

8B

Ventilation for motor neurone disease


Information for people with or affected by motor neurone disease

If your breathing grows weaker with motor neurone disease (MND), your respiratory team may suggest using ventilation, where a machine helps support your breathing.

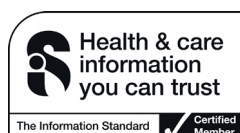
This information sheet explores the different types of ventilation and what to think about when deciding whether to use this support or not.

The content includes the following sections:

- 1: **How can ventilation help me?**
 - 2: **What types of ventilation are available?**
 - 3: **How does non-invasive ventilation work?**
 - 4: **How does invasive ventilation work?**
 - 5: **Can I stop using ventilation?**
 - 6: **How do I plan ahead for my future care?**
 - 7: **How can I find out more?**
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 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

1: How can ventilation help me?

If suitable for you, ventilation can help improve your quality of life by:

- relieving some of the symptoms caused by the weakening of your breathing muscles
- enabling you to breathe more effectively
- reducing fatigue
- reducing anxiety and distress.

However, everyone has a different experience with MND and the benefits may vary. It is also important to understand the different types of ventilation and how these will affect you in the future.

Ventilation may prolong life, but it will not prevent weakening of the breathing muscles or stop the progress of the disease.

When do I need to think about ventilation?

Deciding whether or not to use ventilation can be a difficult choice. It is important to discuss the options with the respiratory professionals involved in your care, so that you can make an informed decision.

Your choice will depend on:

- your own views and preferences
- assessment to see if treatment is suitable for you
- the best timing for ventilation to be introduced
- your needs at that point
- what your wishes might be for your future care.

If possible, find out as much as you can about the options for ventilation as soon as you feel ready to do so.



"This information sheet may be useful to show to your health and social care professionals, who may not always have experience of ventilation with MND."

It is helpful to have discussions with your health and social care team before you develop any symptoms or at the first sign of any changes to your breathing.

You may also find it helpful to discuss the options with your family and anyone involved in your care, as soon as you feel ready to do so.

This will give you time to:

- think about your choices, without a sense of urgency
- understand what your choices mean now and in the future
- ensure your wishes and preferences are known
- ensure everyone who supports you is prepared for the changes ahead, whether or not you decide to use ventilation
- avoid unwanted or unplanned interventions.



“My own experience has shown that people are not always prepared early enough. Or symptoms have not been spotted early enough. In my husband’s case, his breathing problems were too far advanced for him to use non-invasive ventilation effectively.”

2: What types of ventilation are available?

There are two types of ventilation:

Non-invasive ventilation (NIV): where a machine supports your breathing by helping to boost your intake of normal air through a mask. This usually covers either your nose, or your nose and mouth, depending on the type of mask you find most comfortable.

The National Institute for Health and Clinical Excellence (NICE) has produced a guideline: NG42 on the assessment and management of MND, which includes a section on NIV. The section in this document may help when discussing concerns about breathing with your respiratory team or wider health and social care team.



For details, see:
Information Sheet 1A – *NICE guideline on motor neurone disease*

Invasive ventilation (also known as a tracheostomy): where a tube is inserted into your windpipe through the front of your neck, which enables a ventilator to take over your breathing.

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 stop the progress of the disease.

What is full ventilation?

Ventilation is usually needed overnight at first, but as the disease progresses you may need it for longer periods during the day.

If you need to use ventilation for more than 12 hours in every 24, this usually means you are becoming dependent on the machine.

Either type of ventilation can be used part-time if you can still breathe when unsupported. However, invasive ventilation is often used on a continuous basis from the point of introduction.

If you need either type of ventilation continuously, it is called full ventilation. When you are fully ventilated, you are likely to become reliant on this support. Without it, you will become very breathless in a short time and may be unable to breathe effectively on your own.

What happens if I decide not to use ventilation?

If ventilation is not suitable for you or you decide not to use it, your respiratory team, physiotherapist and other professionals, such as your palliative care team, can advise on other ways to help. This may include:

- posture and positioning
- breathing exercises
- assistance if you find it difficult to cough
- ways to relax
- medication to ease symptoms and anxiety.



For details about other breathing therapies, see:
Information sheet 8A – *Support for breathing problems*

Do I need extra oxygen?

In most cases, ventilation for MND uses normal air to help you breathe. Extra oxygen is not usually recommended with MND, as it can upset the balance in your body between oxygen and carbon dioxide.

However, if your oxygen levels are low, it may sometimes be used with caution. 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 with MND during air travel, see:
Information sheet 8E – *Air travel and ventilation for motor neurone disease*

3: How does non-invasive ventilation work?

NIV boosts the flow of normal air into your lungs through a mask that covers your nose, or nose and mouth. This is attached by tubing to a small machine, powered either from a normal electric socket or a battery.

The air flow from the NIV machine is timed to match your normal breathing pattern. Some machines adjust the timing automatically.

Where can I use NIV?

There are several different types of machine, but they are small, portable and can be used anywhere, including at home and on the move.

Even if you need to use a wheelchair, you can still be mobile, as some of the machines can be powered by a battery. If travelling by car, some machines can be plugged into the cigarette lighter.



For details about taking NIV onto an aeroplane, see:
Information sheet 8E – *Air travel and ventilation for motor neurone disease*

The respiratory team will show you how to use the machine. The settings, masks and other parts of the ventilator will be adjusted to suit you. This is usually carried out at hospital as an outpatient, but may require a short stay. However, some of these services may be able to see you at home.

Your usage of the ventilator will be regularly reviewed in case your needs change. The team can provide ongoing support, including advice about maintaining and cleaning the equipment, and out-of-hours urgent support if needed. They may be able to arrange visits at your home if you find it difficult to travel.

Getting used to your machine and the mask does take time. You may adapt very quickly or you may need to try different settings or masks. Your respiratory team will provide support, but if you decide it is not right for you, they may be able to offer other options to help manage your symptoms.

When is NIV not suitable?

Your assessment with the respiratory team is important, as there are various things to consider.

NIV may not be suitable if:

- you do not have either a paid or unpaid carer for long periods during the day or night and you have weakness in your arms or hands – this means you could find it difficult to put on or take off the mask

- you feel claustrophobic or very sore when wearing the mask
- you cannot adjust to the way the flow of air feels when using the machine
- you have swallowing difficulties.

What happens over time with NIV?

At first, you may only need to use NIV at night, to help improve your breathing and quality of sleep. However, as the disease progresses, you may need to use it during the day to help relieve your symptoms.



"I'm at the point where I am using NIV for 15 hours a day."

This means you can become reliant on NIV over time and may reach a point where you need to use it constantly. However, it is not the same as life support.

Even with NIV, there will come a time when the breathing muscles become too weak for the machine to help. For some this can take many months, for others it may happen more quickly. This leads to drowsiness, unconsciousness and ultimately death. This is usually peaceful and your health and social care team can support you to reduce anxiety. See section 5: *Can I stop using ventilation?*

In this situation, resuscitation is unlikely to be helpful, as your NIV will not be able to support you effectively.

Invasive ventilation works in a different way, as it breathes for you. See below, section 4: *How does invasive ventilation work?*

4: How does invasive ventilation work?

Invasive ventilation uses a tube inserted through the front of your neck into your windpipe to help you breathe and enable suctioning of secretions. The insertion of the tube is called a tracheostomy, which is provided under general anaesthetic. The ventilation machine uses this tube to help you breathe.

Invasive ventilation is not always available or offered to people with MND in the UK, but it is sometimes used if NIV is not suitable.

This type of ventilation usually means being fully ventilated and care can be complex. This requires support from an experienced multidisciplinary team and those involved in your care.

What do I need to think about with invasive ventilation?

A facial mask is not required with invasive ventilation, which means you can avoid claustrophobia or discomfort. However, there are other things to consider.

Like NIV, it is portable and can be used at home, but your family and carers may need to provide increasing levels of support. This can be challenging for them and frustrating for you, which could continue for some years with this type of ventilation. Invasive ventilation is most successful where your other symptoms of MND are progressing slowly and your quality of life is good.

If the level of care you require increases, it may no longer be possible to support you at home and may mean moving into a nursing home. In certain circumstances, invasive ventilation may only be offered if you are prepared to move into a nursing home, due to the complexity of care.

If MND causes problems with your speech and communication, invasive ventilation can make this more difficult. Your speaking pattern can be disturbed by the rhythm of the ventilator and with some machines it may be difficult to speak at all.

However, speech and communication problems with MND will continue to progress with or without ventilation, so it may become more difficult to tell people about your wishes for future care. It is important to plan ahead to ensure everyone involved in your care is aware of your wishes. See section 6: *How do I plan ahead for my future care?*

Ask your respiratory team for advice on all these aspects. With invasive ventilation, you may also want to ask about:

- maintenance of the equipment, as this requires input from professionals
- replacing the tube, which is usually done once a month (this is a minor procedure, but does carry some risk)
- suctioning mucus from the airway, which is needed more frequently in the first few weeks of ventilation and whenever chest infections occur
- daily or more frequent care to prevent blockages, infections and skin breakdown around the tubing.

Whether or not to use any type of breathing support is your decision. However, in unexpected situations, it is possible for invasive ventilation to be introduced without your prior consent.

For example, if you are resuscitated in an emergency, it may be used to help you recover. This is usually temporary, but the emergency team may not realise how difficult it can be to stop using invasive ventilation once breathing muscles have weakened with MND. You may then have to accept this type of ventilation as ongoing support, which can affect plans for your future care.

If invasive ventilation is something you definitely do not want in any circumstances, you need to make this clear to all those involved in your care. You may need to write down your wishes to guide people if you become unable to make decisions or communicate for any reason. See Section 6: *How do I plan ahead for my future care?*

5: Can I stop using ventilation?

You can stop using ventilation at any time. It is your legal right to ask that a treatment like breathing support be stopped.

You may wish to stop using ventilation if you feel it is no longer helping or has become a burden. If you use it only some of the time, you may choose not to put the machine back on after a gap. You will probably need other therapies to manage your symptoms, so it is usually best to plan how you will stop with your health and social care team.

However, coming off ventilation is very difficult if you already need continuous support. If you are fully ventilated and can no longer breathe effectively on your own, a natural death is likely to follow in a fairly short period of time.

Your decision to stop must be made with the clear understanding that it will cause a significant risk to your life. Discuss this with your respiratory team or palliative care professionals, who will explain how medication can help you feel calm and relieve distress if you decide to stop in these circumstances.

Your respiratory team, palliative care team and wider health and social care team can answer any questions you may have about planning ahead, including how to manage symptoms and support for your family. You can also record advance decisions to stop using ventilation in specific circumstances, in case you become unable to choose or communicate for yourself. See section 6: *How do I plan ahead for my future care?*

6: How do I plan ahead for my future care?

Using breathing support can raise questions and fears about the way MND will progress. This may be a good time to open conversations with your family and health and social care team about your future care.

This can reduce anxiety and you may find it helpful to talk about:

- choices for end of life care
- options for withdrawal of ventilation, if it is no longer helping or has become a burden
- what will happen in the later stages of MND, as knowing the facts can help reduce fear
- how to record your wishes about future care.

Sharing your thoughts and decisions with everyone involved in your care helps them to meet your needs and wishes. It can also help put your mind at rest.

It is important to have these conversations as early as you can. Speech and communication can be affected by MND and some people also experience changes to thinking and reasoning. This means it may become more difficult to have complex discussions.

In case you become unable to make decisions or communicate, you can record your wishes about future care and treatment. This helps others to understand how you want to be supported and anything you do not want to happen.

This is usually done using one or both of the following:

Advance care plan: this enables you to record your wishes about any aspect of your future care, treatment or practical assistance you might need. It is not a legally binding document, but helps guide everyone involved in your care.

Advance Decision to Refuse Treatment (ADRT): this enables you to record which treatments you do not want introduced or any that you want to be withdrawn under specific circumstances in the future. For example, you may wish to have NIV withdrawn at a particular point. If completed correctly, and you can show that you are able to make reasoned decisions when it is created, your ADRT is legally binding.

As your symptoms progress, your wishes may change. You can review and amend your advance plans or decisions at any time.



For details about how to plan ahead and make advance decisions, see *End of life: a guide for people with motor neurone disease* and Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT)*

Our MND Connect helpline can provide a listening ear or guidance about future planning. See *Further information* in section 7: *How can I find out more?* for contact details.

The helpline team can also direct you to our Association visitors, branches, groups and regional care development advisers, who can all listen to your concerns and help you to find further information.

7: 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.

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 a variety of welfare topics, including support for people with 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

Information on NHS services in Wales, including a directory of the Welsh health boards. This is an online information service only (see also NHS Direct Wales).

Email: through the website contact page
Website: **www.wales.nhs.uk**

MND Scotland

MND Scotland provides care, information and research funding for people affected by motor neurone disease 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. This 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 online/telephone service if you need urgent, but not life-threatening medical help or 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

The equivalent of GOV.UK for Northern Ireland, providing government information on a variety of welfare subjects, including health services and support for disability.

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:

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 for motor neurone disease*

8A – *Support for breathing problems*

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 about MND and how to manage its impact

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 comprehensive guide to making decisions about future care and late stage MND, including advance care planning and advance decisions

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

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



MND Connect

MND Association, PO Box 246, Northampton NN1 2PR

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

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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