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Air travel and ventilation for motor neurone disease

Information for people with or affected by motor neurone disease

With motor neurone disease (MND), you may use assisted ventilation for breathing support. This information sheet explains how flying can affect your breathing and what you need to do if taking medical equipment on board.

If you have Kennedy's disease, you may also experience changes to breathing, but in most cases these are mild.

This content includes:

- 1 How does 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.



Patient Information Forum

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

1 How does flying affect breathing?

The air pressure in an aeroplane is lower than on the ground, like being on a mountain at high altitude. This means there's less oxygen available and your blood oxygen level may drop slightly. This happens to everyone and can make you feel breathless. However, even with MND, you may not notice a difference.

If you have other breathing problems, not caused by MND, lower oxygen levels on a flight may cause:

- breathlessness, drowsiness or confusion
- loss of consciousness in rare, serious cases, which can be life-threatening.

If you use ventilation or have any concerns about flying, speak to your respiratory team or MND specialist before you travel. They can assess your breathing and help you plan a safe trip.



For general tips on travelling with MND, see: our booklet, *Getting around*.

What is assisted ventilation?

If you use a small machine to help you breathe, it's called assisted ventilation. It supports the flow of air into your lungs if breathing muscles weaken.

There are two main types, and your respiratory team can assess your needs and explain the impact of these:

Non-invasive ventilation (NIV): A machine gently increases the flow of air into your lungs through a mask over your nose, or your nose and mouth. It can be used for short periods during the day or overnight.

Tracheostomy ventilation (trache ventilation): Also known as invasive ventilation, this delivers air through a small tube in your windpipe, inserted through an opening made at the front of your neck.



See more about therapies and treatment in: information sheets 8A *Breathing support* and 8B *Ventilation in MND*.

Will I need oxygen on the flight?

Most people with MND don't need extra oxygen (often called supplementary oxygen) when flying. If you use assisted ventilation, this helps the flow of natural air, rather than oxygen. As oxygen therapy can upset your breathing balance with MND, it must be used with caution. However, your respiratory team may recommend it for other underlying problems with your breathing. Ask them for guidance.

If you do need oxygen, you will be given an oxygen prescription and the right type of device, commonly a nasal cannula. You will also be given advice on how to use oxygen safely, including how to use it with your ventilator and any special adaptors required.

Each airline has different rules and costs in relation to oxygen provision and use during flight. Check this in advance. Some may provide oxygen free but there may be an additional charge. Some may ask you to provide your own, with an approved portable oxygen concentrator at your own cost. Either way, pre-flight medical clearance will be required.

Before booking your flight:

- contact the airline before booking your ticket to ask about their oxygen policy, any fees and to compare with other airlines
- ask the airline about any forms that need to be completed to ensure your medical clearance to fly
- explain all your travel needs in full to the airline so they can help meet these (you may need someone to travel with you)
- get advice from your respiratory team before taking any action.



For an *Airline index* with details of oxygen policies and airline contact details, see The European Lung Foundation at:

<https://europeanlung.org/en/information-hub/living-with-a-lung-condition/air-travel/airline-index/>

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

Before booking a flight, seek advice from your doctor and respiratory team. They can assess your health and breathing and let you know if you're well enough to fly.

They can also assist with the documents and doctor's letters that airlines need. Some airlines may require these to be dated in the last month before your flight.

Have an early discussion several months before you plan to travel, and before making any payment towards your journey or holiday. This is important in case you need time for extra checks or breathing tests, which can take time to arrange.

You might be offered a hypoxic challenge test. This checks how your body responds to lower oxygen levels, like those on a plane. Your doctor can look at your overall health and your respiratory team can advise if you might benefit from using oxygen during the flight.



See the heading in the previous section:
Will I need supplementary oxygen on the flight?

You may find it reassuring to see your doctor again, closer to the date of your flight, especially if your condition changes.

Ask for practical advice about any medical issues that may affect you when travelling, such as:

- how to manage your symptoms while you are away
- how to lower your risk of a blood clot, known as deep vein thrombosis (DVT), which can affect anyone on long flights
- emergency medication you might need, such as antibiotics if you're prone to chest infections. You'll need a letter from your doctor to enable you to carry prescribed medications on the plane.

3 Can I take medical equipment on a flight?

Yes, in many cases, you can take your medical equipment on board. Check with your airline before booking as they have different rules. It's essential to plan ahead to make sure they can meet your needs.

If you have been assessed as fit to fly, you should be able to travel with either non-invasive ventilation or trache ventilation.

Your ventilator might need to sit on a seat next to you and you could be charged for that seat. Always ask your airline about their policies.

Check in advance to see if you can take the following devices on board with you:

- machines to assist with coughing
- suction machines
- powered communication aids (take a low-tech back-up too).



For more, see information sheets:

- 8A – *Support for breathing problems*
- 7A – *Swallowing difficulties*
- 7C – *Speech and communication support.*

Travel suggestions for medical equipment

Contact your equipment provider: Ask how best to transport and use your equipment abroad. This will help you in any discussions with your airline.

Get a letter from your healthcare team: This should list equipment you're taking on board and why. Airline staff and security may need to see this.

Prepare for airport security: Medical equipment can set off alarms so take supporting documents to explain each device. You can ask to be checked by a person instead of going through security scanners. This should take place in a private area, and you can have someone with you.

Take the right batteries: You will need to take batteries to power your equipment on the flight, especially if you rely on your ventilation. Most airlines allow dry cell

batteries, but wet cell batteries are usually not permitted. If you're not sure what kind of battery your equipment uses, contact your equipment provider for advice.

Check with your airline in advance, as their rules on batteries can vary. Most will ask that your batteries can last for one and a half times the flight duration (150%). This extra battery power allows for any delays or diversions.

Check plugs and power supply: Make sure you have the right adaptors, batteries, connectors, and cables for the plane and your destination.

What if I use a feeding tube?

If you have a feeding tube, you can usually take your feed and supplies on the plane, but always check:

- in-flight rules with your chosen airline
- how much liquid you can carry on your main flight, but also connecting flights in another country, as the rules may be different there
- with your healthcare team for a letter explaining your feeds and equipment
- with your home enteral feeding team, if they can arrange feed delivery to your destination.

What if I use a wheelchair?

You can take your own wheelchair on a flight, but not on board with you to your seat. It's unlikely it would fit down the aisle of the plane, but your wheelchair will be stored in the hold.

You can use an aeroplane wheelchair to get on and off the plane, and to your seat. Ask about this in advance so the staff are prepared.

If you use a powered wheelchair, the airline may need to immobilise it for safety before it goes into storage in the hold. Ask the airline in advance about their process.

You can buy an Airsafe plug, which immobilises the chair through the charging port. This avoids damaging it by having to cut wires or take it apart to remove the battery. If you're unsure which battery type you have, contact your wheelchair service for advice. Search for *airsafe wheelchair plug* online, as these can be purchased from various suppliers.

Will I need to fill in any forms?

Most airlines require a Medical Information Form (known as a MEDIF), or a letter from your doctor. This should include:

- your diagnosis
- confirmation that you are fit to fly
- your breathing tests results (if applicable)
- a list of the equipment you will be using and the settings needed
- why specific equipment needs to be kept with you as hand luggage.

What questions should I ask the airline?

- What medical forms or letters do I need?
- Do I need permission to take my ventilator or other devices on board?
- Can I take medication in hand luggage, including liquid feed?
- What type of batteries are allowed, and how should I pack them?
- Will I need to be accompanied by a friend or carer?
- Are there extra costs for seating or equipment?
- What are the rules at any connecting airports?

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

Planning ahead can help make your trip as smooth as possible. It's important to tell both the airline and your travel insurance provider as soon as possible that you use breathing support for MND. This will help you get the right assistance and cover.



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

Getting to and from the airport

Think about how you'll travel to and from the airport. You may want to go with a friend, family member, or carer. You can also pre-book support for getting in and out of trains, taxis or coaches.

In the UK and EU, you have a legal right to help when flying if you are disabled. You can request support to help you:

- move through the airport you are flying to and from
- get on and off the plane
- transfer between flights
- get assistance during the flight itself.

Ask the airline for this type of support at least 48 hours before your flight.



“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.”



More information is available from the Civil Aviation Authority:
www.caa.co.uk/passengers-and-public

Choosing the right accommodation

Check if your accommodation will suit your needs. Think about the following:

- Is it wheelchair accessible?
- Does it have the space or support features you need?
- Is the electrical supply compatible with your equipment?
- Have you packed the right adaptors, connectors and cables to match the voltage and socket type at your hotel?
- How many spare batteries will you need, in case of power cuts or emergencies?
- Can you take an extension lead in case the sockets are not close to your bed?



For more guidance on holidays with MND, see:
our booklet *Getting around*.

What if I become ill while I'm away?

If you develop a chest infection or become unwell abroad, you are likely to need immediate treatment before you fly home. Check with your doctor if you have any doubt about flying.

Make sure:

- you are medically cleared to fly back
- your travel insurance covers changes to your plans
- your insurer is aware of your MND or Kennedy's disease diagnosis and breathing support, as well as the travel arrangements
- your policy includes the cost of an air ambulance, in case you're too unwell for a regular 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.

Travel insurance companies change their offers on a frequent basis. Keep watch on organisations that specialise in support for people with existing conditions or illness.

Our MND Connect helpline can provide further information about travel insurance (see *Further information* at the end of this sheet for contact details).



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

Is there anything else that I may need to travel?

To help your trip go smoothly, think about:

Taking documents that could be useful:

- a letter from your doctor (on headed paper) explaining your condition and treatments
- contact details for your specialists

- our *MND Alert Wristband* or *MND Alert Card* to let hospital staff know about your condition
- our *Understanding My Needs* form if travelling to an English-speaking country, which explains your needs if admitted to hospital
- simple printed phrases in both English and the local language to explain your needs during travel or other situations.



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

Before you travel, check:

- how you’ll transfer between your wheelchair and the onboard wheelchair for boarding
- contact numbers for emergency services at your destination
- if you need a letter to carry medications into the country
- local rules on bringing in UK-prescribed medications (you may need to check the country’s government or embassy website)
- if your destination has high levels of pollution or anything that could affect your breathing
- if you’ll need help translating while abroad and how to get support from an interpreter there.

If you travel often, ask the airline if they offer a Frequent Traveller’s Medical Card as this can make future flights easier to arrange.



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

5 How do I find out more?

Other organisations

We do not endorse organisations, but this list may help you search for further support. If details change before next revision, contact our MND Connect helpline (see *Our support* in this section). Find more organisations at:

www.mndassociation.org/organisations

Asthma and Lung UK

For lung condition guidance as well as travel, oxygen and equipment support.

Telephone: 0300 222 5800

Email: helpline@asthmaandlung.org.uk

Website: **www.asthmaandlung.org.uk**

British Thoracic Society

For air travel guidelines and guidance about breathing problems.

Telephone: 020 7831 8778

Email: Through the website contact page

Website: **www.brit-thoracic.org.uk**

Civil Aviation Authority

Guidance on your rights as a disabled passenger and travelling by air.

Telephone: 0330 022 1500

Email: enquiries@caa.co.uk

Website: **www.caa.co.uk**

The Disabled Persons Transport Advisory Committee (DPTAC)

Advises the UK government on transport needs for disabled people.

Email: dptac.enquiries@dft.gsi.gov.uk

Website: **www.gov.uk/government/organisations/disabled-persons-transport-advisory-committee**

European Lung Foundation

Travel guidance and an *Airline index* with oxygen policies for airlines.

Telephone: 0114 322 0635

Email: info@europeanlung.org

Website: **<https://europeanlung.org/en/>**

GOV.UK

Guidance on travelling abroad, welfare benefits and disability support.

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

Home Mechanical Ventilation in Partnership (HMPiP)

Information about ventilation, including patient videos and stories.

Email: gillian@wychwoodcommunications.com

Website: **<https://hmvip.co.uk>**

International Alliance of ALS/MND Associations

A global directory of ALS/MND associations offering care, support and advice.

Email: through website contact page

Website: **www.als-mnd.org**

MND Scotland

Support for people affected by MND in Scotland.

Tel: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

myBreathing

Online resource about NIV with MND, with user videos.

Website: **<https://mybreathing.mymnd.org.uk>**

The National Institute for Health and Care Excellence (NICE)

See guideline NG42 on MND for professionals, including NIV advice.

Telephone: 0300 323 0140

Email: nice@nice.org.uk

Website: **www.nice.org.uk**

NI Direct

Government information for Northern Ireland, including disability and health.

Email: through the website contact page

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

TryB4Ufly

Offers cabin assessments and equipment for use when travelling by air.

Telephone: 0208 770 1151

Website: **www.qef.org.uk/service/accessible-aviation/tryb4ufly**

References

References for this information are available on request from:
infofeedback@mndassociation.org or write to:

Information feedback
MND Association
Francis Crick House
6 Summerhouse Road,
Moulton Park
Northampton
NN3 6BJ

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Our information resources

We have a range of accredited guidance, including the following information sheets.

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 booklets and tools:

Living with motor neurone disease

Caring and MND: support for you

Caring and MND: quick guide

Getting around – advice on travel, transport and holidays

Making the most of life with MND – ways to maintain your interests with MND

Understanding My Needs – to guide others involved in your care

MND Alert Card and our MND Alert Wristband

Search for information by need at: **www.mndassociation.org/careinfofinder**

Find information for professionals at: **www.mndassociation.org/professionals**

Download our information at: **www.mndassociation.org/publications**

Find information in other languages at: **www.mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see *Our support* next).

Would you like to help with user review of our information? If you are living with MND or Kennedy's disease, or a carer, contact us at

infofeedback@mndassociation.org

Our support

Our mission at the MND Association is to improve the lives of people with MND today, while building hope for tomorrow.

Our support is here for everyone affected by MND or Kennedy's disease, in England, Wales and Northern Ireland.

MND Connect

Our helpline team can provide emotional support, guidance and information. They can help you search for organisations, our local branches, groups and volunteers, and explain our services and grants. Interpreter calls can be arranged.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Support services

Find out about our support services at:

www.mndassociation.org/our-services

Local and regional support

Find out about our branches and groups, at:

www.mndassociation.org/local-support

MND Association Benefits Advice Service

Explore benefits for England, Wales and Northern Ireland, with professional advisers. Find contact details and more at:

www.mndassociation.org/benefitsadvice

MND Association website

Find out about our work and how to get involved with membership, fundraising and campaigning at: **www.mndassociation.org**

MND Association online forum

Share experiences with others affected by MND or Kennedy's disease.

View posts or become a member and join chats at:

<https://forum.mndassociation.org>

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you feel we did well and how we can improve this content for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding.

Find our feedback form at: **www.smartsurvey.co.uk/s/infosheets_1-25**

Email your comments to: **infofeedback@mndassociation.org**

Or write to:

Information feedback
MND Association
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6 Summerhouse Road
Moulton Park
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