

8D

# Troubleshooting for non-invasive ventilation (NIV)

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## Information for people with or affected by motor neurone disease


If your breathing muscles weaken with motor neurone disease (MND), you may decide to use non-invasive ventilation (NIV) for support. This can improve your quality of life.

This information sheet looks at troubleshooting for NIV. Using NIV is usually straightforward, but it can be helpful to know how to prevent or manage common problems that may happen. In most cases this means finding the most comfortable way to use the equipment.

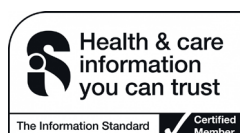
The content includes the following sections:

- 1: **What happens if the equipment goes wrong?**
- 2: **What can I do to feel more comfortable with NIV?**
- 3: **How do 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](http://www.England.nhs.uk/tis)


If you are still trying to decide whether or not ventilation is the right support for you, we provide other sheets in this range to help:

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

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

## 1: What happens if the equipment goes wrong?

You and your main carer will be advised how to use NIV by your respiratory team and the provider of the equipment. Ask them to explain if there is anything you do not understand or if you have any concerns when using NIV.

 *"Ask your professionals to explain things proactively...my own experience has shown that you are often not prepared early enough."*

### Will the equipment need maintaining?

NIV is designed to be hardwearing and reliable, so technical problems are rare. However, as with any piece of equipment, parts may need replacing from time to time.

You and your carers can help by looking after your equipment as shown by the provider. This might include cleaning the mask regularly or replacing inlet filters.

Whoever supplies your NIV equipment will provide contact details for help with any technical difficulty. This will include an out-of-office hours contact.

Keep the telephone numbers in an easily accessible place, including details for your respiratory team.

If you are dependent on NIV or using it more than 12 hours a day, ask your provider about a spare device to keep as back-up.

### What do I need to do in case of power failure?

If you only use NIV some of the time, such as at night, this means you are not reliant on it to breathe. In this case, you will come to no harm if there is a short power cut for a few hours and you cannot use your NIV.

However, if the power cut is likely to last for several days due to an emergency, you may find it more comfortable to stay at another address until the power is reconnected.

This is important if you are reliant on NIV day and night. You may also wish to consider using a power generator. Your respiratory team or the equipment provider can advise.

It can also help to speak to your energy provider about registering as a priority user. This means you should get reconnected as early as possible if there is a power cut. Priority users may also be able to get extra services, such as controls or adaptors to make your power meter or household appliances easier to use.

If you use a battery charged NIV device, always keep your battery charged for use. This also applies to other powered support, such as a spare ventilator, cough devices and suction pumps. If you are dependent on NIV or using it more than 12 hours a day, ask your provider about a device that can be powered both by mains and battery. If you keep a charged battery pack at the ready, this should cover you if:

- you need support away from home, where there is no power supply
- you need back-up during a power cut.

If you have speech and communication difficulties, you can register your mobile phone online with the EmergencySMS service at: [www.emergencysms.org.uk](http://www.emergencysms.org.uk)

This can only be used in emergencies, but enables you or your carer to send an SMS text if you feel your life is in danger. A SMS message would be passed to the police, ambulance, fire rescue, or coastguard as appropriate.

## 2: What can I do to feel more comfortable with NIV?

Your experience with NIV may be different to that of someone else. You may choose not to use it at all or you may find it unhelpful. You may adjust quickly to the feel of the air flow and the equipment, or you may need more support to feel comfortable.

However, your respiratory team can answer questions and assist if you experience any direct discomfort with:

- your face or eyes
- your nose, mouth, or speech and communication
- managing saliva and mucus, or chest infections
- eating and drinking
- anxiety or panic.

## Face and eyes

Sometimes the NIV mask can cause discomfort through:

- air flow leaking around the mask
- pressure of the mask on the skin.

A small amount of air leaking from the mask is acceptable, as long as it is not disturbing you. However, if this blows in your eyes, it may irritate.

Pressure from the mask can cause soreness or redness on your skin, especially early on, when adjusting to how it feels. You may also find it more difficult to close your eyelids as normal, which can irritate.

It may help to:

- reposition the mask and change the tightness of the straps
- check the straps or cushioned areas on the mask are not worn, which can cause leaks
- change to a different mask or use different masks in rotation
- use eye lubricants
- use skincare products and dressings as advised by your health and social care team.

If you need to wear glasses when wearing your mask discuss this with your respiratory team. Some masks have straps that allow you to do this.

## Nose, mouth, or speech and communication

Many people with MND complain of having a blocked nose, dry mouth or difficulties with speech when using NIV.

A blocked nose can be made worse with NIV. It may help to:

- use a steroid spray or nasal decongestant as instructed (long term use of decongestants may cause worse catarrh)
- use a humidifier (or check your humidifier is working)
- place the tubing from your ventilator under the bed clothes to warm air as it filters through the mask (this helps reduce irritation from cold air)
- ask your doctor to check your nose, mouth and sinuses in case there is some other cause.

A dry mouth is common and can be made worse if you breathe through your mouth when sleeping. It may help to:

- increase your daily intake of fluids (aim for around two litres of fluids, thickened fluids, jellies or ices per day)
- review your medications with your doctor, as some can dry the mouth
- use mouth lubricants for temporary relief (your doctor, community nurse, dietitian, and speech and language therapist can advise)
- use a humidifier (or check your humidifier is working)
- try a different mask or a chin strap.

Ask your speech and language therapist for guidance if you notice any problems with the way you speak and communicate. This may not be due to NIV, as MND can affect the muscles in your face and throat.

If your speech remains unaffected by MND, an NIV mask that only covers your nose is less likely to interfere with communication, rather than a mask that covers both nose and mouth. However, this means you lose pressure through the mouth, which can reduce the benefit of using the machine.

## **Managing saliva, mucus and chest infections**

If your symptoms cause difficulties with swallowing, you may find saliva pools in your mouth. This can feel uncomfortable and embarrassing. With NIV, it may make you feel anxious and it can help to:


- sleep in a semi-reclined position or on your side, rather than on your back
- use a suction machine to remove pooled saliva from the front of your mouth – ask your health and social care team for advice
- ask your doctor about medication to dry up the saliva.

You can use medication to either loosen chest secretions or dry up secretions, but it is not advisable to use both together, as they work on the same areas.

Instead of pooling, saliva and mucus can dry out as you breathe, becoming thick and sticky. You may find this difficult to clear. It can help to:

- increase your intake of fluids
- drink certain fruit juices, such as pineapple juice, dark grape juice and papaya (these are thought to help break down mucus and can help hydrate you)
- ask your doctor about medication to thin your saliva
- use a nebuliser, which is a device that produces a fine mist to help you breathe more easily and introduce medicine into your lungs to ease symptoms (ask your doctor or respiratory team for advice)

- ask your respiratory team or respiratory physiotherapist about chest clearance or assisted cough techniques.

 For details about saliva problems, see:  
Information sheet 7A– *Swallowing difficulties*

Contact your doctor immediately if you have any symptoms of infection in your chest or airways.

You may notice:

- a runny nose or increase in mucus
- a sore throat or a cough
- symptoms of fever or just feeling unwell.

Early antibiotic therapy is recommended and flu and pneumonia vaccines can reduce the risk of developing these infections. Ask your doctor about vaccination, as this is available from your GP surgery. It may also be possible for your main carer and close family to receive the vaccinations.

People with MND are rarely offered oxygen, as this can suppress breathing if breathing muscles are weak. However, it may be needed if you have another lung condition or a chest infection. It can be provided through your NIV machine if necessary.

## **Eating and drinking**

Eating and drinking is normally done off NIV as there is an increased risk of food or fluid 'going down the wrong way' into your lungs (known as aspiration). If you are planning to eat and drink while using NIV, discuss this with your respiratory team. They may advise using a different mask or to come off the machine for one or two breaths while swallowing.


With NIV, you may find you swallow more air than normal when you swallow. Constipation can also contribute to trapped air. This can make your stomach feel full and uncomfortable, and may make breathing more difficult.

It may help to:


- ask your respiratory team if your NIV equipment can be adjusted to reduce the risk of trapped air, but this may not be possible if you are reliant on its support
- move around to help air to pass through your system or, if you are no longer mobile, ask someone to help you turn frequently or shift your knees from side to side
- take smaller, more regular amounts of food or fluids to avoid over-filling the stomach at any one time, rather than large meals (this also applies if you have tube feeds)

- if you are using a feeding tube, open the clamp for a short time may allow air to escape from the stomach
- ask your doctor for advice on how to avoid trapped air and for medication to relieve symptoms
- try to drink more fluids and ask your doctor for advice if you are constipated.

It is also important with NIV to maintain good oral hygiene before and after eating. This will help reduce the risk of infection and improve mouth comfort.

 For details about mouth care with MND, see:  
Information sheet 11B – *Mouth care*

If you are finding it more difficult to swallow with MND, you may be at risk of food and drink 'going down the wrong way' and getting into your lungs. This is known as aspiration and can cause chest infections. This may be a good time to consider if tube feeding (gastrostomy) is the right choice for you or not.

 For details about tube feeding, see:  
Information sheet 7B – *Tube feeding*

## **Anxiety or panic**

It is common to feel anxious when using NIV, but there is support available. It may help to:

- discuss your fears or worries with someone close, a health and social care professional or a counsellor
- ask for a review with your respiratory team to discuss any specific concerns about your breathing and the use of NIV
- learn relaxation 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 NIV and can be of major benefit).

We provide a box called the MND Just in Case Kit (JIC Kit) for you to keep medicine at home in case of emergency situations. This can be reassuring if you become breathless, or experience coughing or choking.

We supply the JIC Kit free of charge to your GP, at their request. Your GP prescribes suitable medicine for the box and includes any signed permission for other professionals to use this medication. You then keep the box at home in case you need a doctor or nurse out-of-hours.

Where appropriate, it also provides guidance for your carer and medication they can give to you while waiting for professional medical help to arrive.

If you have any concerns about how to plan for your future care, see *Further information* at the end of this sheet about our end of life and Advance Decision to Refuse Treatment publications.

### 3: 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 to 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).

#### EmergencySMS

If you have speech and communication problems, this service lets you send an SMS text message to the UK 999 service, for the police, ambulance, fire rescue, or coastguard.

Website: [www.emergencysms.org.uk](http://www.emergencysms.org.uk)

#### GOV.UK

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

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

Website: [www.gov.uk](http://www.gov.uk)  
[www.nidirect.gov.uk](http://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](http://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](mailto:info@mndscotland.org.uk)

Website: [www.mndscotland.org.uk](http://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:

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

## **Acknowledgements**

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## **Further information**

We provide other sheets related to this information:

1A – *NICE guideline on motor neurone disease*

7A – *Swallowing difficulties*

7B – *Tube feeding*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

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

11B – *Mouth care*

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

We also provide the following guides:

*Living with motor neurone disease* – our main guide to MND and how to manage its impact

*Caring and MND: support for you* – comprehensive information for unpaid and family carers, who are supporting 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](http://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](mailto:mndconnect@mndassociation.org)

#### **MND Association website and online forum**

Website: [www.mndassociation.org](http://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](http://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](mailto:infofeedback@mndassociation.org)

Or write to:

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

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