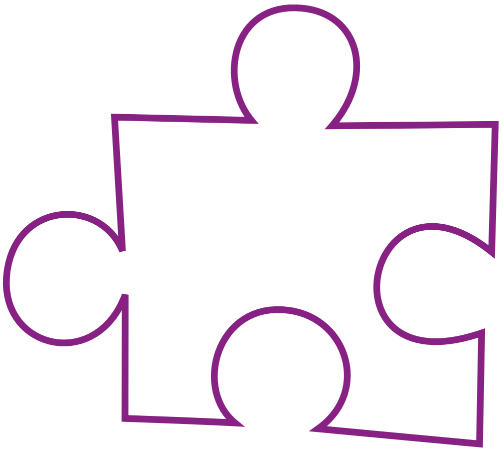
motor neurone disease
association



2: What to expect

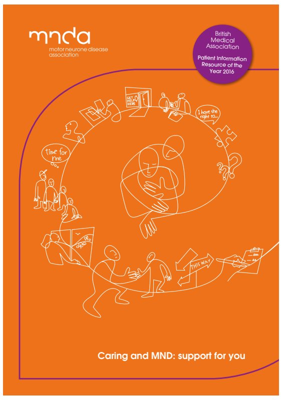
This section provides an overview of MND and the care that may be required.

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: **www.mndassociation.org/carerguide**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**



Caring and MND: support for you

2: What to expect

This section provides an overview of MND and the care that may be required.

Everyone's experience with MND is different, whether living with the disease or providing support. As this guide is about your needs and wellbeing, this section does not tell you how to provide care. The aim is to help you prepare for the challenges you may face, with guidance about where to get support when needed.

When ready, you may wish to read more detail about managing symptoms and care. We guide you to relevant publications in this section.

See *Further information* at the end of this section for a summary list of all relevant publications and how to order these.

> **"I have no knowledge of needs that may arise for him or what support is available."**

Various health and social care professionals are mentioned in this content. You can find out more about their roles later in this guide.

See Section 5: *What kind of support is available?*

> **"You have to think ahead and anticipate future needs and support requirements. Forward planning is essential because there will always be a delay while necessary support is being arranged."**

What is MND?

Nerves in the brain and spinal cord control how muscles work. These nerves are called motor neurones.

With MND, motor neurones gradually stop telling muscles how to move. When muscles no longer move, they become weak, which leads to stiffness and loss of muscle mass (known as muscle wasting).

MND is a life-shortening illness that can affect how someone walks, talks, eats, drinks, breathes and in some cases, how they think and behave.

> **"Although I knew MND was life-shortening, I knew nothing about the symptoms or the fact that it is unpredictable, and can progress so quickly."**

MND is not a common disease. It usually affects adults more than 50 years of age, but younger adults are diagnosed.

There is currently no cure for MND, but a range of health and social care professionals can help manage symptoms to ensure the person has the best possible quality of life.

These professionals can also support you as the carer and should consider you as part of their team. You will become an expert in the care of the person you support and your knowledge is important to the professionals involved.

See our guide, *Living with motor neurone disease* for more detail about the types of MND.

Is Kennedy's disease a type of MND?

Kennedy's disease is a different and rare disorder of the motor neurones. Like MND, it leads to weakness. People with Kennedy's disease often have a normal life span as the condition progresses slowly.

As Kennedy's disease has similar symptoms, it can be confused with MND during diagnosis. However, it is caused by a clear genetic mutation that can be found through gene testing. Normally, Kennedy's disease only affects men, but women carry the genetic mutation. There is some evidence that women can occasionally develop the symptoms, but this is rare.

The MND Association also provides support for people with Kennedy's disease, their families and carers. If you support someone with Kennedy's disease, you may also find this guide helpful.

See information sheet 2B: *Kennedy's disease* for more detail about this condition.

What causes MND?

It is still not possible to be clear about what causes MND, as each person may be affected by different triggers (triggers are things that might cause a disease to start).

> **"He researched other conditions before he was diagnosed with MND, but I think he was exploring possibilities on his own."**

MND usually occurs with no apparent family history of the disease. In these cases, a mix of genetic and environmental triggers is thought to be involved, although genes may play a smaller role.

Environmental triggers could be things that you eat, drink, touch or breathe, or a mix of these. As the triggers can be different for each individual, there is no simple way to find out why someone gets the disease.

Research into the disease and its causes is progressing, including projects funded by the MND Association. As a result, our understanding of how motor neurones work is constantly advancing.

What if there is a family history of MND?

In a small number of MND cases, a mistake in the genetic code is inherited. Other triggers are still thought to be necessary for the disease to actually begin.

See our research information sheets on inherited motor neurone disease.

If you are concerned about the possibility of a family history of MND and what that could mean for those close to you (in terms of inheriting the genetic code), you may wish to seek genetic counselling. This is not a form of psychotherapy, but a genetic counsellor can explain the facts and provide accurate information about the implications for your family.

This includes information about options such as genetic testing, but testing is only available for some of the genes that play a part in inherited MND. Results are not necessarily conclusive.

Choosing to be tested can be a very difficult decision for someone to make, as it affects the wider family. We would advise genetic counselling from a neurological expert experienced in MND. In the first instance, ask the neurologist involved in the diagnosis or care of the person with MND.

What are the likely symptoms of MND?

> "I have no idea if what's happening to my partner is normal."

Muscles in the hands, feet or mouth are usually affected first, but not necessarily all at once.

MND can cause:

- weakness and increasing loss of movement in limbs
- twitching and rippling sensations under the skin
- muscle tightness and cramping (which may cause pain)
- problems with breathing and tiredness
- difficulties with speech, swallowing and saliva
- changes to thinking and behaviour.

Someone may also have unexpected emotional reactions, where they cry when happy, or laugh when sad. This is called emotional lability and can feel distressing, but their health and social care team can provide support. This symptom does not happen to everyone with MND.

See later heading: *Emotional support and emotional lability.*

MND does not usually affect:

The senses: sight, hearing, smell, touch and taste. However, tightening of muscles and lack of movement can cause pain. Exercise and assisted exercise can help.

The bladder and bowel: however mobility problems can make it more difficult to get to the toilet and reduced mobility may also cause constipation (as movement helps the bowel to work).

Primary lateral sclerosis, a type of MND, may cause some people to feel an urgent need to urinate, even when their bladder is empty. The GP or neurologist can advise about medication to help control this symptom.

Sexual function: while function is unaffected by MND, sexual expression may be more difficult due to feeling tired, loss of movement and the emotional impact of dealing with the disease.

See our booklet on *Sex and relationships*.

> "I feel it should be stressed that no two people with MND have the same needs and, as time goes on, care becomes more difficult."

Symptom control can range from exercise and therapy, to treatment and medication. However, the person you support may have other symptoms not mentioned here or other conditions not connected to MND, such as viruses, illness or injury. Always consult a GP or the wider health and social care team if you have any concerns.

See our main guide: *Living with motor neurone disease* and information sheets for symptom control and suggestions on daily living.

How will I be involved?

This may be the first time you have supported someone as a carer. With MND, support needs can be complex and present unusual problems.

> "I wasn't qualified to care, had no training and feel that carers are not understood. At first, I could only bring limited ability to the role."

Ask the GP or another member of the health and social care team for advice when symptoms first appear. This can help you and the person with MND to feel more informed and access help in a timely way. Our MND Connect helpline can help direct you to our own and external services as needed.

See Section 11: *How the MND Association can help you* for contact details and further information about our services.

Many carers have told us they tend to place their own needs after those of the person they support. It can be difficult to find time to look after your own needs when providing care. However, if you become overwhelmed or exhausted, you may reach a point where you are unable to continue in the caring role, even if this is what you wish. Ask your GP for a health check if needed.

> **"The needs of the other person can take over, so you feel you hardly exist anymore."**

See Section 8: *Looking after yourself* for suggestions about how to care for yourself when caring.

The following headings look at the support someone with MND may need and how you may be involved.

> **"What happens next? What can I expect to manage and what happens afterwards?"**

Personal care and household tasks

See our guide: *Living with motor neurone disease* and our booklet: *Personal care* for suggestions on how to manage everyday life with MND.

As symptoms progress, you may find yourself taking on extra work or tasks you never expected to do.

This may include:

- household routines or gardening
- accompanying the person when travelling
- looking after finances
- being responsible for children
- increasing levels of personal care.

> **"I just hope I will be able to maintain the care that I am managing at the moment."**

Even if you enjoy caring, or family and friends help share the load, there may come a time when you need additional help because:

- the demands of care increase
- the person's needs may become complex, requiring medical support
- there may be aspects of personal care that you or the person with MND prefer someone else to support
- you may need someone to provide care while you go shopping, run errands or take a break
- the person may need support both day and night and you need help to rest.

See Section 5: *What kind of support is available* for details about emergency cover, respite care and other support.

If you need professional support, adult social care services can arrange a needs assessment for the person with MND and a carer's assessment for yourself (in Northern Ireland this is called a community care assessment). The aim is to work out what could help and how this can be provided.

See Section 4: *Carer's assessment* for details about how to arrange, prepare for and get the best possible outcome from your assessment.

Further assessment by an occupational therapist (OT) can also help the person with MND remain independent for as long as possible. Support can be provided through equipment, assistive aids and adaptations to the home. This can help you as the carer too, by relieving some of the demands of daily care. Ask your GP or any member of the health and social care team about referral to an OT.

Attending appointments

The person you support may need:

- assistance to and from appointments if mobility is affected
- help to explain their needs if speech and communication are affected
- emotional support if the appointment involves a sensitive conversation.

Lots of professionals may be involved with the care of MND, which can mean lots of appointments. Even home visits by professionals can still be tiring and it can feel as if there is a constant stream of people at the house.

> **"We deal with so many people. We have a list on our fridge – there are about twenty professionals."**

At an MND care centre or network, or neurological clinic, a multidisciplinary team is usually available. This means more than one specialist is present, as part of a co-ordinated care system. This can be less tiring than lots of separate visits.

See Information sheet 3A: *MND care centres and networks* for details about how to access this type of care and Section 5: *What kind of support is available?*

Listing questions before appointments can help you cover everything you need to ask.

See our *Appointment queries* page at the back of this guide to help you. Additional copies can be downloaded at: www.mndassociation.org/carerguide or ordered from our MND Connect helpline.

If you make notes at each discussion for reference, date these and add the name of the professional. This can help if you need to query anything later. You can also ask to record what is being said on a smart phone.

Financial support

Financial support may be necessary to help with the extra costs of long-term illness and care.

> **"There are things that we need but are unable to get because we can't afford them."**

We provide information about benefits and financial support, including guidance on work decisions if either of you are employed.

See Section 6: *Work and financial support* for more on employment, benefits, financial support and social care.

In time, the person you support may need help to physically manage their finances and access their bank account. Ask the relevant bank how to do this in the most helpful and appropriate way. The most effective way is for the person with MND to arrange power of attorney for you, where you have a legal authority to manage their finances.

See our publication: *End of life: a guide for people with motor neurone disease* for more about finances and power of attorney.

Movement and personal mobility

As the disease progresses, muscles stop working. This means the person can develop problems with grip, movement and mobility.

A huge range of equipment is available to help someone maintain independence for as long as possible. This can help you as their carer too. Devices such as adapted cutlery and dressing aids can assist daily living. Rails, walking frames, wheelchairs and hoists can support mobility. Some equipment is provided on loan by health and social care services.

See information sheet 11C – *Equipment and wheelchairs.*

See our guide: *Living with motor neurone disease* for suggestions on how to manage everyday life with MND.

It is important to plan ahead and consider future needs, as MND changes quickly. By the time equipment arrives, it may no longer be of use. To avoid frustration and costly mistakes, the person's needs should be assessed to ensure equipment is suitable.

Occupational therapists and physiotherapists can assess the person's needs and may be able to:

- suggest ways to make daily routines easier
- provide some items free through health and social care services
- advise about suitable additional items that you may need to source.
- advise on access to NHS Wheelchair Services and other providers

> **"My partner is much heavier than I am and I'm finding it difficult to move him despite the equipment we have been given."**

You may have difficulty assisting the person you support from place to place, such as from chair to bed. As well as using equipment and hoists, a carer's assessment may result in support from care workers at certain times of the day.

Training in moving and handling can also help you support someone's weight as safely as possible. At your carer's assessment, ask who can help with this type of training. They may suggest an occupational therapist, physiotherapist or a contact from a local organisation, such as a local carer's centre.

See Section 4: *Carer's assessment* for details about how to arrange, prepare for and get the best possible outcome from your assessment.

Adapting the person's home can make life easier for you both. Examples include:

- widening doorways for wheelchair access
- installations such as through-floor lifts
- converting a downstairs room into a bedroom.

An occupational therapist can help assess the home and advise on options. This is important to ensure any changes suit the needs of the person with MND, as mistakes could be costly and frustrating.

Try to think ahead to future needs, as MND can change rapidly. For example, a stairlift is helpful for someone using a walking frame, but may not be helpful if they use a wheelchair. A stairlift requires a wheelchair on each floor, and possibly a hoist to transfer between chair and stairlift. A through-floor lift or downstairs conversion may provide easier access for wheelchair use.

There may be funding to assist with installations and home adaptations, such as a Disabled Facilities Grant (DFG). Arranging funding can be a lengthy process, so it is worth looking into as soon as possible. This may feel too early, but it is important to plan ahead for adaptations so they are ready when the need arises.

See information sheet 10C – *Disabled Facilities Grants.*

Travel and transport

> **"While we could get out and do things together there were plenty of positives, companionship and trust."**

Travel can become difficult as mobility and disability increase. You may want to explore information about:

- wheelchair accessible vehicles (WAV)
- the Motability scheme, which can help to fund adapted vehicles and WAV vehicles for people with disabilities who receive certain benefits
- the Blue Badge Scheme, which enables people with disabilities to park closer to their destination, by using restricted areas or disabled parking bays
- local taxi services offering wheelchair accessible vehicles
- local transport schemes, such as subsidised taxi rides or Dial-a-ride for people with disabilities (your local authority can advise in England and Wales or your local health and social care trust in Northern Ireland)
- subsidised public transport, which may be available to carers (for example, you may be able to pay a reduced train fare if the person with MND has a disabled person's railcard and you accompany them as their carer)
- non-emergency ambulance or patient transfer services – check with the hospital or clinic concerned to find out what's available.

See our booklet on *Getting around*.

Physiotherapy and flexibility

If movement and mobility are affected by MND, the person will experience stiffness in muscles and joints. They may also have cramp, where muscles tighten suddenly. While MND does not usually cause direct pain, stiffening and cramp can be painful.

Exercise, assisted exercise or passive exercise (where you help the person by moving their limbs for them) can ease muscle stiffening and associated pain. It cannot reverse muscle weakness or slow down the progress of the disease, but where stiffness occurs, exercise may improve range of movement for a period of time.

> **"With gentle persuasion and exercise, my husband regained enough range of movement for me to wash under his arms again and dress him pain free."**

With MND, it is important not to over-exercise as this can cause fatigue. A physiotherapist with experience of MND should assess the person's needs, advise on a suitable exercise plan and review exercise routines as needs change. They can also advise you how to assist with this, keeping safety in mind.

See information sheet: 6A – *Physiotherapy* and 6C - *Managing pain*.

If the person with MND still experiences pain, contact their GP or another member of their health and social care team for advice.

Speech and communication

Speech, gesture and facial expression can all be affected by MND. This can make it harder for the person to explain what they need.

Finding other ways to communicate takes patience and time for you both, which can affect emotions and relationships.

See Section 7: *Making sense of your feelings*.

> **“We just slipped into this home-grown sign language... he’d have a particular way of moving a hand or his eyes and we’d know. And even when he was slurring badly, we could make out what he was saying when no-one else could.”**

Communication aids can help. Depending on the person’s needs and preferences, simple aids such as a notepad and pen, word and image cards, or alphabet boards may be suitable. There are also high-tech aids, such as text-to-speech applications for computers, tablets and smart phones. Adapted switches and controls can help the person to access these in a variety of ways.

See our guide: *Living with motor neurone disease* which has a section on speech and communication.

If the person with MND has never used a computer or keyboard before, it is a good idea if they start practising before they really need communication aids. Whether using adapted switches or a keyboard, it can help to know how to move around the screen and use basic options.

If the person uses a high-tech aid, there is always a risk it might develop a fault or cannot be used for some reason. As a back-up, we recommend the person with MND practises with a simple aid too, such as an alphabet board.

As with all equipment, the person’s needs should be assessed and reviewed if they change. Not all solutions suit everyone and some can be very expensive. Ask their GP or wider health and social care team for referral to a speech and language therapist, preferably with experience of supporting MND. This may also result in supply of communication aids through health and social care funding (statutory services)

We may be able to assist with equipment loan or an MND Support Grant where there is a waiting list or if statutory services have not been able to supply a suitable communication aid.

See Section 11: *How the MND Association can help you* for details about our Communication Aids service, equipment loans and MND Support Grants.

Swallowing difficulties

If the muscles in the mouth, face and throat are affected, someone with MND may experience swallowing difficulties. This can lead to issues with eating, drinking, saliva control and coughing.

The person with MND may experience:

- weight loss
- longer mealtimes
- tiredness
- thick or thin saliva
- drooling
- a dry mouth
- a weak cough or bouts of coughing
- mild or severe choking and aspiration (food or drink getting into the airways)

The person can ask their GP or another member of the health and social care team for referral to specialists, such as:

- a dietitian to advise on nutrition, types of food, supplements and food preparation
- a speech and language therapist to advise on swallowing techniques, food consistencies and thickeners to make drinks easier to swallow
- a GP, dietitian, speech and language therapist or a nurse specialist to advise on tube feeding.

Tube feeding is usually introduced by a hospital procedure known as gastrostomy. Once inserted, the tube can be used to top up or replace eating and drinking as required.

With a tube, the person may still be able to eat and drink by mouth for enjoyment, for as long as they feel safe to do so. They may choose to continue doing this at their own risk.

It is important to consider tube feeding as soon as swallowing difficulties begin. If the person decides to go ahead, it is better to introduce the tube before a significant amount of weight is lost.

Deciding whether or not to use tube feeding needs full discussion between the person with MND, yourself as the carer, and the health and social care team who support. If someone with MND does not wish to use tube feeding, their dietitian and speech and language therapist can support and advise.

See information sheets: 7A – *Swallowing difficulties* and 7B – *Tube feeding*.

See our *Eating and drinking* guide for guidance and easy-swallow recipes. Also https://mytube.mymnd.org.uk for videos about using tube feeding.

Tube feeding may need your support, but can reduce worry about the person getting the food and drink they need. It can also shorten mealtimes, which may have become tiring for you both, and the time you spend preparing foods in different consistencies. Tube feeding also avoids aspiration, where food and drink gets inhaled into the lungs, which may cause repeated chest infections.

> **“Pouring liquid feed down the tube, and flushing with water to clean, very quickly became part of the daily routine. It doesn’t disrupt or prevent any activity.”**

Some carers have told us they feel guilty eating in front of someone who is tube fed. They often rush their own mealtimes or eat alone. If this affects you, try to discuss this with the person you support. You may find they prefer life to be as normal as possible and for you to feel relaxed at mealtimes.

Tube feeding in advance of a meal can also help the person to feel more comfortable at social gatherings, if eating and drinking have become difficult to manage.

Breathing support

MND can affect the muscles involved in breathing.

The person you support may need referral to a respiratory team for assessment if they show any of the following symptoms:

- shallow breathing or feeling breathless
- difficulty breathing when lying flat
- repeated chest infections
- a weak cough, sniff or voice
- disturbed sleep
- morning headaches
- nightmares or hallucinations
- daytime sleepiness or feeling very tired
- confusion, with poor concentration or memory
- poor appetite.

Ask their GP or a member of the health and social care team for advice and referral.

Assistance can include:

- breathing exercises and physiotherapy
- advice on body positioning
- assistance for a weakened cough
- medication
- mechanical breathing support through ventilation.

Ventilation is not suitable for everyone. However, where appropriate, it may help relieve anxiety about breathing, improve sleep and reduce tiredness.

For more detail, see our range of information sheets: 8A – 8D about breathing and ventilation. Also http://mybreathing.mymnd.org.uk for videos about using ventilation.

MND Just in Case kit

We provide an MND Just in Case kit to help if someone with MND experiences a sudden change with symptoms such as breathlessness, anxiety, coughing or choking. Most people never have to use the kit, but it can be reassuring to have it nearby.

The GP of the person with MND can order the kit free of charge from our MND Connect helpline. They should then prescribe suitable medication to keep inside the box. The box has two sections:

- one for medication that can be used by a doctor or nurse
- the other for medication that carers can give to the person with MND (which you must be shown how to use by the GP or district nurse).

Our helpline can be contacted as follows:

Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org

> **"My own experience has shown that you're not always prepared in time or symptoms are not spotted early enough. In my husband's case, his breathing problems were too far advanced for him to use treatments like non-invasive ventilation effectively."**

Tiredness

Tiredness and extreme fatigue can be a common concern with the disease. This can be worrying and you may find yourself having to provide increased levels of support.

There may be various reasons why the person with MND is getting so tired:

- as muscles grow weaker, everyday tasks can take longer and need more effort
- the diagnosis and daily challenges of MND can be emotionally exhausting
- swallowing difficulties may cause the person to eat less, so they are not getting the nutrients they need (see earlier heading, *Swallowing difficulties*)
- breathing problems may lead to disturbed sleep and tiredness (see earlier heading, *Breathing support*)
- there may be another underlying condition that needs to be assessed.

If the person is frequently tired, ask their GP for advice.

Where possible, plan social activities at times when the person with MND tends to feel most alert. Being flexible with routines can help. Focus on essential tasks and let others go if need be, as this may give you both more time to do the things you really want to do.

> **"I never feel like I have enough time to please everyone."**

You may feel extreme tiredness as the carer too and need to be aware of your own energy levels. If your own fatigue is persistent and you find it increasingly hard to cope with the demands of the caring role, ask your own GP for a check up.

See Section 8: *Looking after yourself.*

You may need support. Ask for a needs assessment for the person with MND and a carer's assessment for yourself to find out what help is available. If you have both already been assessed, ask for a review of your needs.

See Section 4: *Carer's assessment.*

Emotional support

A diagnosis of MND can be devastating, both for the individual and yourself as partner, relative or friend. Sometimes there can be a sense of relief after a period of great uncertainty, but most people, including the wider family and friends, need time to adjust. Intense emotions are likely to be experienced.

Emotions can be very mixed too, often including sadness, grief, guilt, anger and fear. Each individual may have a different response, depending on their age, circumstances, culture, beliefs and relationships.

See our booklet, *Emotional and psychological support*.

Open discussion can provide 'permission' for people to express emotion together and find ways to support each other. Laughter and tears are natural responses and can help to release tension.

> **"If I can make her laugh or smile just once a day, I have achieved my goal for that day."**

If strong emotions persist and become distressing, a GP can advise. Counselling can be helpful. You may find this easier to tackle together and referral to a hospice or specialist palliative care team can be valuable. They provide emotional support, as well as symptom control and practical guidance, all of which can ease anxiety and help maintain the best possible quality of life.

If your relationship with the person who has MND was strained before diagnosis, it may be important to seek professional help. The health and social care team can support difficult discussions and help you both manage the way ahead. Again, counselling may help, or you may need more support with care, or alternative care arrangements.

Despite the shock and challenges of MND, for many it can be a time for closeness and building memories. This can help to balance emotions with positive events and shared experiences.

> **"I can spend time with my wife, even though the circumstances and things I need to do for her weren't foreseen as part of our plans."**

Emotional lability

Some people with MND find they laugh or cry at inappropriate times, known as emotional lability (sometimes called pseudo-bulbar affect). The person may laugh when upset or cry when happy. This is an abnormal motor response caused by the disease and often reduces over time.

It can be difficult to control and distressing for the individual and those around them. A GP can advise, but may not be familiar with this symptom. If so, ask an appropriate member of the health and social care team who has experience with MND, as there may be medication to help.

See our booklet *Emotional and psychological support*.

It can help once you and the person with MND fully understand what is happening. Having accepted that these responses are a symptom of the disease, they usually become easier to manage. Rather than trying to avoid them happening at all, you may find shared ways to deal with the effects, which can help the person feel more secure. This may calm situations.

Changes to thinking and behaviour

About 1 in 2 people with MND are thought to have some changes to thinking and behaviour (known as cognitive change). This number increases in the later stages of MND. In most cases, the changes are mild and have little effect on daily life. Where the changes are more severe, the ability to make reasoned decisions may become more difficult.

> **"He relied on people asking him simple, direct questions. You had to give just one choice at a time or he'd get confused."**

The individual is unlikely to be aware of the differences, but you or another relative or friend may notice first. For example, they may show signs of:

- personality change
- apathy
- inappropriate behaviour
- repeated behaviour
- poor concentration
- problems with reading and writing
- aggression.

Some changes may be the result of fatigue, poor sleep or depression, but do seek help if you are concerned. Ask the person's neurologist for advice. There are screening tests to work out if the way they think has changed and more detailed assessments to review the level of change. Guidance and support can be given to help ensure appropriate care and safety in the home.

About 1 in 10 people with MND who experience changes to thinking and behaviour develop a type of dementia called frontotemporal dementia (FTD). This can be very difficult for you to manage as a carer and additional support is likely to be needed. As MND and FTD are rare, not all professionals or care workers will understand the needs that may arise.

Ask for guidance from a professional experienced in MND, such as the person's neurologist. They can refer you to specialists.

See our booklet, *Changes to thinking and behaviour with MND*.

Medication

With MND, someone may take medication to:

- help with problems such as thin or thick saliva
- ease or control other MND symptoms
- manage other conditions or anxiety.

See earlier heading *Breathing support* for details about our MND Just in Case Kit to help with sudden breathlessness and anxiety.

Riluzole is the only licensed drug in the UK known to have a moderate effect on the course of MND. It is thought to slow the disease by several months. If riluzole is suitable for the person you support, ensure the prescribing doctor is aware of any other medications.

See information sheet 5A – *Riluzole.*

There may be soluble or liquid medicines if the person finds it difficult to swallow tablets. Many liquid medicines can also be given via a tube if the person has decided to use tube feeding to top-up or replace meals by mouth.

Always read instructions carefully when giving medication. Ask a GP or district nurse if in any doubt about combining medicines, using over-the-counter remedies or whether to give medication through a feeding tube.

Skin care and pressure relief

If mobility is affected, the person with MND may be in one position for long periods of time. This may cause skin discomfort.

Repositioning at regular intervals can help, but you can ask their GP, district nurse, occupational therapist and physiotherapist for guidance. They may be able to provide specialist equipment to help, such as pressure relief cushions or air mattresses.

If the discomfort continues, the person may be referred by a member of the health and social care team to a specialist nurse, palliative care team or local hospice for symptom control. They can help prevent skin sores from developing.

Planning ahead for future care

Please note, this short section includes information about later stages and end of life decisions. You can return to this later if you do not want to read this now.

MND is life-shortening and in the later stages, care can become complex. Being prepared and well-informed can help the person with MND to receive future care in the way they would prefer. It can also help you get the help and support you may need.

Making plans can be reassuring, as it enables choice and more control over what happens next. If you wait until point of need, you may find that services, equipment or even funding are difficult to arrange at short notice.

Future care arrangements will affect both the person with MND and yourself as their carer. Try to have discussions about this together, along with the health and social care professionals who support. They can help during difficult conversations and advise on how to plan ahead.

Once plans have been made, you can both get on with living. You may find it brings peace of mind knowing that arrangements have been made and agreed.

> **"He wanted to make sure that everything was set up and in order...I found this really hard because I knew what it represented, but that was his way of facing it."**

In addition to getting financial affairs in order and making a will, the person with MND can:

- make an advance care plan to guide professionals about preferences for future care and location of care
- create a legally binding advance decision to refuse or withdraw treatments the person does not want, in specific circumstances (which can include wishes about resuscitation)
- ask you or someone else to make future decisions on their behalf, if needed (usually through Lasting Power of Attorney in England and Wales or Enduring Power of Attorney in Northern Ireland).

These arrangements only become active if the person becomes unable to make decisions or communicate for any reason. However, these plans ensure things happen as the person would wish. This can help you too – with written guidance, you may find it easier to provide support, knowing you are following their choices.

See Section 5: *What kind of support is available?* for details about NHS continuing healthcare, which can assist complex needs.

When you feel ready, we provide comprehensive information about end of life decisions, including aspects like arranging power of attorney.

See our publication, *End of life: a guide for people with motor neurone disease.*

Key points

- Try to anticipate change as much as possible, as equipment and services can take time to arrange.
- Assessments not only lead to general support, but may help empower the person with MND to remain independent for as long as possible.
- Plan joint activities when the person with MND tends to feel most alert.
- If symptoms need specialist help, ask the person's GP or another member of the health and social care team for a referral.

Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

From our information sheet range:

2B: Kennedy's disease

3A: MND care centres and networks

5A: Riluzole

6A: Physiotherapy

6B: Complementary therapies

7A: Swallowing difficulties

7B: Tube feeding

8A to 8D:
our range of sheets on breathing and ventilation support for MND

10A to 10G:
our range of sheets on benefits, financial support and social care

11C: Equipment and wheelchairs

14A: Advance Decision to Refuse Treatment (ADRT)

From our research information:

Research sheet B:

Part one – Introduction to inherited motor neurone disease

Part two – Genetic testing and insurance

Part three – The options available when starting a family

From our other publications:

Living with motor neurone disease: a guide about MND to help manage the impact from diagnosis onwards and maintain the best possible quality of life.

End of life: a guide for people with motor neurone disease: a candid and comprehensive guide about planning ahead and future care.

Personal care: ways to prolong independence in personal routines for the person with MND.

Emotional and psychological support: therapies that can help both the person being supported and the carer.

Changes to thinking and behaviour with MND: how to get support if you think someone with MND is showing these changes.

How to access publications and further information:

Most of our publications can be downloaded at: **www.mndassociation.org/publications** or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and regional staff.

See Section 11: *How the MND Association can help you* for details about our services.

Online forum:
The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:
https://forum.mndassociation.org

Information for professionals
We provide information to help professionals who support people with MND, their families and carers. This can be accessed at:
www.mndassociation.org/professionals

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For references and acknowledgements please refer to the full guide, *Caring and MND: support for you.*

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**

This resource has been evidenced, user tested and reviewed by experts.

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