

8A

Support for breathing problems


Information for people with or affected by motor neurone disease

Motor neurone disease (MND) affects people in different ways. You are unlikely to have exactly the same symptoms in the same order as someone else, but at some point you may experience changes in the way you breathe.

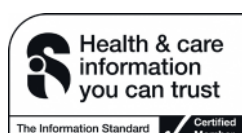
Although weakening of your breathing muscles cannot be reversed with MND, there are therapies and treatments that can help reduce the symptoms.

This information sheet will help answer your questions about breathing with MND. It includes the following sections:

- 1: **What happens when I breathe?**
- 2: **How might MND affect my breathing?**
- 3: **What can I do to help manage any changes to my breathing?**
- 4: **Can I get treatment, therapy or support?**
- 5: **How do I find out more?**

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

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



The MND Association has been certified as a producer of reliable health and social care information.
www.england.nhs.uk/tis

If you have questions after reading this information, your health and social care team will be able to help. You can ask to be referred to specialists for assessment and support if you have any problems with your breathing.

You can also contact our helpline, MND Connect. See *Further information* at the end of this sheet for contact details.

1: What happens when I breathe?

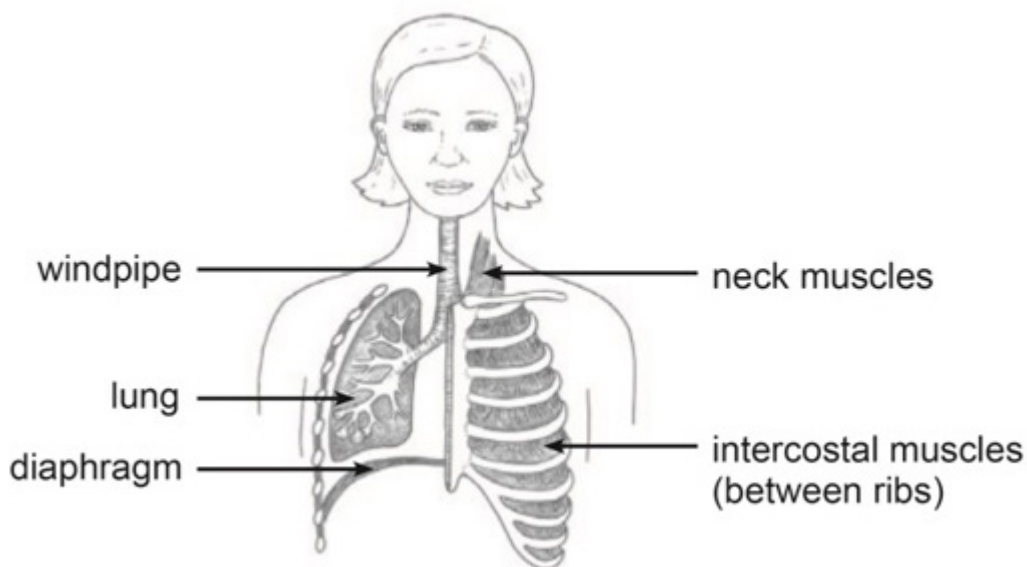
Breathing describes how you move air in and out of your lungs. Oxygen is taken from this air into your bloodstream and carried around your body to help you function.

As this happens, your body produces carbon dioxide as a waste product. This is carried back to your lungs and removed by breathing out. It is important to keep the right balance of oxygen and carbon dioxide in your bloodstream.

You use a number of muscles when you breathe, including:

- the diaphragm - a large muscle beneath your lungs
- the intercostals - muscles between your ribs.

To help you breathe, these muscles tighten to increase the size of your chest, which pulls air into your lungs. When these muscles relax, air is forced out of the lungs.



Muscles involved in breathing

If you have been very active, or your breathing muscles have weakened, your neck and shoulder muscles may also be involved in breathing.

What happens when I cough?

When you cough, you take a big breath in and your stomach muscles tighten to create pressure on the diaphragm. Your voice box and throat close as the muscles tighten to cough, then open as you force air out of your lungs.

This forceful push of air can help clear mucus during a chest infection. Coughing can also help clear any food or drink that 'goes down the wrong way' and enters your windpipe (known as aspiration).

2: How might MND affect my breathing?



"Even though we sometimes fear the truth, it's comforting to read the facts. Not knowing can often create fear."

MND causes muscles to weaken, which may include your breathing muscles. Other muscles tend to weaken first, with breathing getting gradually weaker, but breathing problems are sometimes the first sign of MND. Your ability to cough effectively may also grow weaker.

If your breathing muscles are weak, this affects both breathing in and breathing out. Breathing becomes shallower, pulling less air into the lungs. Less oxygen is absorbed and it is more difficult to breathe out to get rid of carbon dioxide.

This can affect you while you sleep, as oxygen levels in the blood can rise and fall. You may wake up or fail to remain in deep sleep, which can leave you feeling tired instead of refreshed. Carbon dioxide levels may also rise, which can lead to headaches.

You may notice the following signs or symptoms:

- feeling breathless, even when resting or lying flat
- shallow or rapid breathing
- difficulty clearing mucus or phlegm due to a weak cough
- repeated or lengthy chest infections
- a weak sniff
- disturbed sleep or feeling tired when you wake up
- nightmares or hallucinations
- morning headaches
- feeling very tired and sleepy during the day
- poor concentration, poor memory or feeling confused
- your voice getting weaker
- having less appetite for food.

You may also have difficulty taking a deep breath and find that you use your neck and shoulder muscles more to support your breathing.

If you notice any of these symptoms, contact your health and social care team for advice. This is a good time to ask for referral to your local respiratory team, so you can be assessed and discuss options for treatment and care.



"I wish health and social care professionals would plant more seeds to motivate people with MND to find out about breathing support. If you haven't got the symptoms, you may not read about them. More, you hope you don't get them at all."

3: What can I do to help manage any changes to my breathing?

If your breathing muscles are affected by MND, they will continue to weaken as the disease progresses. However, you and your carers can do a great deal to manage these changes. See also section 4: *Can I get treatment, therapy or support?*

The following suggestions may help:

Positioning: Make sure that your chest can expand as fully as possible when sitting, standing or lying. It may be easier to breathe when sitting or standing than lying flat, because gravity helps the diaphragm move downwards to help you take a full breath. A riser recliner chair can help you sit at a comfortable angle. Specialist beds can be adjusted to help you sleep in a more upright position and pillows behind your back and under your arms can help your chest to expand. Your physiotherapist and occupational therapist can advise.

Air flow: Open windows or use a fan to create a flow of air around the room, which can help to stimulate facial nerves if you feel breathless.

Humidity: Some people have found it helps to use a humidifier to improve the level of moisture in the air.

Flu and pneumonia vaccinations: Be cautious about coming into close contact with anyone who has a cough, cold or flu and ask your GP for the appropriate vaccinations. Your main carer may also be able to get the vaccination.

Reduce anxiety: Try to remain calm if you feel breathless, as anxiety or worry can affect breathing and make it worse. A calm, confident approach by your carer is also helpful. Ask your health and social care team about helpful techniques to use when you feel breathless.

See later heading, *MND Just in Case Kit (JIC Kit)*.

Breathing exercises: These can help you manage mucus and reduce the risk of chest infections. Exercises may enable you to take deeper breaths to help expand the lungs more fully. Ask your GP or health and social care team for a referral to a physiotherapist or respiratory physiotherapist.



"I started to have a few symptoms when I woke up in the morning, but these eased once I was up and had done a few stretching exercises. I now know this helped my lungs to breathe better."

Coughing techniques: You and your carer can learn techniques to improve the way you cough. Ask your health and social care team for advice. If your coughing is due to food or drink going down the wrong way, ask your speech and language therapist for guidance on swallowing techniques.

Save energy: Try not to push yourself too hard and take activity in stages. Save energy to do the things you really want to do, rather than tasks that are not really needed.

Eating: It may help to eat more often in smaller amounts, rather than eating bigger meals. When the stomach is full, it can affect the action of the diaphragm and you may find it more difficult to breathe.

4: Can I get treatment, therapy or support?

Breathing support and therapies are usually referred to as respiratory care or respiratory management.

If you show signs of breathing problems, you will be referred to a respiratory team or you can ask to be referred. This is important to ensure you are fully informed about all of the options and how you can be supported. This will enable you to make timely decisions that feel right for you.

Not all health and social care professionals will have experience of working with MND, but your GP or other members of your health and social care team can refer you to specialists, as needed.

You are also likely to receive support from professionals linked to an MND Care Centre or your local neurological service.

Your GP can also refer you to palliative care services for wider support to help you achieve the best possible quality of life.

What can the respiratory team do?

They can:

- offer a series of tests to assess your breathing
- identify therapy and treatment options that are suitable for you
- provide information to help you make informed choices according to your wishes
- help you plan ahead to ensure future care or treatments happen in the way you want.

Tests to assess your breathing may include:

Forced Vital Capacity: to measure how strongly you can breathe out. Sometimes this is done through a facemask.

Maximum Inspiratory Pressure (MIP): to measure the strength of the muscles you use to breathe in.

Maximum Expiratory Pressure (MEP): to measure the strength of the muscles you use to breathe out.

Sniff Nasal Inspiratory Pressure (SNIP): to measure how strongly you can breathe in. This is done by placing a small tube with a bung into the nostril.

Arterial or Capillary Blood Gases: to measure the levels of oxygen and carbon dioxide in your blood, using blood samples taken from an artery or ear lobe. Breathing problems are indicated by a low concentration of oxygen and high concentration of carbon dioxide.

Pulse Oximetry: to measure the oxygen level in your blood using a sensor clipped on your finger.


Transcutaneous Carbon Dioxide Measurement (TOSCA): to measure your carbon dioxide level using a monitor on your skin, usually a clip on your ear. This test is usually done overnight.


What therapies and treatments are likely to be offered?

After assessment, your respiratory team will explain the available options. Depending on your needs, these may include support for:

- your breathing
- a weakened cough
- the clearing of mucus, especially if you have repeated chest infections.

You may want to take time to think about these options, so that you can make an informed choice. Try to think about your preferences for your future care. Your wider health and social care team can help you plan ahead, as can palliative care professionals.

 For more detail about breathing support and ventilation, see:
Information sheets 8B to 8E

 For guidance about saliva, coughing and choking, see:
Information sheet 7A – *Swallowing difficulties*

Share any decisions you make about breathing support with your carers and your health and social care team. This will help them manage your future care according to your wishes. This is important in case you become unable to communicate or make decisions for any reason. For example, you may wish to avoid unplanned or unwanted treatments.

Your health and social care team or your respiratory team may offer the following, depending on your needs:

Symptom monitoring: You may be referred to a specialist palliative care team or a respiratory nurse, who can work with your GP to help manage your symptoms.

Medication: There may be medicines to help with mucus or thin or thick saliva. These can be difficult to clear if you have a weakened cough, problems with swallowing or changes to your breathing. Other medicines may be helpful, for example, to ease breathlessness or anxiety (see also the heading, MND Association Just in Case Kit).

Exercises: A respiratory physiotherapist may be able to advise on exercises to make best use of your lung capacity and help you learn how to cough more effectively.

Breath stacking: This practical therapy is not always suitable for MND, but may be used depending on your symptoms. It helps you place additional air on top of the air already in your lungs, which can add extra force to your cough. Sometimes an inflatable bag with a mask is used to help. When the bag is squeezed, it gently encourages more air to be inhaled.

Chest clearance and assistance to cough: You may be shown breathing exercises and coughing techniques to clear mucus from your chest by a respiratory physiotherapist. A small machine can also help you clear mucus. The machine uses a face mask and creates a rapid shift of pressure to your airway that acts like a natural cough.

Ask your local respiratory centre about availability, as it may not be accessible everywhere in the UK. It may not be suitable for you, as some people find it difficult to adjust to the way it feels, so you will need guidance from your respiratory team. It is generally easier to get used to, if introduced when you first get signs of a weakened cough.

Suction unit: This device can be used to clear secretions from the mouth. You or your carer can do this, once you have been shown how to use it.

Non-invasive ventilation (NIV): This is where a machine supports your own breathing by boosting the amount of normal air you inhale. This is done through a mask over your nose, or nose and mouth.

Invasive ventilation (also known as a tracheostomy): This is where a tube is inserted into the windpipe through the neck so that a machine can help you breathe.

Ventilation is usually needed overnight at first, but as the disease progresses you may become reliant and need it during the day too. If you need it continuously, it is called full ventilation. This can happen with both types.

Using ventilation may not be suitable for everyone. If appropriate, it may help to relieve breathing problems, improve sleep and reduce fatigue, but it will not prevent the progress of the disease.



For more details about both types of ventilation, see:
Information sheet 8B – *Ventilation for motor neurone disease*

Oxygen: This does not help with breathlessness and is not usually recommended with MND, as it can upset the balance between oxygen and carbon dioxide in your body.

However, it may sometimes be used with caution if your oxygen levels are low. Any decisions regarding oxygen for home use should be discussed with your respiratory team, as high levels of oxygen in your blood can be harmful.



For details about the use of oxygen and air travel with MND, see:
Information sheet 8E – *Air travel and ventilation for motor neurone disease*

MND Just in Case Kit (JIC Kit)

The JIC Kit is a box you can keep in your home, which contains medication for use in emergency situations.

Having a JIC Kit nearby can be reassuring should you become breathless or experience coughing or choking.

We supply the JIC Kit box free of charge to your GP, at their request. Your GP then prescribes suitable medicine for you to keep in the box. This ensures medication is on hand for a doctor or community nurse, if they are called out of hours.

Your GP may need to include a signed permission for other professionals to use the medication.

The box also contains written guidance for professionals and (if your GP feels it is appropriate), medication for your carer to give to you while you are waiting for professional medical help to arrive.

Your GP can contact our helpline, MND Connect, for advice about the JIC Kit. See *Further information* in section 5: *How do I find out more?* for contact details.

5: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

GOV.UK

Online government advice on benefits and welfare, including support for disabilities.

Email: email addresses are provided on the website, related to each enquiry

Website: **www.gov.uk**
www.nidirect.gov.uk (Northern Ireland)

Health in Wales

Online help about NHS services and health boards in Wales (see also NHS Direct Wales).

Email: through the website contact page

Website: **www.wales.nhs.uk**

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

The National Institute for Health and Clinical Excellence (NICE)

An independent organisation providing national guidelines on preventing, diagnosing and treating ill health, including NG42 on the assessment and management of MND. The guideline includes a section on NIV.

Address: 10 Spring Gardens, London SW1A 2BU

Telephone: 0845 003 7780

Email: nice@nice.org.uk

Website: **www.nice.org.uk**

NHS Choices

The main online reference for the NHS, including information on continuing healthcare.

Address: Customer Service Centre, The Department of Health
Richmond House, 79 Whitehall, London SW1A 2NL
Telephone: 0207 210 4850
Email: through the website contact page
Website: **www.nhs.uk**

NHS 111

The NHS helpline for non-emergency advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England)

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647
Website: **www.nhsdirect.wales.nhs.uk**

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page
Website: **www.hscni.net**

NI Direct

Like GOV.UK for Northern Ireland, providing welfare and health service information.

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

Reference list

References used to support this information are available on request from

Email: infofeedback@mndassociation.org

or write to:

Care Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Acknowledgements

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Further information

We provide other information sheets related to breathing support and MND:

1A – *NICE Guideline on motor neurone disease*

8B – *Ventilation for motor neurone disease*

8D – *Troubleshooting for non-invasive ventilation (NIV)*

8E – *Air Travel and ventilation for motor neurone disease*

14A – *Advance Decision to Refuse Treatment (ADRT)*

We also provide the following guides:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

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

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser.



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<http://forum.mndassociation.org>** or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/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, MND Association, PO Box 246, Northampton NN1 2PR

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