

8E

# Air travel and ventilation for motor neurone disease

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


If you have motor neurone disease (MND), you may be using a ventilation device to support your breathing. In most cases, you can travel by air whether you use ventilation some of the time or need it continuously. However, you may need to be assessed to see if you are fit to fly.

This information sheet explains how air travel can affect your breathing and what you need to do if you wish to take ventilation equipment on a flight.

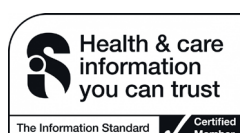
The content has been split into the following sections:

- 1: How will flying affect my breathing?**
- 2: How do I find out if I am fit to fly?**
- 3: Can I take medical equipment on a flight?**
- 4: What else do I need to think about before travelling?**
- 5: How to 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)

## 1: How will flying affect my breathing?

Air pressure inside an aeroplane is lower than at ground level, which means flying is like being high up on a mountain – at high altitudes, the oxygen level falls in the atmosphere and in your blood too. This applies to everyone and can make you feel breathless.

For most people this has no effect on their health, but it can be a problem for people with MND who have weak breathing muscles. You may:

- already have low oxygen levels, so further loss from being inside an aeroplane can cause shortness of breath
- feel drowsy and confused
- fall unconscious, which can be life threatening.

If you wish to travel by any means of transport and need support with your breathing, ask your health and social care team for advice.



For general details about travelling with MND, see: Information sheet 12C – *Travel and transport*

### What is ventilation?

A ventilator is a machine designed to support your breathing. There are two types:

**Non-invasive ventilation (NIV):** where the machine helps 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.

If you are not already using non-invasive ventilation (NIV), your respiratory team may advise NIV for the flight.

**Invasive ventilation (also known as a tracheostomy):** where a machine takes over your breathing for you through a tube, which is inserted into the windpipe through the front of the neck.

On a flight, your ventilator may have to be placed on the seat next to you and you may be charged for this extra seat. Your airline will be able to advise.



For more details about breathing with MND and the types of support available, see the other sheets in this range, Information sheets 8A to 8E.

### Will I need extra oxygen on the flight?

Extra oxygen is not usually recommended with MND, but may be helpful when flying. Your health and social care team or respiratory team will be able to advise and assess your needs.

Once you have been assessed, you will be provided with an appropriate oxygen mask and an oxygen prescription. This can be done as part of a fitness to fly test, but this test can only be completed if you can breathe without ventilation support (see section 2: *How do I find out if I am fit to fly?*).

If you are fully dependent on ventilation and cannot breathe on your own, you will not be able to undertake a fitness to fly test. However, you can still be assessed and provided with an oxygen prescription. In this case, it will depend on the oxygen levels you may need on the plane while using ventilation.

You may also need a special adaptor and training from your respiratory team to use oxygen with your ventilator.

You cannot take your own oxygen supply in an aeroplane, as it has to be provided through a special valve to cope with differences in air pressure. Most airlines will provide oxygen for you according to your medical prescription, but each will have their own rules and there will probably be a charge (see section 2: *How do I find out if I am fit to fly?* for more details about oxygen prescriptions).

For short-haul flights, the oxygen may be able to go under your seat. You may need help to reach this when needed.

For long-haul flights the oxygen may have to go on the seat next to you, which means you may be charged for this extra seat. Your airline will be able to advise.

If you require oxygen during the flight:

- tell the airline before booking your ticket, so you can find out the cost and compare this between airlines
- explain all your travel requirements to the airline to help them meet your needs
- ask your respiratory team for advice before taking any action.

The British Lung Foundation at [www.blf.org.uk](http://www.blf.org.uk) provides a document called Airline oxygen policies that gives a summary of what to expect from many of the commercial airlines flying in and out of the UK. The British Thoracic Society at [www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk) also make recommendations about flying with breathing problems, but these apply to all affected travellers and may not be specific to MND (see *Useful organisations* towards the end of this sheet for full contact details).

## 2: How do I find out if I am fit to fly?

You will need to plan ahead and seek advice from your doctor and respiratory team. They can help assess your fitness to fly and assist with the documents and doctor's letters that airlines are likely to request.

Try to get an appointment with your doctor several months before you wish to travel, and before making any payment towards your journey or holiday. This is important in case you need breathing tests, which take time to arrange.

A member of your respiratory team will usually assist if breathing tests are required. The fitness to fly test can only be carried out if you can still breathe without your ventilator for support. However, if you are fully dependent on ventilation, your doctor can still assess whether you are generally fit to fly and your respiratory team can advise about an oxygen prescription for use with your ventilator (see previous heading *Will I need extra oxygen on the flight?*).

You may find it reassuring to see your doctor again nearer to the date of the flight, especially if your condition has changed. Ask for practical advice about any medical issues that may affect you when travelling, such as:

- how to manage your wider symptoms while you are away
- how to reduce the risk of a blood clot, known as deep vein thrombosis or DVT (this is something that can happen to anyone on a long flight)
- what medication to carry in case you become ill, such as emergency antibiotics to take at the first sign of a chest infection (your doctor will need to provide a letter explaining the purpose of the medication to enable you to carry this on the aeroplane).

### 3: Can I take medical equipment on a flight?

You will need permission from the airline to use electrical equipment and medical devices while on board the aeroplane.

If you have been assessed as fit to fly, you should be able to travel by air with any of the following:

- non-invasive ventilation, where your breathing is supported by a machine that boosts your intake of air through a mask
- invasive ventilation (through a tracheostomy), where a machine helps you breathe through a tube inserted into your windpipe at the front of your throat
- a diaphragm pacer, where an electrical current is used to stimulate the diaphragm (this is not generally available as a new treatment, but you may have an existing pacer fitted if you were part of the trial into its use).

However, the airline makes the final decision.

Always check to see if you can take other medical equipment, such as devices to help you cough more easily. Some airlines may not allow suction machines on board.

There may be problems in carrying liquid feeds (you may need these if you have had a feeding tube fitted). This may be allowed from UK airports, but check the rules of airport security at your destination.

These suggestions may be helpful:

**Contact your equipment provider:** Ask the support service for your equipment about transporting and using your equipment abroad. This will help you in any discussions with your airline.

**Ask for a manual screening with airport security:** Medical equipment is likely to set off security alarms and airport security will need documentation about all devices and equipment. You may find it easier and less stressful to request a manual screening at the airport, instead of passing through the automatic screening.

**Check how power will be supplied:** Before flying, check with the airline and your planned accommodation about their electrical supply. You need to know if the voltage and power output is right for your equipment. Ensure you have the correct adaptors, connectors and cables to run the equipment on the aircraft and at your destination.

**Take batteries:** In some situations you may need to use a dry cell battery (wet-cell batteries are not allowed on flights). This is required for back-up power and during take off and landing. It may also be a requirement on long haul flights.

## Do I have to fill in any forms?

Your airline may ask for a completed Medical Information Form (known as a MEDIF) or they may accept a letter from your doctor stating:

- your diagnosis
- your fitness to fly
- the blood gas results from your breathing tests
- the type of equipment you will be using and the settings required
- that you need to carry the equipment on-board as cabin luggage.

## What questions should I ask?

When you contact the airline for advice, the following questions may be helpful:

- What documents do I or my doctor need to complete before the flight?
- Do I need further documentation for any medication?
- If I use tube feeding, can I carry liquid feeds in my luggage and will these need documentation?
- Can I use my ventilator and any other electrical equipment on-board?
- Is power available for use on the flight and if so what voltage, power output and type of plug socket?
- Will I need an escort to be able to fly, eg carer, nurse or doctor?

- Are there any extra costs involved?
- What kind of insurance cover do I need?
- Will any of the other airports I travel through have rules about electrical equipment or need additional documentation?

## 4: What else do I need to think about before travelling?

To ensure you receive appropriate support, it is important to plan your travel to and from the airport. You may need to pre-book help to get in and out of a train, coach or taxi.

Services can often be pre-booked with the airline to help you move around at the airport and assist with your luggage.

You will also need to think about the type of accommodation you need and the suitability of facilities on offer, particularly if you need wheelchair access.



For general advice on travelling and accommodation with MND, see: Information sheets 12C - *Travel and transport* and 12D - *Planning a holiday*

### What if I get a chest infection or fall ill when I'm abroad?

Any chest infection should be treated and cleared before you fly home. Try to ensure that:

- you have medical approval before flying home
- your medical insurance covers you for any problems and your insurer is informed of any changes to your circumstances and travel arrangements.

It is important that your travel medical insurance includes the cost of return by air ambulance. This may be necessary if you become too ill to return on a commercial flight.

Always check your insurance policy carefully. Some exclude costs from pre-existing health conditions and many ask for a written letter from your doctor to confirm you are fit to fly. Our MND Connect helpline can provide further guidance about travel insurance (see *Further information* at the end of this sheet for contact details).

Check with your doctor if you have any doubt about your fitness to fly.

## Are there any other arrangements that will help me?

You may wish to think about:

- applying for a European Health Insurance Card (EHIC) to entitle you to low-cost or free medical treatment if you need support in a European Economic Area (EEA) country or other countries in Europe (see the online information service GOV.UK at: [www.gov.uk](http://www.gov.uk))
- carrying a doctor's letter in your hand luggage to explain your medical condition and treatment, with contact details for your specialists
- taking our MND Alert Card in your wallet, purse or key documents when travelling to English speaking countries – this alerts hospital staff that you have MND if admitted in an emergency and shows key contacts for specialist advice (see *Further information* at the end of this sheet for details about ordering our publications)
- taking any documents you may have about your wishes for care when travelling to English speaking countries, such as our Understanding My Needs leaflet – this provides details about your needs, wishes and preferences if you are admitted to hospital for any reason (see *Further information* at the end of this sheet for details about ordering our publications)
- carrying a set of printed phrases or key information in the local language and English, to help you explain your needs when abroad – these can also save time and anxiety at the airport and during the flight if you have speech and communication difficulties
- arranging access to an interpreter if you think you will need someone to translate while abroad
- finding out contacts for emergency services at your destination
- finding out if any features of your destination may cause problems, such as altitude or high pollution levels?
- asking the airline for a Frequent Traveller's Medical Card if you often travel by air, as this helps to make it easier to arrange each journey
- if you are travelling by air and use a powered wheelchair, the airline may immobilise your chair for safety reasons. Contact the airline you are travelling with in advance to find out what their requirements are. An 'airsafe' plug can be purchased to inhibit most powered wheelchairs on flights. It plugs into the charging socket to immobilise the chair, and can prevent costly damage to powered wheelchairs, such as wires being cut or disassembly to remove the battery. Search for *airsafe wheelchair plug* online to purchase, as may be available from various suppliers.



*"If you have speech problems with MND, a pre-printed list of useful phrases for the airport, airline and customs can be helpful."*



## 5: How to 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, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

#### Aerospace Medical Association

This is an American organisation involved in medical research for air and space travel, providing medical information and recommendations for airline passengers.

Address: 320 South Henry Street, Alexandria, VA 22314, USA  
Email: [inquiries@asma.org](mailto:inquiries@asma.org)  
Website: [www.asma.org](http://www.asma.org)

#### British Airways

For online information about medical conditions regarding air travel and fitness to fly.

Website: [www.britishairways.com/en-gb/information/special-assistance/medical-conditions](http://www.britishairways.com/en-gb/information/special-assistance/medical-conditions)

#### British Lung Foundation

For information and support on a number of subjects including travel and transport, oxygen and equipment.

Address: 73-75 Goswell Road, London EC1V 7ER  
Telephone: 03000 030 555  
Email: [helpline@blf.org.uk](mailto:helpline@blf.org.uk)  
Website: [www.blf.org.uk](http://www.blf.org.uk)

#### British Thoracic Society

For information on air travel guidelines, with recommendations about breathing problems.

Address: 17 Doughty Street, London WC1N 2PL  
Telephone: 020 7831 8778  
Email: [bts@brit-thoracic.org.uk](mailto:bts@brit-thoracic.org.uk)  
Website: [www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)

#### The Disabled Persons Transport Advisory Committee (DPTAC)

DPTAC advises the government on transport legislation and the transport needs of disabled people.

Website: [www.gov.uk/government/organisations/disabled-persons-transport-advisory-committee](http://www.gov.uk/government/organisations/disabled-persons-transport-advisory-committee)



### **GOV.UK**

Online government advice on a variety of welfare topics, including support for people with disabilities. The site provides guidance about travelling abroad.

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

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

### **International Alliance of ALS/MND Associations**

For a directory of associations around the world who are dedicated to supporting people with motor neurone disease.

Email: through website contact page

Website: **www.alsmndalliance.org**

### **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**

### **NI Direct**

Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page

Website: **www.nidirect.gov.uk**

### **Swiss Assist**

An organization offering an insurance scheme that will arrange for your return flight by air ambulance if needed in an emergency.

Telephone: 0041 91 649 37 69

Email: admin@swissassist.ch

Website: **www.swissassist.ch**

## Reference list

References used to support this information are available on request from:

email: [infofeedback@mndassociation.org](mailto: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*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

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

12C – *Travel and Transport*

12D – *Planning a holiday*

We also provide the following guides and tools:

*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 and family carers, who are supporting someone living with MND

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

*MND Alert Card* – a card for your wallet or purse to help alert hospital staff that you have MND if admitted in an emergency, on which you can write your key contacts for specialist advice

*Understanding My Needs* – this helps you record details about your needs, wishes and preferences to help if you are admitted to hospital or residential care for any reason

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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