance

Some policies allow for early pay-out following confirmation of an MND diagnosis by a doctor. Check with your insurer.

Equipment

Equipment is provided through the Ministry of Health Equipment and Modification Services (EMS). A local occupational therapist will advise what is available and help you access this through either Enable (www.enable.co.nz) or Accessable (www.accessable.co.nz).

Orthotics services are available around the country to construct and fit braces and splints that provide support and increase mobility in the presence of weak muscles.

Mobility services provide specialised assessment and advice on manual and electric wheelchairs to suit individual needs. An approved range of chairs is government funded.

Talklink (www.talklink.org.nz) is a non-profit agency that provides assessment, information and advice on technology options to support communication. They can arrange assistive communication technology such as iPads with appropriate software, and advise on government funding available. Ask to be referred to Talklink early you are interested in voice banking.

Support for carers.

Most people with MND remain living at home with the support of family, friends, service providers and the local community. The needs of the primary carers must be remembered to sustain this.

Good outcomes for carers occur when:

- the carer is able to cope with their caring role
- the carer gets a regular break from caring
- the carer is informed and knowledgeable about their caring role and the needs of the person they care for
- the carer feels valued, supported and listened to

You may not recognise yourself as a carer. Perhaps you say, "I'm just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a good neighbour".

However it is important to identify yourself as a carer and seek help in the form of informal sharing, information, counselling, financial entitlements, respite and perhaps medications to help cope with the challenges.

The focus naturally gravitates to the person with MND but we encourage those involved with their support to get the support they need for themselves.

Talk with your GP, any of the service providers involved or contact a MND Support Advisor, as there may be services or support groups in your local area that might suit your needs.

An informative booklet, *A Guide for Carers*, is available from the Ministry of Social Development (www.msd.govt.nz). See mnd.org.nz/for-carers for more information and resources.

Managing symptoms.

Mobility

Most people with MND will develop mobility problems to some degree. Symptoms vary across MND sub-types.

Not all will need a wheelchair and some will continue to be able to walk with care. Falling is a risk for many as muscles weaken and balance is affected.

Occupational therapists (OT) and physiotherapists (PT) are available through your local hospital to advise you on how to remain as mobile and independent as possible.

A physiotherapist can advise on what activities you can do to maintain mobility and comfort. Exercise is good to whatever level is safe and enjoyable; it cannot reverse the nerve damage but maintains mobility and quality of life as long as it does not result in excessive fatigue.

An occupational therapist can suggest changes to improve access around your home and they know what equipment/aids will improve mobility and safety. They can also advise which equipment is government funded.

Wheelchair therapists are specialists in arranging appropriate seating solutions to suit individuals with reduced mobility.

Equipment and housing modifications

Much of the equipment available to support your independence and daily living activities is provided at no cost to you through the Ministry

of Health Equipment and Modification Services (EMS). Your occupational therapist can access this through Enable (www.enable.co.nz) or Accessable (www.accessable.co.nz).

Less expensive aids to make life easier, such as modified cutlery, need to be self-funded.

Information on what aids are available can be found at local disability information centres and websites such as the Independent Living Service website (www.ilsnz.org).

Depending on the nature of your accommodation, housing modifications may be needed (to maintain access, use of the bathroom etc). An occupational therapist can offer suggestions and will know what funding might be available.

Fatigue

Fatigue is common in people living with MND. For many this is related to the extra effort required to move, support the body and maintain balance. Some people experience a level of fatigue beyond this.

Fatigue may indicate depression and/or respiratory issues. It should be discussed with your specialist as help may be available to improve your quality of life.

What might help

- Identify factors that make fatigue worse and plan activities accordingly – don't do too much.
- Plan to do activities when you are at your best and schedule regular rest periods.
- Do not exercise to the point of excessive fatigue, cramps, or muscular weakness.
- Follow advice, use aids and equipment that can make tasks easier.
- Take shortcuts where possible, sit rather than stand, use the wheelchair to save energy.
- Try to establish a good sleep routine and talk with your doctor if this is a problem – medication might help

Speech and communication

Difficulties with communication can lead to feelings of isolation, vulnerability, loss of control and frustration. Ask for help early and choose to keep communication flowing one way or another.

Some people notice changes in voice and speech as their initial symptoms and may progress to significant difficulties. Others experience less involvement of these muscles.

Muscle weakness in the face, mouth, throat and chest can result in difficulties such as slurred speech, difficulty producing certain sounds and/or a hoarse or a weak voice.

A speech-language therapist (SLT) is available through your local DHB to assess and advise on how to keep communicating at your best.

What might help

- Slow down, take regular pauses and fresh breaths.
- Get your audience's attention before you start and ask people to give you enough time to finish.
- Use more natural gestures and facial expression to illustrate your message.
- Spell a key word out loud or write it with your finger on the table or in the air.
- Use pen and paper or a small whiteboard.
- Simplify your sentences when people are not understanding, give them a key word to get the idea.
- If significant communication difficulties develop then options exist using assistive technology. You can be referred to Talklink (see page 19).

Swallowing problems

The muscles involved with voice and speech production are also involved in eating, chewing and swallowing.

Early symptoms of MND may be difficulty moving food to move to the back of the mouth, getting

food stuck in cheeks, or noticing drinks trigger coughing episodes. Some may notice saliva and even strong smells set off a coughing episode, and your gag reflex may become more sensitive than usual. Many people notice this sensitive gag reduces over time. Some may have difficulty managing their saliva or feel mucus builds up in your throat and can't be cleared.

Speech-language therapists (SLT) and dietitians (DT) are available through your local DHB and are experienced with disorders of eating and swallowing. Together they can assess and advise you on how to continue to eat and drink comfortably and maintain good nutrition and hydration if you are noticing changes in this area.

What might help

- Foods that are smooth, moist and free from lumps are usually easier to swallow.
- Avoid mixed textures such as soup with vegetable pieces.
- Stronger flavours and hot or cold foods may be easier than bland, warm foods.
- Thicker fluids such as nectars and milk based drinks and fizzy drinks may be easier.
- Small mouthfuls of food and drink per swallow are often easier to manage and less likely to trigger coughing.
- Sit as straight as possible looking forward with head upright; avoid tilting the head back.
- Concentrate on swallowing and avoiding talking, laughing at the same time as eating.
- Allow more time to eat and drink. Do not try to keep pace with others during meals.
- Consider eating before going to a social event so you can just 'graze' when in company.
- If swallowing becomes too tiring or too difficult and you are struggling to take sufficient food and fluids orally then a gastrostomy might be suggested to you.

Gastrostomy (PEG or RIG)

This is a surgical procedure completed under a light anaesthetic and involves a tube being inserted through the abdominal wall into the stomach.

There are two types of gastrostomy available depending on the method used: a percutaneous endoscopic gastrostomy (PEG) and a radiologically inserted gastrostomy (RIG). Inserting the tube is a straightforward process under sedation and after a few weeks the body adapts to the changes.

A complete liquid nutrition, such as Ensure or Fortisip, goes through the tube into the stomach either manually several times a day or slowly overnight using a small pump machine. **Eating and drinking by mouth can continue alongside the use of a gastrostomy tube.**

Alternative feeding methods are not necessary or suitable for everyone and your specialists can advise on your individual circumstances.

Respiratory function needs to be adequate for this procedure to be carried out, so the correct timing of this procedure is important. If you are considering such a procedure ask for more details from the specialists involved with your care and the following website might help your understanding: mytube.mymnd.org.uk

Sensitive throats and spasm

Some people with MND experience a sensitive throat and/or a hyperactive gag reflex.

Coughing and throat spasms might be triggered easily, even just by saliva.

This can feel like choking and can be frightening, but as long as there is nothing blocking your airway the feeling will pass if you are able to relax and wait. Breathing will continue adequately during these episode.

If these episodes happen frequently and are distressing, ask your GP/specialist about medications that may help.

Choking related to total airway obstruction is NOT a common occurrence in people with MND when care is taken.

Be sure to follow advice from a speech-language therapist and/or dietitian regarding safe swallowing techniques and modified

textures, to reduce the chance of food and drink 'going down the wrong way'.

We are all at risk of airway obstruction if food or any small item is inhaled. You may want to ask your GP to remind you of what to do should this occur, or view the information available on the St John website: www.stjohn.org.nz

Saliva and mucus

Some people experience problems with saliva and mucus. If lip muscles become weaker and reflexive swallowing becomes less efficient, watery saliva may escape from the mouth.

Others experience thicker secretions in the throat that can be difficult to clear.

What might help

- If excessive saliva or mucus is a problem ask your speech-language therapist for suggestions for controlling it.
- Ask your physiotherapist to teach assisted cough techniques to clear your throat
- Thick saliva/mucus may be improved by drinking juice that contains mucolytic enzymes such as dark grape, papaya (pawpaw), cranberry, pineapple, kiwifruit. Papaya enzyme tablets can also help.
- Regular decongestant cough medicines may help.
- A cough assist machine might be available through your local hospital.
- Medications may help dry up secretions but can also thicken them, so ask your GP/specialist.

Sleep

Understandably many people will experience difficulty sleeping following a diagnosis of MND and the subsequent challenges of living with MND.

Do speak with your GP or specialist about counselling, ongoing support and medications to relieve anxiety or depression.

Various issues may disrupt your sleep patterns and in turn impact your quality of life. Discuss these with those involved with your care as there are often solutions, such as changes to your bedding through to medication.

Some people find they are not refreshed in the morning and are slow to 'get going'. Some people will need daytime naps to maintain energy levels.

Sleep is often disrupted if respiratory issues develop, and this should be discussed with your specialist. A respiration assessment and overnight sleep study may be useful if you wake up regularly during the night and don't feel refreshed by sleep.

What might help

- Bedroom temperature around 18–21 degrees. Dark, well-ventilated rooms aid sleep.
- Satin/silk sheets are light and slippery and may help you move so you don't disturb.
- Extra pillows or raising the head of the bed can make breathing easier.
- An electric (hospital) bed can be adjusted to maintain comfort –ask your occupational therapist.
- Special mattresses can improve comfort.
- Pillows can support limbs.
- Rails and hoists can help getting in and out of bed.
- If saliva or mucus are a problem, sleep with your head elevated or to one side to prevent secretions from pooling in the upper airway.

Breathing difficulties

Chest muscle weakness can affect lung capacity, making everyday activities and effort harder. Respiratory difficulties can develop at any stage of the disease progression and may cause shortness of breath, frequent waking during the night, fatigue, impaired quality of life and sleepiness.

Some people find their cough is less forceful, making it more difficult to clear their throat. Some may experience shortness of breath on exertion or the feeling of not being able to get enough air.

Discuss concerns with your GP/specialist and ask if a respiratory physician should assess your breathing function.

What might help

- Sitting up may be better than lying down – you may prefer to sleep in a reclined chair.
- Shortness of breath can be distressing and may be helped by deliberately breathing in a calm and purposeful way until the sensation has passed.
- Fresh air and air movement may help – try an open window and a small fan.
- Avoid contact with colds or flu and talk with your GP about vaccination.
- Medications such as morphine may relieve feelings of breathlessness.

Non-invasive ventilation (NIV)

If respiratory muscle weakness becomes increasingly symptomatic and impacts on quality of life, some people with MND will benefit from using non-invasive ventilation (NIV).

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

There are different forms of NIV. In New Zealand BiPap (Bilevel Positive Airway Pressure) is commonly used to help people with MND. The machine is similar to the more familiar CPAP machine (Continuous Positive Airway Pressure) used for those with sleep apnoea.

NIV is not oxygen. It provides measured air pressure via a mask that helps the lungs inflate despite the weak muscles. It is usually used at night and improves well-being through the day. It can equally be used during the day if that helps. Over time, NIV will be less effective in controlling respiratory symptoms.

Pain

Pain is not necessarily a part of the experience with MND. The sensory nerve pathways involved with pain, touch, heat, cold and pressure are not typically affected.

Some experience muscle cramps early in the condition but these resolve for many people over time. Lack of mobility and muscle weakness can cause discomfort and joint stiffness, particularly in shoulders, hips and knees.

What might help

- Ask a physiotherapist about strategies, positional changes and perhaps passive movements or stretching exercises that might help, particularly if you are sitting for long periods and at night in bed.
- Care should be taken not to pull on the arms when assisting a person to move. If arms become weak it is important not to leave the weak arm hanging and unsupported.
- Ask your occupational therapist about equipment to help –electric recliner chairs and beds, special cushioning and mattresses can relieve pressure and improve comfort.
- You may benefit from non-prescription analgesics such as aspirin or paracetamol. Warm packs or baths may bring relief. Ask your GP/specialist about other medications.
- Relaxation strategies, acupuncture and massage are reported to provide relief for some.
- Some people use medicinal cannabis to reduce pain, help with muscle spasticity, and manage other symptoms of MND. Medicinal cannabis is legal with a prescription from your GP or doctor at a medicinal cannabis clinic. See mnd.org.nz/cannabis.

How will we manage at home?

The majority of people with MND remain at home with support from family, friends and service providers.

Some people modify their home or choose to move if their accommodation is not suitable. An occupational therapist can help you consider what is best. Carers can be arranged to help with personal needs as mobility declines. Respite care can provide a break for the family.

In some circumstances, as independence declines, residential care is chosen as the better option.

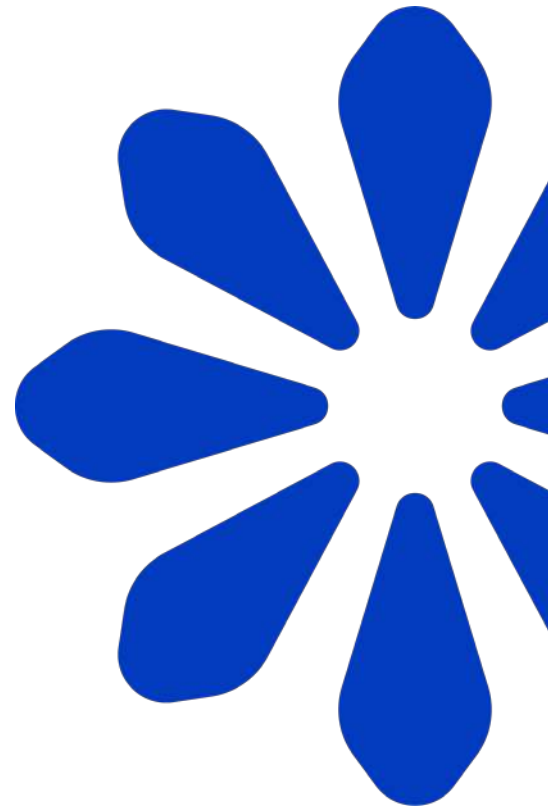
Social workers and NASC needs assessors can help with information and the decision-making involved around this option if home-based care is no longer adequate.

Travel and transport.

Mobility Parking Permits can be arranged through your GP to enable parking close to facilities if mobility is an issue for you. See www.ccsdisabilityaction.org.nz/mobility-parking

Total Mobility Scheme provides a subsidy for use of taxis/mobility taxis for those unable to use public transport. We can organise your application for this. See www.transport.govt.nz

For information about modified vehicles, rental vehicles, holidays and air travel, see mnd.org.nz/living-with-mnd/getting-about



Planning ahead.

Some people like to know everything from the beginning. Others prefer to take one day at a time. Some family members and friends want or need to plan ahead. Others prefer to just focus on now.

The following section is for those with further questions about death and dying that they would like answered now. Others might prefer to wait and address issues as and when they arise.

What does a progressive, life-limiting condition mean?

A very natural question in response to receiving a diagnosis such as motor neurone disease is to ask for some idea of a time frame. Unfortunately there are no straightforward answers.

You will find references to an average number of years after diagnosis or after the first symptoms. Averages offer little help in predicting what will happen for any one individual.

Some people continue to live with the challenges of MND for many years after diagnosis; for some the journey is very much shorter.

Discussions with the specialists monitoring individual symptoms will offer your best guide.

Getting your affairs in order

If you have not done so already, you might respond to the diagnosis by considering such issues as Wills and Enduring Power of Attorney, so that your personal care and finances can be managed as you wish when the need arises.

Some local Citizens Advice Bureau provide free initial legal advice to help identify what you might consider doing (www.cab.org.nz).

You may be eligible for free legal advice through a local Community Law Centre (www.communitylaw.org.nz). A useful brochure is available from the **NZ Law Society** (www.lawsociety.org.nz).

Life insurance

Some policies pay out in the event of a diagnosis such as motor neurone disease. Details vary so check your policy.

Advance care planning

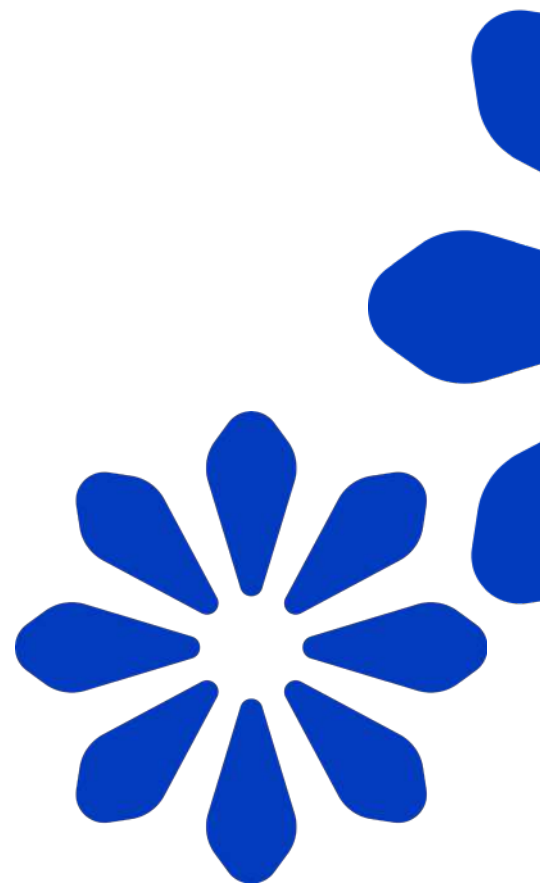
Some people are open to considering what they want in terms of care and quality of life as their needs increase.

Advance care planning gives you a chance to say what's important to you. Knowing your wishes and decisions have been recorded gives many people peace of mind. It also helps your family and your healthcare team plan ahead.

See the 'Helpful websites' list on page 25 for resources that can help.

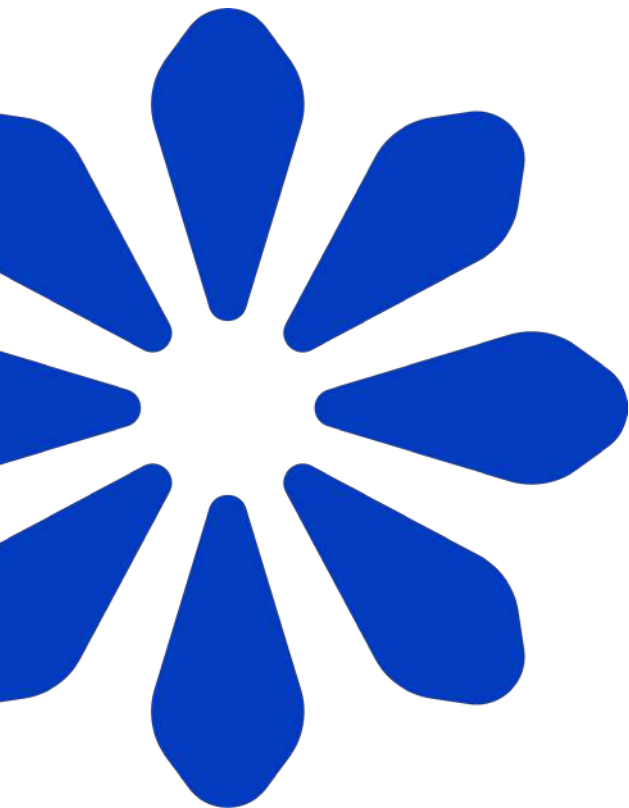
Please contact us if you have further questions.

Notes.



I walked the Walk 2 D’Feet MND last year. It put a joy in my heart and a spring in my step to see all these people coming out to support people with MND and research. That’s the beauty of the walk.

– Jac Kluts (MND client)



Actions you can take.

An MND diagnosis can make you feel helpless. Some actions you might want to consider soon after diagnosis include:

- Connect with your MND Support Advisor.
- Meet your multidisciplinary team.
- Register with the New Zealand MND Registry (**mnd.org.nz/registry**).
- Talk to your Support Advisor, speech-language therapist or Talklink about voice banking.
- Request a respiratory assessment and possibly non-invasive ventilation.
- Discuss Riluzole with your neurologist.
- Write a bucket list. Include all the activities you want to do and places you want to see and try to do as many of them as you can.
- When you are ready, some people find that planning for the end of their life is helpful (see 'Helpful websites', right).



Helpful websites.

The following websites may be of interest. You will find more links on our own website, **www.mnd.org.nz**

MND Associations

New Zealand **www.mnd.org.nz**

Australia **www.mndaust.asn.au**

International ALS /MND alliance **www.alsmndalliance.org**

MND management guidelines

UK National Institute for Health and Care Excellence (NICE)

www.nice.org.uk/guidance/ng42

Best Practice Recommendations for the care of people with MND

www.mnd.org.nz/research/bpr

Online communities

Patients Like Me **www.patientslikeme.com**

Health Talk **www.healthtalk.org**

Research

Clinical trials international database **clinicaltrials.gov**

UK Research Blog **mndresearch.wordpress.com**

ALS News Today **www.alsnewstoday.com**

Alternative therapies

ALS Untangled (reviews of alternative therapies) **www.alsuntangled.com**

I've Got Nothing To Lose By Trying It

www.senseaboutscience.org/activities/ive-got-nothing-to-lose-by-trying-it

Support for children

Skylight (for support information tailored to your situation) **www.skylight.org.nz**

'Information for children' at **<https://mnd.org.nz/about-mnd/newly-diagnosed/>**

Advance care planning

Advance Care Planning **www.advancecareplanning.org.nz**

End of Life Services **endoflife.services.govt.nz/create-my-plan**

We're here to help. Please keep in touch

We hope you will connect with us for support as you adjust to living with the implications of this diagnosis.

Phone: 09 624 2148 or 0800 444 474

Email: admin@mnda.org.nz

Website: www.mnd.org.nz

Facebook: www.facebook.com/mndanz

Instagram: https://www.instagram.com/mnd_nz

Your regional MND Support Advisor is:

