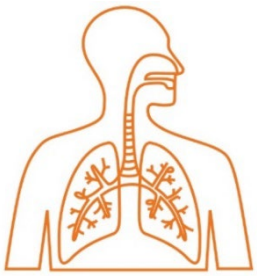
mnda
motor neurone disease association



8A

Support for breathing problems

Information for people with or affected by motor neurone disease

With motor neurone disease (MND) your breathing muscles can weaken. Although these changes cannot be reversed and will progress, therapies and treatments are available to help ease symptoms and improve comfort.

If you have Kennedy's disease, you may also experience changes to breathing, but in most cases these are mild.

This information sheet explores the support available and includes the following sections:

This symbol is used to highlight our other publications. To find out how to access these, see *Our information resources* at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND.

This information sheet has been endorsed by the Association of Chartered Physiotherapists in Respiratory Care (ACPRC).

This information has been evidenced, reviewed by experts and tested with users.

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1 What happens when I breathe?

Breathing is how your body moves air in and out of your lungs. It plays a vital role in keeping your body working. When you breathe in, oxygen enters your lungs and passes into your bloodstream. This oxygen is carried around your body to give your cells the energy they need.

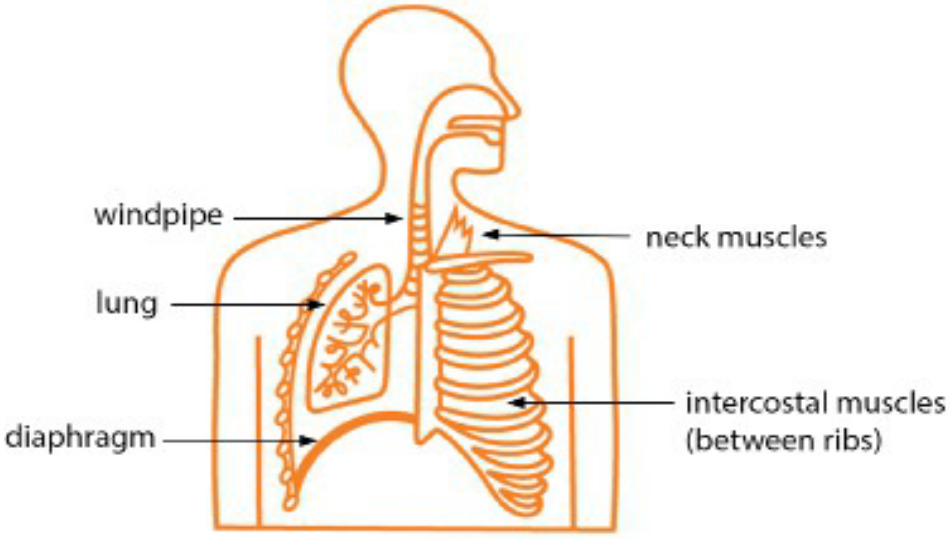
At the same time, your body makes a waste gas called carbon dioxide. This travels back to your lungs and is breathed out. Your body needs to keep the right balance of oxygen and carbon dioxide in your blood to work properly.

You use several muscles when you breathe, including:

- your diaphragm - a large muscle below your lungs
- the intercostals - muscles that sit between your ribs.

These muscles work together. When they tighten, they make space in your chest for your lungs to expand and pull in air. When they relax, the air flows out again.

If you've been very active, or if your breathing muscles have weakened, your neck and shoulder muscles may get involved too.



Muscles involved in breathing

What happens when I cough?

Coughing is your body's way of clearing your airways. You take a deep breath, and your stomach muscles tighten. This pushes your diaphragm up and builds

pressure. Your voice box and throat close briefly, then open quickly to force air out of your lungs.

This strong burst of air helps clear mucus from your lungs, especially if you have a chest infection.

Breathing problems often affect the way you cough. If the muscles in your chest or stomach area become weaker, you may find it harder to clear your airways.

This may affect how you eat and drink, as coughing helps if food or drink 'go down the wrong way' and enter your windpipe (known as aspiration).

2 How might MND affect my breathing?

"Forewarned is forearmed to what may lie ahead, I always feel it better to know what's ahead and ways of dealing with it, the unknown is always more frightening."

When breathing muscles don't work as well as they should, you can't take air in or out as deeply.

This means less oxygen gets into your lungs when breathing in. Also, you may not breathe out as fully, which means your body holds on to more carbon dioxide than it should do.

This imbalance can make you feel breathless, tired, drowsy and confused. It can also cause headaches.

For most people with MND, other muscles are affected first, but breathing problems can sometimes be one of the first symptoms.

Breathing often becomes more difficult during sleep. You might find your sleep is disturbed as breathing muscle weakness can cause dips in oxygen levels. You may feel exhausted when you wake up.

Other signs of breathing changes can include:

- shallow or fast breathing
- feeling breathless, even when resting or lying flat
- a weak cough or trouble clearing mucus or phlegm
- more chest infections than usual
- a weak sniff
- disturbed sleep, nightmares or vivid dreams

- poor memory or concentration
- morning headaches
- feeling very sleepy during the day
- your voice getting weaker
- losing your appetite
- needing to use your neck or shoulder muscles to help you breathe.

If you notice any of these signs, speak to your healthcare team. Ask how to ensure that your breathing is assessed and monitored regularly.

Recommendations to professionals about treatment and care for people with MND are provided by the National Institute for Health and Care Excellence (NICE). Their NICE guideline on MND (NG42) recognises that breathing assessment and monitoring should happen as part of your ongoing care.

If this isn't happening yet, ask to be referred to a specialist respiratory team. They can assess your needs and explain all options.

"A proactive approach from the care team may take pressure off the person with MND and their carer facing a difficult aspect about their condition."

For more about the NICE guideline, see:
information sheet 1A – *About the NICE guideline on motor neurone disease*

3 What can I do to manage changes to my breathing?

If your breathing muscles are affected, they will gradually become weaker as MND progresses. Although these changes cannot be reversed, there are lots of ways to manage the symptoms and feel more comfortable.

Ask for referral to a respiratory team for guidance. Your GP or a member of your wider healthcare team can refer you. Your physiotherapist or occupational therapist can also tailor support to help your breathing needs.

Here are some things that might help:

Sit or lie in a good position: Try to keep your chest open and supported, so your lungs can expand as fully as possible. It's usually easier to breathe if you're not lying flat. When sitting upright or standing, gravity assists the diaphragm to move downwards to help you take a deeper breath.

Use assistive equipment: A riser recliner chair can help you sit at a comfortable angle. An adjustable bed or extra pillows behind your back or under your arms can help at night. Ask your physiotherapist or occupational therapist for advice on the best positions for you.

Improve air flow: Fresh air indoors can make breathing more comfortable. Try opening a window or using a room fan. Take a small hand-held fan with you when out and about.

Add moisture to the air: Some people find it easier to breathe when the air isn't too dry. A humidifier can help keep the air in your home more comfortable.

Stay protected with vaccinations: Try to avoid close contact with people who have coughs, colds or flu. Ask your GP about the annual flu jab, usually given in the autumn. You may be able to get vaccinated for covid and pneumonia too. Your main carer may also qualify for these vaccinations.

For more details, see:
www.mndassociation.org/treatments

Keep calm if you feel breathless: Feeling anxious or worried can make breathing harder. Take slow, steady breaths. It can help if your carer stays calm when supporting you with this. Ask your respiratory team for breathing techniques or see later heading: *What can be done if I feel anxious?*

Try breathing exercises: These can help you take deeper breaths, which make it easier to shift mucus or avoid chest infections. Ask your respiratory physiotherapist for guidance.

Learn coughing techniques: You and your carer can learn techniques to help you improve your cough if it weakens. Ask your healthcare team for advice. If your coughing is caused by food or drink going down the wrong way, ask your speech and language therapist for advice on safe swallowing.

Save your energy: Try not to push yourself too hard. Break tasks into smaller stages and pace your activity throughout the day. Use your energy for the things that matter most to you.

Adjust your eating habits: If your stomach feels full, it can press on your diaphragm and make it harder to breathe. Try eating smaller meals more often rather than large meals.

Loosen mucus with juice: Some people find that pineapple or grapefruit juice (not from concentrate) helps loosen phlegm or mucus, so it's easier to clear.

4 Can I get treatment or therapy?

Yes. If you notice any changes to your breathing, there is support available.

This type of care is usually called respiratory support or respiratory management. It can include tests, equipment, therapies, medications and emotional support, depending on your needs.

Getting support early means you'll have time to understand your options and make decisions that feel right for you.

If you're showing signs of breathing problems, you should be referred to a specialist respiratory team who have experience with MND. Ask your GP or another member of your healthcare team to refer you if needed.

They may suggest that you visit:

- a respiratory specialist or team
- a palliative care team
- an MND care centre or network
- a local neurology service.

These professionals can work together to support your breathing, manage symptoms and help you achieve the best possible quality of life.

For more on palliative care, see:
information sheet 3D – *Hospice and Palliative Care*

What can the respiratory team do?

They can:

- check how your breathing is working using a series of tests
- explain treatments or therapies that are suitable for you
- support you to make informed choices, based on your preferences
- help you plan ahead so your future care can match your wishes.

Breathing tests may include:

Forced Vital Capacity (FVC): to show how much air you can breathe out. This helps measure the strength of your breathing muscles. It's sometimes done with a face mask.

> **"When I visit the MND clinic every three months I have a vital capacity test and a cough test. I am sure my care team would step in and give me advice and recommendations as and when they observed my lung capacity declining to a worrying level."**

Maximum Inspiratory Pressure (MIP): this measures the strength of your breathing-in muscles.

Maximum Expiratory Pressure (MEP): this measures the strength of your breathing-out muscles.

Sniff Nasal Inspiratory Pressure (SNIP): to measure how strongly you can breathe in through your nose, using a small tube with a bung in one nostril.

Arterial or Capillary Blood Gases: to look at the levels of oxygen and carbon dioxide in your blood, using a sample from an artery or earlobe.

Pulse oximetry: uses a fingertip sensor to check how much oxygen is in your blood. This can sometimes be monitored overnight.

Transcutaneous Carbon Dioxide Measurement (TOSCA): to measure carbon dioxide through a clip on your ear, usually while you sleep.

Peak expiratory cough flow (PECF): to check how forcefully you can cough.

What therapies and treatments are likely to be offered?

After assessment, your respiratory team will explain the best options available for your needs. These could help with:

- your breathing
- a weakened cough
- clearing mucus, especially if you've had chest infections.

You don't need to decide everything straight away. Take time to think about your preferences and discuss them with your healthcare team, family or others close to you.

Planning ahead can help make sure your wishes are known, especially if there's a time when you're unable to make decisions or speak for yourself.

For more about breathing support and assisted ventilation, see: information sheets 8B to 8D

For saliva, coughing or choking issues, see: information sheet 7A – *Swallowing difficulties*

It's a good idea to share any decisions you make about breathing support, so that your wishes can be respected.

Share with your family, carers and healthcare team, as this helps everyone understand:

- what matters to you
- how you'd like to be supported if you become unable to communicate or make decisions yourself
- your preferences about treatments you do or don't want in the future.

Depending on your needs, your respiratory or wider care team may suggest:

Symptom monitoring: with a respiratory nurse, physiotherapist or a specialist palliative care team, who work with your GP to help manage symptoms and advise as things change.

Medication: to help manage secretions, such as thin, watery saliva or thick, sticky saliva or mucus, so it's easier to clear. Your doctor may also suggest medication to ease breathlessness or reduce anxiety.

Exercises: with a respiratory physiotherapist, for exercises to make the most of your remaining lung strength and improve your ability to cough.

Breath stacking: to learn how to build extra air in your lungs and make your cough more effective. This technique isn't suitable for everyone, but your care team can advise. It may involve using an inflatable bag and mask. When the bag is squeezed, it gently helps you take in more air before you cough.

Ways to help clear your chest: A respiratory physiotherapist can teach you breathing exercises and coughing techniques to help shift mucus and reduce chest infections. You may also be offered a machine to help you cough which uses a mask and a rapid shift in air pressure to mimic a natural cough. Your respiratory team will assess your needs, but these machines aren't suited to everyone or available everywhere in the UK.

Suction unit: This small device helps to clear saliva or mucus from your mouth. You or your carer can use it, once trained. If your healthcare team can't access one, contact MND Connect for help on **0808 802 6262** or email: **mndconnect@mndassociation.org**.

For more on suction units, see:
information sheet 7A – *Swallowing difficulties*

Assistive ventilation: This is where a machine supports your breathing to maintain or increase the flow of natural air. You can become dependent on this support. There are two types:

- **Non-invasive ventilation (NIV)** boosts air through a mask over your nose, or nose and mouth.
- **Tracheostomy ventilation (trache ventilation):** sometimes called invasive ventilation and different to NIV. This machine provides air flow through a tube, placed directly into your windpipe through your neck.

For detailed information see:
information sheet 8B – *Ventilation for motor neurone disease*

"I started with just using NIV for an hour each day and slowly increased and so found it easy when I used it all night."

Oxygen: This is not usually recommended for MND. It can upset the delicate balance between oxygen and carbon dioxide in the body. However, oxygen may be used during a chest infection, other lung problem or to help during the later stages of MND.

What can be done if I feel anxious?

It's completely natural to feel anxious by breathing changes or breathlessness. You might find it helps to:

- explain how you're feeling with a member of your healthcare team or ask for a referral to a counsellor, psychologist, or specialist nurse
- ask your respiratory team about any concerns with your breathing
- use relaxation or mindfulness techniques to help calm breathing
- explore hospice and palliative care, which may include complementary therapies such as aromatherapy, or music and art therapies
- use medication for anxiety, prescribed for use with breathing support.

For more about support with anxiety, see:

- information sheet 3D – *Hospice and palliative care*
- information sheet 6B – *Complementary therapies*
- our booklet, *Emotional and psychological support*

5 How do I find out more?

Other organisations

We do not endorse organisations, but this list may help you search for further support.

If details change before next revision, contact our MND Connect helpline (see *Our support* in this section).

Find more organisations at: **www.mndassociation.org/organisations**

GOV.UK
Online government advice about support services, benefits and more.

Website: **www.gov.uk**

Health and Care Professions Council (HCPC)
Check their register to find qualified healthcare professionals.

Telephone: 0300 500 6184
Website: **www.hcpc-uk.org**

MND Scotland
Support for people affected by MND in Scotland.

Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **www.mndscotland.org.uk**

myBreathing
Online resource about NIV with MND, with user videos.

Website: **https://mybreathing.mymnd.org.uk**

The National Institute for Health and Care Excellence (NICE)
See guideline NG42 for professional recommendations on MND care.

Telephone: 0300 323 0140
Email: nice@nice.org.uk
Website: **www.nice.org.uk**

NHS and UK healthcare
Information about NHS services and healthcare across the UK.

Main website: **www.nhs.uk**

For England:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **https://111.nhs.uk**
For Wales:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **https://111.wales.nhs.uk**
For Scotland:
Telephone: 111 (for urgent medical advice, available 24/7)
Website: **www.nhs24.scot**
For Northern Ireland:
Telephone: Available via individual trusts website contact page
Website: **www.hscni.net**

NI Direct
Government support and information for people living in Northern Ireland.

Email: through the website contact page
Website: **www.nidirect.gov.uk**

References

References for this information are available on request from: **infofeedback@mndassociation.org** or write to:

Information feedback, MND Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton NN3 6BJ

Acknowledgments

Thanks to our user reviewers and for sharing their experiences with MND and carer support.

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Alison Armstrong, Nurse Consultant, North-East Assisted Ventilation Service, Newcastle upon Tyne Hospitals NHS Foundation Trust

Sarah Ewles, Clinical Specialist Physiotherapist in Respiratory Medicine, The Respiratory Centre, University Hospitals Southampton NHS Trust

Christina Faull, Palliative Medicine Consultant, LOROS, Leicester

Charlie Hardaker, Respiratory Physiotherapist and Co-Lead Home Ventilation Service, University Hospitals Bristol and Weston NHS Trust

Leah Gallon, Clinical Specialist Respiratory Physiotherapist, Respiratory Department, Salisbury Foundation Trust

Martin Latham, Specialist Nurse, Sleep Service, St James Hospital, Leeds

Andria Merrison, Consultant Neurologist with Specialist Interest in Neuromuscular Disease, Director of Bristol MND Care Centre

Dr Naveed Mustfa, Consultant Respiratory Medicine, University Hospital of North Midlands.

Our information resources

We have a wide range of accredited guidance, including the following information sheets.

1A – *NICE guideline on motor neurone disease*

3D – *Hospice and palliative care*

7A – *Swallowing difficulties*

8B – *Ventilation for motor neurone disease*

8C – *Withdrawal of ventilation with MND*

8D – *Air travel and ventilation for motor neurone disease*

14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

We also provide the following booklets and tools:

Living with motor neurone disease

Caring and MND: support for you

Caring and MND: quick guide

What you should expect from your care – to support conversations with your health and social care team

End of life: a guide for people with motor neurone disease – to help you plan ahead for your future care

Getting around – travel, transport and holiday guidance

Understanding my needs – to guide others about your care needs

MND Alert Wristband and our *MND Alert Card*

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

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

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

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

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

Would you like to help with user review of our information? If you are living with MND or Kennedy's disease, or a carer, contact us at **infofeedback@mndassociation.org**

Our support

Our mission at the MND Association is to improve the lives of people with MND today, while building hope for tomorrow.

Our support is here for everyone affected by MND or Kennedy's disease, in England, Wales and Northern Ireland.

MND Connect
Our helpline team can provide emotional support, guidance and information. They can help you search for organisations, our local branches, groups and volunteers, and explain our services and grants. Interpreter calls can be arranged if needed.

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

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

Local and regional support
Find out about our branches and groups, at:
www.mndassociation.org/local-support

MND Association Benefits Advice Service
Explore benefits for England, Wales and Northern Ireland, with professional advisers. Find contact details and more at:
www.mndassociation.org/benefitsadvice

MND Association website
Find out about our work and how to get involved with membership, fundraising and campaigning at: **www.mndassociation.org**

MND Association online forum
Share experiences with others affected by MND or Kennedy's disease. View posts or become a member and join chats at: **https://forum.mndassociation.org**

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you feel we did well and how we can improve this content for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding.

Find our feedback form at: **www.smartsurvey.co.uk/s/infosheets_1-25**

Email your comments to: **infofeedback@mndassociation.org**

Or write to Information feedback, at:

MND Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton
NN3 6BJ

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