

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 ease the symptoms.

This information sheet may 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.



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

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

If you have questions after reading this information, your health and social care team can 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 team, MND Connect. See *Further information* at the end of this sheet for contact details.

1: What happens when I breathe?

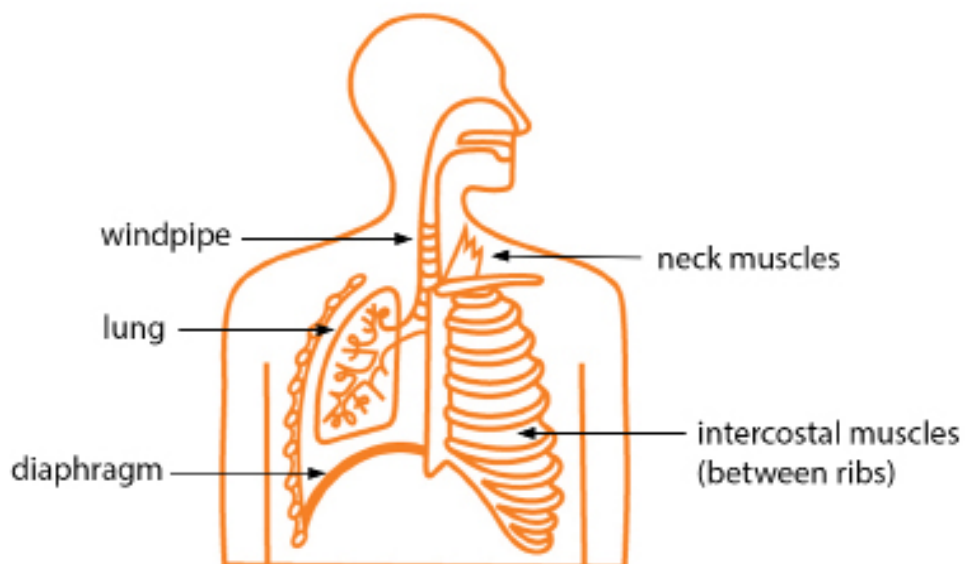
Breathing describes how you move air in and out of your lungs. Oxygen is taken from this air into your bloodstream and carried around your body to help you function.

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 below 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?



"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."

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, drawing less air into the lungs, so less oxygen is absorbed. Breathing muscle weakness also makes it more difficult to breathe out to get rid of carbon dioxide.

This can affect you while you sleep, when breathing is most difficult, with dips in blood oxygen levels that can disrupt sleep. You may wake up often or fail to remain in deep sleep, which can leave you feeling tired instead of refreshed. You may also start waking up with a headache, which can be caused by carbon dioxide levels rising, but can also be caused by not getting a good night's sleep.

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.

The NICE guideline on MND (NG42) recommends that your healthcare team should assess you for breathing difficulties and provide ongoing monitoring of your breathing. If you notice any of the symptoms listed above, and your health and social care team are not already monitoring your breathing, contact them for advice. This is also a good time to ask for referral to your local respiratory team, so you can be assessed and discuss options for treatment and care.



“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 information on the NICE guideline, see:
Information 1A – NICE guideline on motor neurone disease

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, there are ways you and your carers can help 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 assists the diaphragm to 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 enable you to 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: Maintaining a good airflow in the room may be helpful. This may include opening windows or using a fan.

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

Flu and pneumonia vaccinations: Be careful about coming into close contact with anyone who has a cough, cold or flu and ask your GP for the appropriate vaccinations. These may include:

- the yearly flu vaccine (usually given in autumn)
- the one-off pneumonia vaccine.

Your main carer may also be able to get these vaccinations.

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. If available, psychological support may help you feel less anxious and some psychological techniques may reduce anxiety related to breathing too.

See also later headings *What can be done if I feel anxious?* and *MND Just in Case 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.

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, take activity in stages and pace yourself instead. 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 big meals. When the stomach is full, it can affect the action of the diaphragm and you may find it takes more effort to breathe.

Thick and difficult to clear mucus: It is thought that pineapple juice, ideally not from concentrate, can help loosen up sputum and phlegm.

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. If this does not happen, you can ask to be referred. This is important to ensure you are fully informed about all 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 network, or your local neurological service.

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



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

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 one or more of the following:

Forced Vital Capacity (FVC): to measure the volume of air you can breathe out and provides information on how strong the breathing muscles are. Sometimes this is done through a facemask.



“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): 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. This can often be done overnight.

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.

Peak expiratory cough flow (PECF): to measure the strength of the coughing muscles.


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
- clearing 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 assisted ventilation, see: Information sheets 8B to 8D

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

It is a good idea to share any decisions you make about breathing support with your family, 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 about breathing support for any reason in the future. There may be some forms of treatment you do not wish to have.

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 physiotherapist or nurse, who can work with your GP to help manage your symptoms.

Medication: Some medicines can be used to dry up thin, watery saliva and others can help make thick saliva thinner and easier to clear. Mucus and saliva can be difficult to clear if you have a weakened cough, problems with swallowing or changes to your breathing. Other medicines can be used to ease breathlessness or anxiety (see also the heading: *MND 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 people living with 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 (a cough assistance device). 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 cough machines, as they may not be available everywhere in the UK. These machines are not always suitable, so you will need guidance from your respiratory team.

Suction unit: This device can be used to clear saliva and mucus from the mouth. You or your carer can do this, once shown how to use it. If your health and social care team are struggling to get a suction unit, contact our Support Services team on 0808 802 6262 or email: support.services@mndassociation.org

 For more details about suction units, see:
Information sheet 7A – *Swallowing difficulties*


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

 *"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."*

Tracheostomy ventilation (trache ventilation): This is where a machine supports your breathing, through a tube inserted into the windpipe through the neck. You may hear this type of ventilation be called 'invasive ventilation'.

NIV is usually needed overnight at first, but as the disease progresses you may need it during the day too. If you need support from either type of ventilation all the time, it is called being dependent on it. This can happen with NIV or trache ventilation.

Using assisted ventilation may not be suitable for everyone. If appropriate, it may help to relieve breathing problems, improve sleep and reduce fatigue. However, it will not prevent weakening of the muscles used for breathing, or stop the progress of the disease.

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


Oxygen: This is not usually recommended with MND, as it can upset the balance between oxygen and carbon dioxide in your body. However, you may need to have oxygen if you have a chest infection or another problem with the lungs. Any decisions about oxygen for home use should be discussed with your respiratory team.

Oxygen is sometimes used in the late stages of the disease and during end of life care to provide comfort and ease symptoms.

What can be done if I feel anxious?

Breathing problems cause many people to feel anxious. Support is available and it may help to:

- discuss your fears or worries with someone close to you, a member of your health and social care team or ask for a referral to a counsellor or psychologist
- ask for a review with your respiratory team to discuss any specific concerns about your breathing
- learn and practice some relaxation or mindfulness techniques
- consider using complementary therapies, music therapy, art therapy or similar activities, as some people find these help reduce anxiety (these are often provided through palliative and hospice care services)
- use medication to control anxiety, whether for occasional feelings of panic, constant worry, or feelings of depression (when taken as prescribed by your doctor, it is quite safe to use with assisted ventilation too, and can be of major benefit).

 For more information on complementary therapies and palliative care, see:
Information sheet 3D – *Hospice and palliative care*
Information sheet 6B – *Complementary therapies*

MND Just in Case Kit

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

Having the kit nearby can be reassuring should you become breathless or experience coughing or choking.

We supply the 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. If your GP feels it is appropriate, they may also prescribe 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 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, for people living in England or Wales. See NIDirect below for Northern Ireland.

Website: www.gov.uk

Health and Care Professions Council (HCPC)

A regulatory body who keep a register of health professionals who meet their standards of practice.

Address: Park House, 184 Kennington Park Road, London SE11 4BU

Telephone: 0300 500 6184

Website: www.hpc-uk.org

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 Care Excellence (NICE)

An independent organisation providing national guidelines and advice to improve health and social care, including NG42 on the assessment and management of MND.

Address: 10 Spring Gardens, London SW1A 2BU
Telephone: 0300 323 0140
Email: nice@nice.org.uk
Website: **www.nice.org.uk**

NHS UK

The main online reference for the NHS.

Website: **www.nhs.uk**

NHS 111

The NHS helpline if you need urgent, but not life-threatening medical help or advice. Available 24 hours a day, 365 days a year.

Telephone: 111 (England and some areas in Wales)

NHS Direct Wales

Health advice and information service for Wales. Available 24 hours a day, 365 days a year.

Telephone: 0845 4647 or 111 (if available in your area)
Website: **www.nhsdirect.wales.nhs.uk**

Health and Social Care Online (NHS Northern Ireland)

Online information on health and social care services in Northern Ireland.

Website: **www.hscni.net**

NI Direct

Online government advice on benefits and welfare, including support for disabilities, for people living in Northern Ireland.

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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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Further information

We provide the following information sheets related to this information that may be helpful:

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 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

What you should expect from your care – our pocket sized booklet using the NICE guideline on MND to open conversations with your health and social care team

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

MND Alert Wristband – to wear at all times if you wish, to let hospital and emergency staff know you have MND and may be at risk with oxygen

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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

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

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 or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at: **www.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, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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