1A

About the NICE guideline on Motor Neurone Disease

Information for people with or affected by Motor Neurone Disease (MND)

The National Institute for Health and Care Excellence (NICE) provides national guidance to improve health and social care. This includes clinical guidelines with recommendations for treatment and care about specific diseases and conditions. This information sheet is about the NICE guideline on MND (NG42), which applies to anyone affected by MND. The content includes:

1. **What are NICE guidelines?**
2. **What is the NICE guideline on MND?**
3. **How can the guideline help me?**
4. **What does the guideline cover?**
5. **How do I find out more?**

"This patient guide accurately reflects recommendations in the NICE guidance on motor neurone disease. It also supports statement 1 in the NICE quality standard for motor neurone disease." National Institute for Health and Care Excellence, 2019

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Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk

This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5 **How do I find out more?**

1. What are NICE guidelines?

In 2016, NICE released its clinical guideline (NG42) on the assessment and management of motor neurone disease (MND).

This replaces a previous NICE guideline (CG105, published July 2010), which only covered non-invasive ventilation.

There is also a NICE quality standard (QS126), which sets out the priority areas for quality improvement in health and social care for MND.

NICE guidelines are produced by a team of experts, known as a guideline committee, using the best possible evidence. Guidelines are used by the NHS and other bodies to develop standards, assess their practice and support education and training.

The guidelines also give recommendations about treatment, care and support. The aim is to improve the quality of health and social care and promote best practice among professionals.

Recommendations made by NICE are not a legal requirement, but should be taken into account by health and social care professionals alongside:

- other professional guidelines, standards and law
- your personal needs and choices
- the need to protect people from abuse.

More information about NICE and their guidelines is available from their website.

See section 5: **How do I find out more?** for organisations and contacts.

2. What is the NICE guideline on MND?

The guideline covers the assessment and management of MND, and aims to improve care from the time of diagnosis. NICE guidelines are evidence-based recommendations for health and care in England and Wales. They are also considered in Northern Ireland, but may vary on the health and social care service. Topics include:

- diagnosis
- organising your care
- psychological and social support
- changes to thinking and behaviour
- muscle problems and exercise
- equipment and adaptations
- communications
- nutrition and tube feeding
- saliva
- breathing
- non-invasive ventilation (NIV)
- coughing
- planning for end of life.

The NICE guideline stresses your rights, and those of your carers, to be involved in discussions and make informed decisions about your care.

Always ask if you need any kind of health and social care information at a relevant appointment. If you are disabled, you may require this information in a particular format,such as large print or easy-read. Health and social care services in England must now give information in a format you can access. For more details, search for accessible information standard at: **england.nhs.uk**

3. How can the guideline help me?

You can check if you are receiving suitable treatment and care by using the NICE guideline on MND. Being familiar with the guideline can help you and your carer to:

- recognise what good care should look like
- have better discussions with healthcare professionals about your care
- make informed decisions
- challenge decisions with more confidence.

> **"Now we have the NICE guideline, every person living with MND who points it out to health and social care professionals is making a short-term practical step towards improving standards of care."**

It also gives health and social care professionals evidence-based information to help them offer better care for people with MND.

The MND Association will use the guideline in its campaigning work to make sure it is used to improve standards of care for people with MND.

We have created a pocket-sized booklet to support discussions with your health and social care professionals about your treatment and care. This is based on the main points from the NICE guideline. We include the pocket booklet in the folder of our larger guides on MND.

See section 5: **How do I find out more?** about our resources.

What can I do if my needs are not being met?

If you are not receiving the care or treatment you need, discuss this first with the relevant health or social care professional or provider. If this does not improve the situation, make a formal complaint or appeal to the service involved. They should be able to offer information or advise how to do this.

See section 5: **How do I find out more?** for other organisations or refer to our webpage at: **mndassociation.org/mycare**

4. What does the guideline cover?

The following information gives an overview of the NICE guideline on MND.

For more detailed information, see the guideline or the extended version, with the methods and evidence used. NICE have also produced a version of the guideline specifically for patients.

These are available from the NICE website at: **nice.org.uk/guidance/ng42**

Diagnosis

This topic is covered in section 1.1 and 1.2 of the guideline.

The guideline recommends that healthcare professionals should recognise the symptoms of MND, and that the condition affects people in different ways.

It highlights potential first symptoms of MND, including:

- speech or swallowing problems
- twitching or rippling sensations in the tongue
- muscle problems, such as weakness, wasting, twitching, cramps and stiffness
- the impact of muscle problems, such as clumsiness in your hands or trips and falls
- breathing problems, such as shortness of breath or other breathing symptoms
- the impact of breathing difficulties, such as excessive daytime sleepiness, fatigue, early morning headache or shortness of breath when lying down
- changes to thinking, reasoning and behaviour, including frontotemporal dementia (FTD) which affects a small number of people with MND
- laughing or crying at inappropriate times, known as emotional lability.

Healthcare professionals should know who to refer you to if they suspect you have MND and make the referral without delay.

You, your family and carers should be offered information and support throughout the diagnosis process.

You should receive your diagnosis by a neurologist with up-to-date knowledge of MND.

They should set aside enough time to discuss any concerns or questions you may have and arrange a follow-up appointment with a member of the multidisciplinary team (MDT) within four weeks.

See next heading: **Organising your care** for more about MDTs.

If you have any social care needs, you should be referred to adult social care services for an assessment. If you are a carer, you will be referred for a carer's assessment.

The MDT must make sure you are provided with information about MND and support at diagnosis or when you ask for it. Information should be oral and written.

This guidance may include:

- what MND is, likely symptoms and how these can be managed
- how the disease is likely to progress
- where your appointments will be, which professionals will be involved and likely waiting times
- local services (including social care and specialist palliative care services) and how to get in touch with them
- local support groups, online forums and national charities, and how to get in touch with them
- your legal rights, including social care support, employment rights and benefits
- who you need to inform of your diagnosis, such as the Driver and Vehicle Licensing Agency (DVLA)
- who to contact between appointments, during ‘out of hours’ or in an emergency
- how you can plan for your future care, known as advance care planning.

Organising your care

This topic is covered in section 1.5 of the guideline.

The guideline recommends that you should be given a single point of contact for the specialist MND multidisciplinary team (MDT).

An MDT is where a range of health and social care professionals work together to provide care and support. This allows them to share information more easily and co-ordinate your care more effectively. The specialist MND team could be based at a clinic, usually in a hospital, or in the community.

You may have appointments with them as separate individuals, but they should liaise about your treatment and care. The team should include staff with expertise in MND, including a:

- neurologist
- specialist nurse
- dietician
- physiotherapist
- occupational therapist
- breathing physiologist or a healthcare professional to assess your breathing
- speech and language therapist
- professional with expertise in palliative care (with knowledge and training in supporting people with life shortening diseases).

In addition, the specialist MND team should have access to a range of other professionals and teams you may need support from. This is likely to include:

- clinical psychology, neuropsychology and counselling
- social care
- ventilation services to help with your breathing
- specialist palliative care
- a gastroenterologist to help manage your nutrition and tube feeding
- orthotics who provide braces, splints and other items that provide support
- wheelchair services
- assistive technology services, who are experts in daily living aids and equipment
- alternative and augmentative communication (AAC) services, who are specialists in various methods of communication if you have speech problems
- community neurological care teams.

The specialist MND team should carry out regular, co-ordinated assessments of your symptoms and needs. Your individual needs should be taken into account when they tailor how often they assess and review your symptoms. They will continue to be involved in your care and you will not be discharged from their caseloads.

Although it is difficult to predict the progression of MND, healthcare professionals should consider the likely course when planning your care. They should understand that MND can progress quickly. They should think about what equipment and support you might need, before you need it, and regularly review your needs.

Psychological and social support

This topic is covered in section 1.6 of the guideline.

Living with MND can involve a range of emotional challenges and changes that may be difficult to cope with. The guideline recognises the emotional and psychological impact of MND.

At your appointments, healthcare professionals should talk with you about the thoughts and feelings that you and your family have about MND. The guideline gives suggestions of topics to discuss. Healthcare professionals should offer you information about how to access support, and refer you on to counselling or psychology services if needed.

See our booklets: **Emotional and psychological support** and **Telling people about MND**

They should offer your family and carers information about how to access support to take breaks from caring (known as respite care), their right to a carer's assessment and other sources of help.

See our guide: **Caring and MND: support for you.**

Changes to your thinking and behaviour

This topic is covered in section 1.3 of the guideline.

Up to half of people with MND experience some changes to how they think and behave. These changes affect people in different ways. For many people, the changes are usually subtle and have little or no effect on daily life.

For some, the changes may be more apparent and intensive support may be needed to manage daily routines. A small number of people with MND develop a condition called frontotemporal dementia (FTD).

The guideline states that healthcare professionals should explore any changes to your thinking or behaviour with you, your family and carers. Discussions should be tailored to your needs, taking into account your communication, understanding and ability to make decisions for yourself.

You should be referred for a formal assessment if needed.

See our booklet: **Changes to thinking and behaviour.**

Muscle problems and exercise

This topic is covered in section 1.8 of the guideline.

People with MND can experience muscle problems including cramps and pain.

Your healthcare professionals should consider how to relieve these symptoms, including suitable medications. They should review whether any treatment is working and monitor for side effects you may experience. If these medications do not work for you, you should be referred to a specialist service for further support.

Healthcare professionals should explore a suitable exercise programme to help you maximise use of muscles not yet affected by MND, reduce stiffness and discomfort, and maintain movement in your joints.

Exercise should be tailored to your needs, abilities and preferences. The professional recommending the programme should check whether your family or carers are able to support you with your exercises, if needed, and offer them advice and equipment to support them to lift and move you safely.

See information sheet: **6A Physiotherapy** for more on exercise.

Equipment and adaptations

This topic is covered in section 1.10 of the guideline.

The guideline recommends that your daily living needs, such as personal care, shopping, meals and housework, should be assessed and reviewed. This will help get support and equipment in place for when you need it.

Equipment or building works can make your home more suitable for your needs and help you to continue to live there. These changes are known as adaptations. Healthcare professionals should consider your home environment and mobility, and consider whether you need any adaptations.

Equipment and adaptations should take into account likely changes in the future and be readily adapted to cope with these changes. They should also consider the use of other assistive technology, such as environmental control systems which can help you operate your lighting, door entry, appliances and heating systems.

Equipment, including wheelchairs if needed, should be provided without delay. Any items of equipment should be reviewed regularly to ensure they are still suitable for you. You should be referred to specialist services for equipment if your needs are more complex.

See our resources on equipment, wheelchairs and environmental controls.

Communication

This topic is covered in section 1.12 of the guideline.

With MND you may get weakness in your tongue, lips, vocal cords and chest, causing speech to become faint, slurred or unclear. The guideline recommends that a speech and language therapist should assess and review your communication without delay.

All your communication needs should be explored, including face-to-face dicussions, phone and email. You should be referred for a specialist assessment if your needs are more complex. Communication aids to meet your needs should be provided as quickly as possible. Both low-tech and high-tech options should be considered.

If appropriate, the speech and language therapist should involve other professionals to ensure your communication aid works well alongside any other equipment you may have, such as environmental controls. There should be ongoing support and review of your communication needs and aids.

See information sheet: **7C Speech and communication support**.

Nutrition

This topic is covered in section 1.11 of the guideline.

MND can cause difficulties with eating and drinking. Muscles in your throat and mouth may become weak, slow or uncoordinated. This can affect your ability to chew and swallow, leading to weight loss, dehydration and lack of energy.

The guideline recommends that your weight and ability to eat and drink should be assessed and monitored. This should take into account any equipment you use and whether you need someone to help you eat or drink. It should also consider your seating, positioning and posture.

The guideline recommends you are referred for an assessment if swallowing difficulties are suspected. You should be offered support, information, advice and interventions to support you with your nutrition if needed.

Some people with MND choose to have a feeding tube. This is a way of passing fluids, specially prepared liquid feed and medication straight into your stomach through a tube in your stomach.

The guideline recommends that tube feeding should be discussed early, as risks increase the later you have one fitted. Your healthcare professionals should explain this to you. If you choose to have a feeding tube fitted, the guideline recommends that the operation to insert the tube should take place as quickly as possible.

See our resources:
- Information sheet **7A Swallowing difficulties**
- Information sheet **7B Tube feeding**
- Our guide: **Eating and drinking with MND**.

With treatment interventions such as tube feeding, clinicians may need guidance from a partner, family member or close friend if the person with MND is unable to make decisions for any reason. In this situation, the trusted contact may need a power of attorney if they are to make a decision on behalf of the person with MND.

If you wish to make sure you do not have a tube fitted, even in an emergency, you can state this in an Advance Decision to Refuse Treatment (ADRT).

An ADRT tells people involved in your care which treatments you want to refuse in the future and will only be used if you become unable to make decisions or communicate for any reason.

See our information sheet: **14A Advanced Decision to Refuse Treatment (ADRT) and advance care planning**.

Saliva

This topic is covered in section 1.8 of the guideline.

Some people with MND find that they have problems with their saliva. If this is the case, you may experience:

- pooling of thin, watery saliva
- discomfort if saliva collects at the back of the throat
- saliva leaking out from the mouth if you are unable to close your lips fully
- dehydration, if the fluids you lose are not replaced
- thick, sticky saliva which is difficult to clear from your mouth and throat.

If you have problems with saliva, healthcare professionals should assess your:

- saliva, for example the amount and thickness
- breathing
- swallowing
- diet
- posture
- mouth care.

The guideline suggests options for managing and treating saliva problems.

Breathing

This topic is covered in section 1.13 of the guideline.

MND can affect the muscles involved in breathing. The guideline recommends that your breathing should be assessed and monitored. If you have breathing difficulties and tests show you may benefit, you should be offered a trial of non-invasive ventilation (NIV) - see next heading.

You should receive support and information about breathlessness, and guidance on how psychological techniques, support and medication may help.

See our information sheet range **8A-8D** for breathing support.

Non-invasive ventilation (NIV)

This topic is covered in section 1.15 of the guideline.

Non-invasive ventilation (NIV) uses a portable machine to support your breathing. This machine helps boost the flow of air into your lungs, using a mask that covers your nose, or your nose and mouth.

The guideline recommends that healthcare staff discuss NIV with you soon after your diagnosis and on an ongoing basis, explaining the advantages and disadvantages. They should be clear that, although it can help with breathing difficulties and may prolong your life, it will not stop the progression of MND. They should explain that you may become dependent on NIV.

See information sheet: **8B Ventilation in MND**.

Before you start using NIV, the specialist MND and respiratory teams should prepare a detailed care plan and discuss it with you and your family and carers.

The plan should include information about:

- how you will be supported
- how often your NIV will be reviewed
- how to maintain the equipment
- who to contact for technical or clinical support.

Your family and carers should be asked whether they are willing to assist in providing NIV and what training they might need. They should have the opportunity to discuss any concerns with members of the specialist MND or the respiratory team, or another relevant professional.

Your healthcare team should explain that NIV can be stopped at any time you choose and that help and advice is available. If you wish to stop using NIV, you should be supported by professionals with knowledge and experience of stopping NIV, end of life care and the legal framework. If withdrawing NIV is causing distress, they should offer medication to help.

If you don't want to receive ventilation, even in an emergency, you can state this in an Advanced Decision to Refuse Treatment (ADRT) form. This tells people involved in your care which treatments you want to refuse in the futur and in which precise circumstance. Your ADRT will only be used if you become unable to make decisions or communicate for any reason.

See our information sheet: **14A Advanced Decision to Refuse Treatment (ADRT) and advance care planning**.

Coughing

This topic is covered in section 1.14 of the guideline.

If you have difficulty clearing mucus from your chest, you should be shown breathing exercises and techniques to help you improve the strength of your cough.

If these are not effective for you, you should be offered use of a machine to help you cough.

Planning for end of life

This topic is covered in section 1.7 of the guideline.

MND is a progressive life-shortening condition. You should be given opportunities to discuss your concerns and preferences about care at the end of your life, whenever you want to. Healthcare professionals should take into account how you feel and whether you are ready to have discussions about this.

The guideline suggests times when it might be appropriate to talk about end of life, including at diagnosis, if your symptoms change significantly, or if you need to think about tube feeding or ventilation.

You should receive support and advice about how you can plan in advance for your future care, and the guideline gives suggested topics for discussion.

You should be given additional support as end of life approaches. This could include additional care support to help your family spend more quality time with you. Healthcare professionals should make sure you have access to any specialist support, equipment and medications you may need.

See our guide: **End of life: a guide for people with motor neurone disease** for more about planning future care.

The guideline also recommends that your family should be offered bereavement support after you die.

See our booklet: **Finding your way with bereavement.**

5. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Adult social care services
Contact adult social care services for a needs assessment or carer's assessment.
Website: search for:
find your local council at **gov.uk** (England and Wales)
health and social care trusts at **nidirect.gov.uk** (Northern Ireland)
find my council at **careinfoscotland.scot** (Scotland)

Government information
Online government information about benefits and support. in.
Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

MND Scotland
Care, information and research funding for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

Care Quality Commision (CQC)
Independent regulator of health and social care in England.
Tel: 03000 616161
Website: **cqc.org.uk**

Care Inspectorate Wales (CIW)
Independent regulator of health and social care in Wales.
Tel: 0300 7900 126
Email: ciw@gov.wales
Website: **careinspectorate.wales**

Regulation and Quality Improvement Authority (RQIA) (Northern Ireland)
Regulator of health and social care in Northern Ireland.
Tel: 028 9536 1111
Email: info@rqia.org.uk
Website: **rqia.org.uk**

Community Health Councils
For confidential advice and making a complaint about healthcare in Wales.
Website: **llaiswales.org**

NHS and UK healthcare
Information about NHS Services and healthcare across the UK.
Tel: 111 (England, Wales and Scotland)
Available via individual trusts website contact page (Northern Ireland)
Website: **111.nhs.uk** (England)
111.wales.nhs.uk (Wales)
hscni.net (Northern Ireland)
nhs24.scot (Scotland)

National Institute for Health and Care Excellence (NICE)
Provides national guidance and advice to improve health and social care.
Tel: 0300 323 0140
Email: nice@nice.org.uk
Website: **nice.org.uk/guidance/ng42**

Patient Advice and Liaisons Service (PALS)
Confidential advice, support and information on health-related matters in England.
Website: **nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/**

Patient and Client Council
For confidential advice and making a complaint about healthcare in Northern Ireland.
Tel: 0800 917 0222
Email: info.pcc@hscni.net
Website: **patientclientcouncil.hscni.net**

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Dr Aleksander Radunovic	Consultant Neurologist and Honorary Clinical Senior Lecturer and Director, Barts MND Centre.

References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:

Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

See the NICE guideline for MND at: **nice.org.uk/guidance/ng42** and the NICE quality standard for MND at: **nice.org.uk/guidance/qs126**

We offer a wide range of information about MND and Kennedy's disease.
You may find the following resources helpful, relating to this sheet.

Information sheets

7A	Swallowing difficulties
7B	Tube feeding
7C	Speech and communication support
8A	Support for breathing problems
8B	Ventilation for motor neurone disease
8C	Withdrawal of ventilation
11C	Equipment and wheelchairs
14A	Advance decisions to refuse treatment (ADRT) and advance care planning

Booklets

What you should expect from your care
Types of care
Personal care
Caring and MND: quick guide
Changes to thinking and behaviour
Emotional and psychological support
Telling people about MND
Finding your way with bereavement

Large guides

Living with MND
Caring and MND: support for you
End of Life: a guide for people with motor neurone disease

Other resources

Understanding my needs
MND alert card
MND checklist

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: **mndassociation.org/our-services**

Local and regional support

Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on any of our information sheets, access our online form at:
smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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