MND Association

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Air travel and ventilation for Motor Neurone Disease

Information for people with or affected by Motor Neurone Disease (MND)

With motor neurone disease (MND), you may use assisted ventilation for breathing support or other medical equipment. Kennedy's disease has similar symptoms to MND, but changes to breathing are usually more mild. This information sheet explains how flying can affect your breathing and what you need to do if taking your equipment on board. 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 highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in Section 5: **How do I find out more?**

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, MND specialist or Kennedy's disease specialist before you travel. They can assess your breathing and help you plan a safe trip.

See our booklet: **Getting around** for more on travelling with MND.

What is assisted ventilation?

A small machine called assisted ventilation can support 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.

- With non-invasive ventilation (NIV), the 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.
- With trache ventilation (tracheostomy ventilation, also known as invasive ventilation), air is delivered through a small tube in your windpipe, inserted through an opening made at the front of your neck.

See information sheets: **8A Support for breathing problems** and **8B Ventilation in MND** for more about therapies and treatments.

Will I need oxygen on the flight?

Most people with MND don't need extra oxygen (often called supplementary oxygen) when flying. Even 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:
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 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 may be offered a hypoxic challenge test to see how your body responds to lower oxygen levels, as 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 heading in section 1: **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 but it's essential to plan ahead. Check with your airline before booking as they have different rules. 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).

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 the 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. Check in advance, as their rules on batteries can vary.

Most airlines will ask that your batteries can last for one and a half times the flight duration (150%) to allow for any delays or diversions.

If you’re not sure what kind of battery your equipment uses, contact your equipment provider for advice.

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 where rules may be different
- with your healthcare team to get 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.

Buy an Airsafe plug to immobilise the chair through the charging port. This avoids damage by having to cut wires or take it apart to remove the battery. These can be purchased from various suppliers. Search online for: airsafe wheelchair plug.

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?

> **"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!"**

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

Planning ahead can help make your trip as smooth as possible. 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.

Getting to and from the airport

Think about travel to and from the airport and if you need to go with someone for support. You can pre-book help to get in and out of trains, taxis or coaches. Ask the airline for their support at least 48 hours before your flight. In the UK and EU, you have a legal right to help when flying if disabled and you can request support to:

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

> **"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 and does it offer the space and support you need?
- Will the electrical supply work with your equipment and have you packed correct adaptors, connectors and cables to match the voltage and sockets 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?

See our booklet, **Getting around** for guidance on holidays with MND.

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
- your travel insurance covers possible 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 as some may 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 offers change frequently. Keep watch for companies that specialise in support for people with existing conditions or illness. Our MND Connect helpline can provide further information about travel insurance.

See section 5: **How do I find out more?** for cotact 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?

Think about taking documents that could be useful, such as:

- a headed letter from your doctor to explain your condition and treatments
- contact details for your specialists
- our MND Alert Wristband or Card to let medical staff know you have MND
- our Understanding My Needs form if travelling to an English-speaking country, to explain 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.

See information sheet: **14A Advance Decision to Refuse Treatment (ADRT) and advance care planning** for more on care planning documents.

Before you travel, check:

- how you'll transfer between your wheelchair and the onboard wheelchair for boarding
- that you have contact numbers for emergency services at your destination
- if you need a letter to carry medications into the country
- any 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.

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

"You get the kerfuffles with the planes where they put you in the back when you're supposed to be loaded from the front, and all the fun that comes along with, you know, accessibility. But at the end of it, he gets to spend a week wherever he's gone."

5 How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Asthma and Lung UK
For lung condition guidance as well as travel, oxygen and equipment support.
Tel: 0300 222 5800
Email: helpline@asthmaandlung.org.uk
Website: **asthmaandlung.org.uk**

British Thoracic Society
For air travel guidelines and guidance about breathing problems.
Tel: 020 7831 8778
Email: Through the website contact page
Website: **brit-thoracic.org.uk**

Civil Aviation Authority
Guidance on your rights as a disabled passenger and travelling by air.
Tel: 0330 022 1500
Email: enquiries@caa.co.uk
Website: **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: **gov.uk/government/organisations/disabled-persons-transport-advisory-committee**

European Lung Foundation
Travel guidance and an Airline index with oxygen policies for airlines.
Tel: 0114 322 0635
Email: info@europeanlung.org
Website: **europeanlung.org**

GOV.UK
Guidance on travelling abroad, welfare benefits and disability support.
Website: **gov.uk/browse/abroad**

Home Mechanical Ventilation in Partnership (HMViP)
Information about ventilation, including patient videos and stories.
Email: gillian@wychwoodcommunications.com
Website: **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: **als-mnd.org**

MND Scotland
Support for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

myBreathing
Online resource about NIV with MND, with user videos.
Website: **mybreathing.mymnd.org.uk**

The National Institute for Health and Care Excellence (NICE)
See guideline NG42 on MND for professionals, including NIV advice.
Tel: 0300 323 0140
Email: nice@nice.org.uk
Website: **nice.org.uk**

NI Direct
Government information for Northern Ireland, including disability and health.
Email: through the website contact page
Website: **nidirect.gov.uk**

TryB4UFly
Offers cabin assessments and equipment for use when travelling by air.
Tel: 0208 770 1151
Website: **qef.org.uk/service/accessible-aviation/tryb4ufly**

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References

References used to support this document are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease.
You may find the following resources helpful, relating to this sheet.

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

Booklets

Caring and MND - quick guide
Getting around
Making the most of life with MND
Understanding my needs

Large guides

Living with MND
Caring and MND - support for you

Other resources

MND Alert wristband
MND Alert card

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

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

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

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

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

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

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 give feedback on any of our information sheets, access our online form at:
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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

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

Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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