

8A

Support for breathing problems

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

With motor neurone disease (MND) your breathing muscles can weaken. Although these changes cannot be reversed and will progress, therapies and treatments can ease symptoms and improve comfort. With Kennedy's disease, you may also have changes to breathing, but in most cases these are mild. This content includes:

1. What happens when I breathe?
2. How might MND affect my breathing?
3. What can I do to manage changes to my breathing?
4. Can I get treatment or therapy?
5. How do I find out more?



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



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 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.

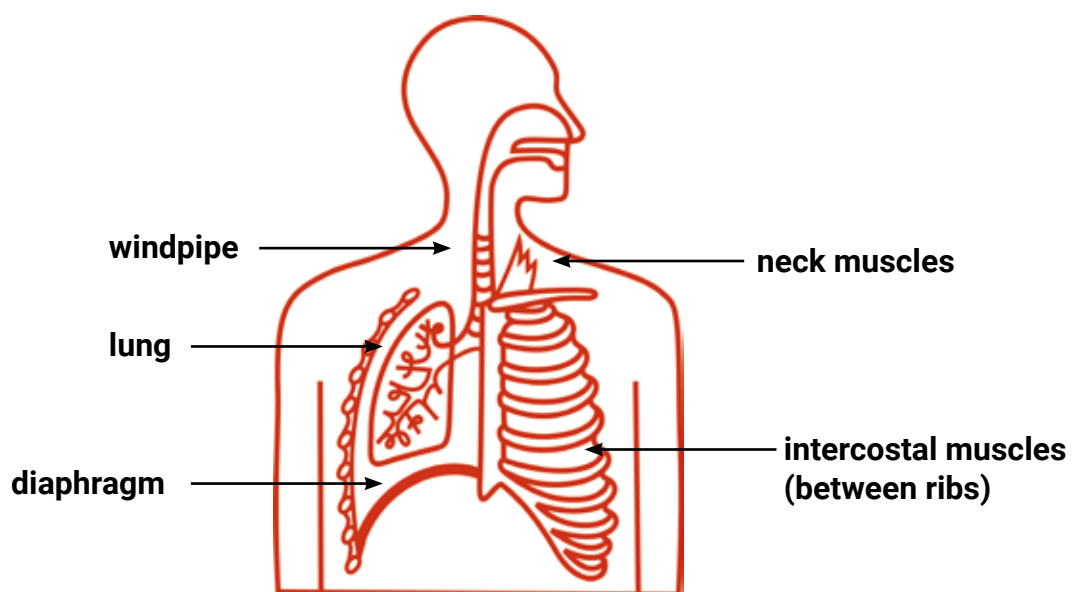
At the same time, your body makes a waste gas called carbon dioxide. This travels back to your lungs and you breathe it out. Your body needs to keep the right balance of oxygen and carbon dioxide in your blood to work properly.

You use several muscles when you breathe, including:

- your diaphragm, which is a large muscle below your lungs
- the intercostals, which are muscles that sit beneath 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, where:

- you take a deep breath
- your stomach muscles tighten
- your diaphragm pushes 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).



“As mum’s condition progressed, we ended up having to transition to using a cough support machine. We used to have an LVR (Lung Volume Recruitment) bag before that.”

2. How might MND affect my breathing?

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.



“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.”

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.



“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.”

Recommendations to professionals about treatment and care 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.



See information sheet: **1A About the NICE guideline on MND** for more about the NICE guideline.

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

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

If your breathing muscles are affected, they will gradually weaken as MND progresses. These changes cannot be reversed, but symptoms can be managed to help you feel more comfortable. Ask your GP or a member of your healthcare team to refer you to a specialist respiratory team. Your physiotherapist or occupational therapist can also tailor their support to help your breathing needs.

Here are some things that might help:

Sit or lie in a good position

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

Sit at a more comfortable angle using a reiser recliner chair to support you. Using 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 about positioning.

Improve air flow and moisture

Fresh air can make breathing feel more comfortable. Open a window or use a fan. Take a small hand-held fan with you when out and about. Some people find it easier to breathe if the air isn't too dry. A humidifier adds moisture to the air in your home.

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, as you are identified as being at risk.



See: mndassociation.org/treatments for more about vaccinations.

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.

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.

Save your energy

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

Keep calm if you feel breathless

Feeling anxious can make breathing harder. Take slow, steady breaths. It helps if your carer stays calm if supporting you when breathless. Ask your respiratory team for breathing techniques.

Learn coughing techniques

You and your carer can learn techniques to 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.

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, you can access care known as respiratory support or respiratory management. It can include tests, equipment, therapies, medications and emotional support, depending on your needs.



“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.”

Getting support early helps you understand your options to make decisions that feel right for you. If you have signs of breathing problems, your GP or another member of your healthcare team can refer you to specialist help. They may suggest:

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



See our booklet: **Types of care.**

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

What can the respiratory team do?

They can assess your needs and explain treatments or therapies that are suitable. Their support can help you make informed choices and plan future care, based on your wishes and preferences. As part of the assessment, Breathing tests may include:

Forced Vital Capacity (FVC)

This test shows how much air you can breathe out, by measuring the strength of your breathing muscles. It's sometimes done with a face mask.

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)

Used 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

This looks at the levels of oxygen and carbon dioxide in your blood, using a sample from an artery or earlobe.

Pulse oximetry

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

Transcutaneous Carbon Dioxide Measurement (TOSCA)

This measures carbon dioxide through a clip on your ear, usually while you sleep.

Peak expiratory cough flow (PECF)

This checks how forcefully you can cough.

What therapies and treatments are likely to be offered?

Take time to think about your choices. You don't have to decide straight away. but after assessment, your respiratory team will explain available options. These can help with breathing, a weak cough and clearing mucus, especially if you get chest infections.



See information sheets: **8B to 8D** for more on breathing support.

Planning ahead can help make sure your wishes are known and respected. Share your decisions about breathing support with your family, carers and healthcare team, so they understand what you want.

Let them know:

- 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.



See our web page on planning ahead, for resources to help you with decisions about future care and how to guide others:

mndassociation.org/planningahead

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

Symptom monitoring

You usually receive this through a respiratory nurse, physiotherapist or a specialist palliative care team, who work with your GP and advise as your symptoms change.

Exercises

Although exercise cannot reverse symptoms or stop them progressing, a respiratory physiotherapist can help you make the most of your remaining lung strength and improve your ability to cough.

Breath stacking

Learn how to build extra air in your lungs and make your cough more effective with this technique. It 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 clear saliva or mucus from your mouth. You or your carer can use it, once trained. Suction units may be provided by your GP or district nurse, or in some areas through a local MND care centre or network. If they are unable to get a unit, ask your GP or a member of your healthcare team to email our Support Services team for guidance: **support.services@mndassociation.org**

Medication

This can help you manage secretions, such as thin or thick saliva or clearing mucus. Your doctor may also suggest medication to ease breathlessness or reduce anxiety.

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.

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 (also called trache ventilation or invasive ventilation) provides air flow through a tube, placed into your windpipe through your neck.



“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.”



See information sheet: **8B Ventilation for motor neurone disease.**

What can be done if I feel anxious?

It's completely natural to feel anxious by breathing changes or breathlessness. Always ask your respiratory team about any concerns with your breathing. 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
- 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.



See our resources:

- 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 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.

Government information

Online government information about benefits and support. in.

Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

Health and Care Professions Council (HCPC)

Check their register to find qualified healthcare professionals.

Tel: 0300 500 6184
Website: **hcpc-uk.org**

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**

myBreathing

Online resource about NIV with MND, with user videos.

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

The National Institute for Health and Care Excellence (NICE)

See guideline NG42 for professional recommendations on MND care.

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

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website: **nhs.uk**

Tel: 111 (for urgent medical advice in England, available 24/7)

Website: **111.nhs.uk** (For England)

Tel: 111 (for urgent medical advice in Wales, available 24/7)

Website: **111.wales.nhs.uk** (For Wales)

Tel: Find individual trusts in Northern Ireland on website contact page

Website: **hscni.net** (For Northern Ireland)

Tel: 111 (for urgent medical advice, available 24/7)

Website: **nhs24.scot** (For Scotland)

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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.

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

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

- 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

Booklets

Caring and MND - quick guide
What you should expect from your care
Getting around
Understanding my needs

Large guides

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

Other resources

MND Alert wristband
MND Alert card

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 this or 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

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