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Air travel and ventilation for motor neurone disease


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 many cases, you can travel on a plane if you use assisted ventilation. However, you may need to be assessed to see if you are fit to fly.

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

The content has been split into the following sections:

- 1: How can flying affect breathing?**
 - 2: How can 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 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.



This information sheet has been endorsed by the Civil Aviation Authority (CAA)

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

1: How can flying affect breathing?


Air pressure inside an aeroplane is lower than at ground level. This means flying is like being high up on a mountain (known as being at a 'high altitude'). When you are at high altitudes, the oxygen level falls in the atmosphere and by a small amount in your blood too. This happens to everyone, whether or not they have MND, and can make some people feel breathless.

However, for most people with MND this has no noticeable effect while flying.

It is usually an issue for people who have another breathing problem that is not linked to MND. While on a plane, these people may:

- already have low oxygen levels, so having even lower levels inside an aeroplane causes shortness of breath
- feel drowsy and confused
- even fall unconscious, which can be life threatening.

If you wish to travel by any type of transport and need support with your breathing, ask your respiratory team or MND specialist for advice.

 For more general information about travelling with MND, see our booklet, *Getting around*.

What is assisted ventilation?


Assisted ventilation is where a small machine helps increase the flow of air into your lungs. For the rest of this sheet, we will shorten the term 'assisted ventilation' to 'ventilation'.

There are two types:

Non-invasive ventilation (NIV): where the machine helps boost your intake of air, through a mask. The mask may cover either your nose, or your nose and mouth, depending on what best suits your needs.

If you are not already using NIV to support your breathing, your respiratory team may advise it for the flight.

Tracheostomy ventilation (trache ventilation): where a machine supports your breathing through a tube, which is inserted into the windpipe through an opening made in the front of your neck.

 For more details about breathing with MND and the types of support available, see: Information sheets 8A and 8B.

Will I need extra oxygen on the flight?

It is unlikely that you will need extra oxygen on the flight. Extra oxygen is not usually recommended with MND. However, if you have a breathing problem **not** caused by MND, oxygen during the flight may be helpful for you. Your respiratory team or MND specialist can assess and advise whether oxygen would be helpful for you.

If you have been assessed as needing oxygen for the flight, you will be given an appropriate oxygen mask and oxygen prescription. You may also need a special adaptor and training from your respiratory team to use oxygen with your ventilator.

If you need 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 needs to the airline to help them meet these (you may need to be accompanied on the flight by a carer, family member or friend)
- ask your respiratory team for advice before taking any action.

You cannot take your own oxygen supply on the plane. Most airlines will provide oxygen for you according to your medical prescription, but each will have their own rules and you may have to pay extra for this. Contacting the airline as soon as possible can help organise this, including how to store the oxygen while on the flight.

The European Lung Foundation at:

www.europeanlung.org/en/lung-disease-and-information provides an *Airline index* that details the oxygen policies and contact details of different airlines.

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

Before flying, 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 need.

Make 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 help if breathing tests are needed. The fitness to fly test can only be carried out if you can still breathe without a 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 whether an oxygen prescription for use with your ventilator would be helpful (see *Will I need extra oxygen on the flight?* in section 1: *How can flying affect breathing?*).

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 can happen to anyone on a long flight, whether or not they have MND)
- 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?

Medical equipment is delicate and can be easily damaged. Where possible, medical equipment should be taken on board as hand luggage. You will need permission from the airline to use electrical equipment and medical devices while on board the aeroplane.

You may also wish to ask about insurance for expensive medical devices and check all the paperwork carefully.

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

- non-invasive ventilation (NIV), where your breathing is supported by a machine that boosts your intake of air through a mask
- tracheostomy ventilation (trache ventilation), where a machine helps you breathe through a tube inserted into your windpipe at the front of your neck.

However, the airline always makes the final decision.

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. Ask the airline you plan on travelling with to advise on this.

Always check in advance with the airline if you can take the following on board with you:

- devices to help you cough more easily
- suction machines
- powered communication aids (taking a low tech communication aid as a back up may be helpful while flying).

- i** For more information on cough devices, suction machines and communication aids, see Information sheets:
8A – Support for breathing problems
7A – Swallowing difficulties
7C – Speech and communication support
(see Further information at the end of this sheet for more details).

These suggestions may also 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.

Get a letter from your health and social care team: This may help when letting the airline know what equipment you need to take onto the aeroplane with you.

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. Manual screening may be more intense than standard screening, and so should take place in a private room or area, and you should be able to have someone with you during the screening.

Take batteries: You will need batteries to power any medical equipment you take on board with you. This is especially important if you are dependent on ventilation (meaning you cannot breathe effectively on your own without it). Check your airline's requirements on batteries before you fly. You may need to use a dry cell battery as wet cell batteries are not allowed on flights. Contact whoever provided your equipment if you need more information about the batteries.

Check how power will be supplied: Ensure you have the correct adaptors, connectors and cables to run the equipment on the aircraft.

What about tube feeding equipment?

If you have a feeding tube fitted, you may wish to take liquid feeds or other tube feeding equipment on to an aeroplane.

Before flying with tube feeding equipment, always check:

- the security rules of the airports you are travelling to and from
- the rules of the airline you are travelling with
- whether or not you can have feed delivered to your destination (your home feeding team can help organise this)
- with your GP, neurologist or wider health and social care team, as they may be able to provide you with a letter on headed paper giving details of your equipment and feeds.

What about wheelchairs?

If you use a wheelchair to get around, you will probably not be able to take this on board with you, as it is unlikely to be able to fit down the aisle of the plane. You will most likely need to use an aeroplane wheelchair to get on and off the plane, and to your seat.

If you use a powered wheelchair, this will most likely need to be placed in the hold. The airline may need to immobilise your chair, (stop 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 bought 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 cutting wires or taking the chair apart to remove the battery. Search for *airsafe wheelchair plug* online to purchase, as they may be available from various suppliers. Contact your wheelchair service if you need more information about the batteries in your wheelchair.

Do I have to fill in any forms?

Your airline may need your doctor to complete a Medical Information Form (known as a MEDIF), or a letter stating:

- your diagnosis
- your fitness to fly
- the results from your breathing tests
- the type of equipment you will be using and the settings needed for this
- that you need to carry the equipment on board as hand luggage.

What questions should I ask?

It may be helpful to ask the airline the following:

- What documents do my doctor or I need to complete before the flight?
- Do I need extra documentation for any medication?
- If I use a feeding tube, can I carry liquid feeds in my cabin luggage, and will these need documentation?
- Can I use my ventilator and any other electrical medical equipment on board?
- What sort of batteries can I take on board, and how do these need to be stored?
- Will I need to have someone with me to be able to fly?

- Are there any extra costs involved?
- Will any of the other airports I travel through have rules about electrical equipment or need additional documents?

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



"Your information on travel reassured me that it would probably not be too stressful and worth 'having a go'. As it turned out, both ventures were successful!"

Tell your travel insurance company and the airline as soon as possible that you have motor neurone disease and if you use ventilation equipment to support your breathing.

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

In the EU it is your legal right to have support when travelling by air if you are disabled.

You can get help:

- getting through the airports you are flying to and from
- getting on and off the aeroplane
- during the flight
- transferring between flights.

If you feel this would be helpful, let the airline you are travelling with know up to 48 hours before your flight. The Civil Aviation Authority provide more information about this on their website, at: **www.caa.co.uk/Passengers**



"Informing in advance that I am a disabled wheelchair user made transferring between interconnecting flights a breeze, and I was assisted every step of the way."

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.

Before flying, check that your accommodation has a suitable electrical supply to power your equipment. You need to know if the voltage and power output is right for your equipment. You will also need to have batteries as back up to run your medical equipment in case of emergencies. Ensure you have the correct adaptors, connectors and cables to run the equipment on the aircraft and at your destination.



For general information on travelling and accommodation with MND, see our booklet *Getting around*.

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

Any chest infection needs to 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 information 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 flying.



"I had a heart attack while on holiday. I had informed the insurance company of my MND and they processed the claim straightforwardly as I had no previous heart problems."

Are there any other arrangements that will help me?

It is helpful to think about:

- taking out travel medical insurance
- carrying a doctor's letter in your hand luggage to explain your medical condition and treatment, with contact details for your specialists (it may help for this to be on headed paper)
- 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 advance care planning 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)
- 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
- if the country you are visiting has any rules on importing medications that are allowed in the UK (it may be helpful to check the country’s website, or contact their embassy to find out more)
- finding out if any features of your destination may cause problems, such as high pollution levels
- asking the airline if a Frequent Traveller’s Medical Card would be helpful (this can help make it easier to arrange each journey if you often travel with the same airline)
- how you will transfer between your wheelchair and the onboard wheelchair.



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



For more information on advance care planning documents, see:
 Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

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

Asthma and Lung UK

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

Address: 18 Mansell Street London, E1 8AA
Telephone: 0300 222 5800
Email: helpline@asthmaandlung.org.uk
Website: www.asthmaandlung.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: Through the website contact page
Website: www.brit-thoracic.org.uk

Civil Aviation Authority

For information and advice on travel by air. Website features a page on your rights to help while travelling by air if you're disabled.

Address: Aviation House Beehive Ringroad Crawley West Sussex RH6 0YR
OR
Canary Wharf, London E14 4HD
Telephone: 0330 022 1500
Email: infoservices@caa.co.uk
Website: www.caa.co.uk

The Disabled Persons Transport Advisory Committee (DPTAC)

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

Address: Disabled Persons Transport Advisory Committee (DPTAC) c/o Department for Transport, Great Minster House, 33 Horseferry Road, London SW1P 4DR
Email: dptac.enquiries@dft.gsi.gov.uk
Website: www.gov.uk/government

European Lung Foundation

Provide information on lung conditions. Also provide an *Airline index*, detailing the oxygen policies of many different airlines.

Address: 442 Glossop Road, Sheffield S10 2PX
Telephone: 0114 322 0635
Email: Through the website contact page
Website: **www.europeanlung.org**

GOV.UK

Online government advice on a variety of welfare topics, including support for people with disabilities, for people living in England and Wales. The site also provides guidance about travelling abroad, including some of the items allowed in cabin and hold luggage.

Website: **www.gov.uk**
www.gov.uk/browse/abroad

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: Unit 8, 76 Firhill Road, Glasgow, G20 7BA
Tel: 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 on preventing, diagnosing and treating ill health, including NG42 on the assessment and management of MND. This guideline includes a section on NIV.

Address: 2nd Floor, 2 Redman Place, London, E20 1JQ
OR Level 1A, City Tower, Piccadilly Plaza, Manchester, M1 4BT
Telephone: 0300 323 0140
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**

TryB4UFLy

Provide information and advice for disabled people who wish to travel by air, plus cabin assessments and hire equipment to help make journeys easier.

Telephone: 020 8770 1151

Website: www.tryb4ufly.org.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, 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 sheets related to this information that may be helpful:

1A – *NICE guideline on motor neurone disease*

7A – *Swallowing difficulties*

7B – *Tube feeding*

7C – *Speech and communication support*

8A – *Support for breathing problems*

8B – *Ventilation for motor neurone disease*

14A – *Advance Decision to Refuse Treatment and advance care planning*

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

Making the most of life with MND – our quality of life booklet to help you find ways to maintain your interests with MND

Getting around – travel, transport and holiday guidance for people living with MND.

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. Alert cards come supplied with our *Living with MND* and *End of life* guides, but are also available to order from MND Connect.

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 or order in print from the MND Connect team, who can provide additional information and support:

MND Connect

Telephone: 0808 808 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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