

Motor neurone disease

Information for the public

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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about motor neurone disease (MND) that is set out in NICE guideline NG42. It also covers advice on non-invasive ventilation that NICE produced in 2010.

Does this information apply to me?

Yes, if you are 18 or over and have MND.

It does not cover other nerve-related conditions, or a condition called Kennedy's disease.

What is motor neurone disease?

Motor neurone disease is commonly known as MND. It is also known as amyotrophic lateral sclerosis, which is usually shortened to ALS.

The motor neurones are nerves in the brain and spinal cord that control the muscles used for gripping, walking, moving, speaking, swallowing and breathing. In MND the motor neurones

gradually stop working properly, so their messages do not get through to the muscles. This means that MND affects how you grip, walk, move, speak, swallow and breathe.

There is no cure for MND, but treatment aims to help people have the best quality of life possible by managing their symptoms, providing equipment and devices that can help with day-to-day activities, and supporting the person and their family or carers.

MND can also affect the areas of the brain involved in thinking, language, behaviour and personality. Doctors call this 'cognitive change'.

Motor neurone disease with frontotemporal dementia

For most people, any cognitive changes will be mild. A small number of people may have more severe cognitive changes that may affect the way they behave, their personality and thinking. This is called 'motor neurone disease with frontotemporal dementia'. It is sometimes shortened to FTD.

If your GP thinks you could have MND

If your GP thinks you could have MND, they should refer you straightaway to a consultant neurologist. A neurologist is a hospital doctor who specialises in disorders of the nervous system, including the brain, spinal cord and nerves.

MND can sometimes be difficult to diagnose, so while you are waiting to find out what's wrong, your GP should give you and your family or carers the information and support you need.

If MND is diagnosed

Information and advice

A consultant neurologist with expertise in MND should tell you about the diagnosis, how they think MND is likely to progress, and explain what will happen next. They should also tell your GP straightaway.

You should be given the contact details for the healthcare team that will be looking after you ([your MND multidisciplinary team](#)), and advice about what to do if you have any worries or concerns.

You should be asked if you would like to have a face-to-face appointment with a member of the

multidisciplinary team. The appointment should happen within 4 weeks of being told you have MND.

You should be given information and advice about MND when you are first diagnosed, in appointments with your team, and whenever you ask for it. The information can be shared with your family or carers if you would like to include them.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

Questions you might want to ask about MND

Questions about MND

- What is MND and what causes it?
- Are there different types?
- What are the symptoms and how can I deal with them?
- How might the symptoms get worse?
- What are cognitive changes and how do I know if I've got any?
- What is frontotemporal dementia and how do I know if I've got it?
- What will happen next with my healthcare?
- Are there any treatments available?
- Is there a cure?
- How long will I live?
- What will be the impact on my day-to-day life?
- Will my children get MND?
- How do I tell my family and friends?

- What about when it comes to the end of my life?

Questions about your care

- Where will my appointments take place?
- Which healthcare and social care professionals will be looking after me?
- Who will organise my care?
- Who do I contact if I've got any worries or concerns?
- How long might I have to wait for consultations, tests and treatments?
- What local services (including social care services) are available and how can I get in touch with them?
- What local support groups, online forums and national charities are available and how can I get in touch with them?
- What about legal rights, including social care support, employment rights and benefits?
- Are there any legal requirements I need to know about, for example, I drive, so do I need to tell the Driver and Vehicle Licensing Agency (DVLA)?
- Can I carry on with my job?

Help with social care

If you need support from social services, for example, if you live alone or care for someone else, you should be referred to social services because you may be able to get some support. Anyone who cares for you can have a Carer's Assessment of their needs because they may be able to get some support too. Your multidisciplinary team can give you more information about the help that is available.

Help with communicating

MND can cause problems with talking and communicating, so you should get extra help in appointments if you are having these problems.

Help with making decisions

MND can cause cognitive changes – problems with thinking, language, behaviour and personality. You should get extra help and support in your appointments if you need it.

These changes can be part of the normal ageing process, but they can also be linked with a type of dementia called frontotemporal dementia that affects some people with MND. You may be referred for an assessment to see if you have any signs of frontotemporal dementia. NICE has produced separate guidance and information for the public on dementia – see [other NICE guidance](#) for more information.

Your MND multidisciplinary team

If you have MND, the healthcare team that will be looking after you is called an MND multidisciplinary team. This is a group of different people who work together. The multidisciplinary team is often based in a clinic at a hospital. The team looks after your care wherever you are – in the hospital, clinic or GP surgery, and also in your own home.

Your MND multidisciplinary team should include the following people:

- Neurologist, a doctor who specialises in the nervous system.
- Neurology specialist nurse, a nurse who specialises in caring for people with conditions affecting the nervous system.
- A healthcare professional with expertise in palliative care. Palliative care aims to improve a person's quality of life throughout the course of their illness if they have a life-limiting illness.
- Dietitian, to help with diet and nutrition, and problems with eating.
- Physiotherapists and occupational therapists, to help with staying active and independent as far as possible.
- Respiratory physiologist, to help with breathing problems.
- Speech and language therapist, to help with speech, communication and swallowing problems.

The team should also work with other teams and services, such as:

- Psychology and counselling services.

- Social care.
- Respiratory medicine.
- Specialist palliative care.
- Gastroenterology (for conditions affecting the stomach and intestines).
- Community neurology teams.
- Services that provide equipment, such as orthotic devices to help your posture, wheelchairs and communication equipment.

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your multidisciplinary team.

Appointments with your multidisciplinary team

How often will I have an appointment?

You should have an appointment every 2–3 months. The exact timing of the appointments will depend on how things are going and how you are feeling. For example, if you or your family or carers suddenly notice a major change in your symptoms, you should be seen sooner.

You should be offered help if you are having problems with communicating or making decisions.

What will happen during appointments?

During your appointment you will see different members of your multidisciplinary team. The team will ask about you, your symptoms and your needs, and what has changed since your last appointment. They will also ask how MND is affecting you and your family or carers, and how any treatments have been working.

You might also be referred to a specialist palliative care team. Palliative care is specialist care that aims to improve a person's quality of life if they have a life-limiting illness, by easing their pain and discomfort and providing physical, psychological, spiritual and emotional support.

These are some of the areas that the team should ask about.

What your multidisciplinary team should ask about

- Your weight, diet and nutrition, and if you have any problems with drinking, eating and swallowing.
- If you have any muscle problems, for example, weakness, stiffness or cramps.
- How MND is affecting you physically, for example, how it affects you in terms of moving around (your mobility) or carrying out day-to-day activities.
- If you have any problems with saliva, for example, drooling or thick, sticky saliva.
- If you have any problems talking or communicating.
- How well you are able to cough and if you are having any breathing problems.
- If you have any pain.
- If you have any other problems, such as constipation.
- If there have been any changes in how you think or behave.
- How MND is affecting you emotionally and psychologically.
- If you need any support from social services.
- If you and your family need any information or support.

Emotional support

Your multidisciplinary team should talk with you and your family or carers about how MND is affecting you all, and find out if you need any help or support.

You should get information about sources of emotional support, such as support groups, online forums and respite care for yourself and your family or carers. You may be referred to psychology or counselling services if you need more expert help and support.

These are some of the areas that you and your family or carers might want to talk about.

Emotional support

- Your understanding of MND and how it affects your daily life.
- How you feel about the diagnosis.
- Worries and fears about dying.
- Adjusting to the changes that MND brings.
- How MND is affecting your ability to continue with your job and other activities.
- How relationships within the family can change.
- Sexuality and intimacy.
- Worries about family members or carers.
- Making decisions.
- The care you need on a day-to-day basis.

Social care support

You and your family or carers should be asked about your needs and the type of care you want, and get information and support on an ongoing basis. You should be given information about how to get in touch with support services and who to contact if there are problems – for example, what to do if you have a paid carer and they do not come.

These are some of the areas that you and your family or carers might want to talk about.

Social care support

- Personal care (the carers who come to look after you).
- Home adaptations and practical support.

- Financial support and advice, for example, managing your money and help with getting benefits and grants.
- Support to continue working.
- Help with getting involved with social activities and hobbies, for example, using the internet, and activities outside your home.
- Care at home and respite care.
- Carer's assessments for family and carers.

Problems with muscles and moving around

MND causes problems such as muscle weakness, muscle twitching, stiffness and cramps.

Medicines

Some medicines can help with stiffness or cramps. A member of your multidisciplinary team will talk about what can help and explain the different medicines you could try. They should ask about your needs and what you prefer, and if you have any problems taking medicines, for example, swallowing tablets.

In your appointments, you should be asked about how muscle problems are affecting you, how any treatments have been working, and if you've had any side effects from the medicines you've been taking.

Exercise programmes

Exercise programmes can help with muscle and joint problems. Although exercises will not strengthen your muscles, they can help to keep you as active as possible and reduce stiffness and discomfort. There are different types of exercise programmes available, depending on your needs and what you prefer.

Your family or carers will be asked about whether they can help with the exercises, and should be given advice about helping you safely without hurting themselves.

Orthoses

Orthoses are devices that are used to support areas of the body – for example, your feet or neck. If you need orthoses to help with muscle problems you should be referred to an orthotics service so that orthoses can be provided quickly.

Equipment and adaptations for your home

Your multidisciplinary team will ask how you're coping with day-to-day activities, such as personal care, dressing, bathing, housework, shopping, food preparation, eating and drinking, and how you are finding work and day-to-day activities. They will ask about any falls and if you have problems with your hands.

Help with equipment or adaptations for your home that meet your needs should be provided promptly, so that you can get the most out of what you can do.

If you need a wheelchair, you should be referred to wheelchair services and get one that is right for you quickly.

Your needs will change as MND progresses, so your team should make sure that the equipment changes as your needs change.

Diet and nutrition, eating and swallowing

MND causes problems with being able to eat, drink and swallow.

In your appointments, you will be weighed and asked about your diet and what you eat and drink. Your team will ask if you have problems with eating, drinking or swallowing, or if you have any stomach problems such as feeling sick or constipation.

If you are having problems with eating or drinking and you're not getting the nutrients you need, you should get advice about diet and nutrition, and ways of making eating easier. This might include changing your position when you eat, changing what you eat, and using eating and drinking aids and special cutlery that may help make things easier.

Your team can help if you have worries that mean you are not eating, for example, if you feel depressed and have no appetite, if you are worried about eating when people are around or if you

are worried about choking. They can also help if you sometimes feel sick or constipated, because this can also affect your appetite.

If you are having difficulty swallowing, you should have a swallowing assessment.

Gastrostomy

As MND progresses, problems with eating and drinking can get worse so a procedure called gastrostomy may help.

In a gastrostomy, a thin tube is inserted into your stomach from your abdomen, which means food and liquid can go directly into your stomach, rather than having to be swallowed.

Your team should discuss gastrostomy at an early stage after diagnosis and at regular intervals as MND progresses. They should explain about the best time to have a gastrostomy, take into account your MND symptoms, and find out about what you prefer. This is so you can decide together if a gastrostomy might be a good option for you.

Saliva

MND can cause drooling of thin, watery saliva, and thick, sticky saliva, which can be difficult to clear.

If you're having problems with saliva, you should have information and advice about what can help. A member of your multidisciplinary team will talk about what can help and explain the different medicines you could try. You may also be referred to a specialist.

Speech and communication

In your multidisciplinary team appointments, the speech and language therapist should talk about speech and communication with you, and talk to you about different ways of communicating, for example, face-to-face conversations, talking over the phone, by email or using the internet and social media.

If you're finding it difficult to speak clearly, communication equipment can help. This is called Augmentative and Alternative Communication (AAC). This could be an alphabet, word or picture board and/or speech software on a computer or tablet device. If you need more complex

equipment you should be referred to a specialist centre.

As MND progresses, you may need different equipment as your needs change, so this will be reviewed regularly in your team appointments. You should have the equipment you need without any delay. You and your family or carers should get any support and training that is needed in using communication equipment.

Breathing

In most people with MND the muscles used for breathing (called the respiratory muscles) are affected at some stage. This can cause breathlessness and other symptoms such as tiredness, disturbed sleep and poor concentration. You may find that you cannot cough properly to clear your throat.

Your multidisciplinary team will ask if you are having any problems with coughing or breathing, and you may need to have some tests to find out how well your lungs and respiratory system are working.

Your team may also talk about referring you to a specialist respiratory service or clinic if you need it.

Cough

If you are finding that you cannot cough well enough to clear your throat, you should be given information about treatments that can help.

Symptoms of breathing problems

If you notice any of the following symptoms, these might mean that you are starting to develop breathing problems, so you should get information and advice about what can help:

- Breathlessness, especially when lying flat.
- Breathing more quickly or more shallowly.
- Not being able to clear your throat properly when you cough, or you can only cough weakly.
- Frequent chest infections.

- Waking up several times in the night, maybe with nightmares.
- Feeling tired, sleepy and physically exhausted in the daytime.
- Confusion and problems with remembering and concentrating.
- Having hallucinations.
- Having headaches in the mornings.
- Having a poor appetite.

Treating breathing problems (non-invasive ventilation)

Non-invasive ventilation uses a portable ventilator, which is a machine that supports the person's breathing. Non-invasive ventilation can improve quality of life and length of life, but it cannot stop MND progressing.

Information and support about non-invasive ventilation

Your multidisciplinary team should talk about non-invasive ventilation with you, and explain what it can do and what the other options are, including medicines. They should explain that it can be stopped whenever you want, and reassure you that you can ask for help and advice at any time.

If you decide to use non-invasive ventilation, your team will check that you understand it and what is involved. They will check that your family or carers are able and willing to help, and talk to them about any training they will need, and any concerns they have. Your team will provide you and your family or carers with the support you need to use non-invasive ventilation.

Starting non-invasive ventilation

If your team thinks non-invasive ventilation could help, you can use it for a trial period.

Before starting it, your team should prepare a care plan. They should talk about this plan with you and your family or carers, and offer you a copy. These are the areas your care plan should cover.

Non-invasive ventilation care plan

- How your team will support you.
- How often you will see the team for respiratory tests and to check if non-invasive ventilation is helping you.
- What help you will have from family or carers.
- The training and support that you and your family or carers will need.
- The equipment needed and arrangements for its maintenance.
- What to do if you decide that you do not want to continue with non-invasive ventilation.

You should have the chance to get used to the equipment during the day. If this goes well, it is likely that you will start regular treatment at night, as you are settling down to sleep and when you are asleep. The amount of time that you use the ventilator for can be increased gradually as needed.

Many people with MND find that non-invasive ventilation helps them, but it does not suit everyone. You should have regular checks, and your team should discuss with you whether or not to continue the treatment, depending on whether it is helping you.

A member of your team may also talk about medicines to ease breathlessness that you can keep at home and use as you need them.

Stopping non-invasive ventilation

If you no longer want to have non-invasive ventilation, your team will support you and your family or carers with this.

If you have frontotemporal dementia

If a person with MND and frontotemporal dementia has breathing problems, the neurologist should talk about whether non-invasive ventilation may be suitable. This may depend on how the dementia is affecting the person, whether the person is able to make decisions and agree to treatment, and whether the treatment is likely to help. The person's family or carers should be involved in the discussions.

Support with decisions about end of life care

It is not possible to cure MND, so whenever you want to talk about any concerns you have about dying and what you would prefer to happen (or not happen), your multidisciplinary team will be there to talk about these with you. You should be asked if you would like to talk about end of life care, but it is completely up to you when you want to talk about it. Your family or carers can be involved in the discussions if you would like them to be.

These are some of the areas that you might want to talk about.

Areas of end of life care to talk about

- Things that you might wish to plan for, such as what you do want to happen and what you don't want to happen, for example, whether you would want a gastrostomy or non-invasive ventilation.
- Treatments that may be offered – what they involve and how you feel about them.
- What could happen when you die.
- Where you would like to be cared for and where you would like to die.
- Who will be there to represent your wishes.
- Legal issues to plan ahead for your future care.
- Having medicines at home that can help with problems like breathlessness.

You might be referred to a specialist palliative care team if you and your team think this would help.

When it comes to the end of your life, your team should make sure that you and your family or carers have the equipment, care, support and medicines that you need to make you as comfortable as possible, and that bereavement counselling is available for your family or carers.

Off-label medicines

Some medicines for problems such as muscle stiffness or cramps, thin, watery saliva, and

breathlessness may be recommended for 'off-label' use in this guideline. In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically for. This is called 'off-label' use. Off-label use might also mean the medicine is taken at a different dose or in a different way to the licence, such as using a cream or taking a tablet. Your doctor should tell you this and explain what it means for you. There is more information about licensing medicines on [NHS Choices](#).

Sources of advice and support

- Motor Neurone Disease Association, 03457 626 262
www.mndassociation.org
- Brain and Spine Foundation, 0800 808 1000
www.brainandspine.org.uk
- Marie Curie, 0800 090 2309
www.mariecurie.org.uk

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31
- [Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97

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