

Commercial air travel

A Handbook for People with Neuromuscular Weakness

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Introduction from the Muscular Dystrophy Campaign *Trailblazers* network

Trailblazers is the Muscular Dystrophy Campaign's young campaigners network. With over 450 members, the network tackles social issues affecting young disabled people, such as access to higher education, employment and social and leisure opportunities, including access to air travel.

In Autumn 2012, *Trailblazers* launched their *Up in the Air* report on access to air travel and met with representatives from the airline industry in Parliament to work together to improve the experiences of disabled people. The meeting resulted in the formation of an industry-led steering group and the group is now working closely with the Civil Aviation Authority to improve the experience for passengers with reduced mobility.

Communication is so important, and resources like this are a valuable tool for people to explore options when planning their air travel. This handbook is most welcome, as it provides a step-by-step guide to improving respiratory management when planning a trip away.

The goal of the *Trailblazers' Up in the Air* campaign was to overcome the barriers to air travel by putting forward the opinions and recommendations of young disabled people, so that disabled people can travel with confidence. This handbook complements quite neatly the campaigning efforts of the *Trailblazers*.

The Muscular Dystrophy Campaign *Trailblazers* also provide advocacy support for anyone who has faced challenges related to disability when accessing air travel. To find out more information about *Trailblazers* or to obtain a copy of the *Up in the Air* report please do get in touch with us on 020 7803 4846 or trailblazers@muscular-dystrophy.org or visit www.muscular-dystrophy.org/trailblazers

The Muscular Dystrophy Campaign is the leading UK charity fighting muscle-wasting conditions. We are dedicated to beating muscular dystrophy and related neuromuscular conditions by finding treatments and cures and to improving the lives of everyone affected.

“This guide is a really useful resource for people with neuromuscular conditions. Information, clarity and advice is required so people know what can be possible, and how to be organised in advance of flying. **Hayleigh Barclay, Scottish *Trailblazers* Ambassador and founder of the 'Plane Fair campaign'**”

“This is an excellent booklet filled with useful tips for aspiring travellers with neuromuscular conditions. And of course the point of all respiratory treatments such as ventilatory support is not just to improve symptoms and oxygen and carbon dioxide levels, but also to enable individuals to achieve important goals whatever, and wherever they might be. Careful planning and consultation with your respiratory team is key; but with this booklet you are already on your way!”

Anita Simonds, Professor of Respiratory and Sleep Medicine at National Heart & Lung Institute

Setting the scene

What are the aims of this guide?

Each year over one billion people travel by air worldwide. For the vast majority of travellers air travel is safe and a very convenient way to travel. However in a small number of people with conditions that severely affect their lungs or breathing, air travel can potentially cause difficulties. In people who also use a ventilator to support their breathing on a day-to-day basis at home, air travel may require some additional considerations and advance planning.

This guide aims to:

- Enable as many people as possible with complex respiratory care needs to enjoy worldwide travel by air
- Encourage ventilator users to fly safely
- Help you make plans to travel and provide practical advice on each stage of the journey, particularly covering the important preparation stages.

Who will find this guide useful?

We hope this guide will be useful to individuals who use a ventilator at home, either on an intermittent basis during the day or only during sleep at night. This will include people a wide range of conditions causing muscle weakness, sometimes with associated problems due to altered chest wall shape, and/or different types of sleep disordered breathing (e.g. obstructive sleep apnoea), and compounded by other respiratory illness such as chronic obstructive pulmonary disease (COPD).

It applies to people who use any form of non-invasive [mask delivered] breathing support such as a bi-level positive airway pressure machine or a continuous positive airway pressure machine.

The families or carers of ventilator users should also find this guide useful in helping plan a trip abroad, and it is hoped that health care professionals will find the book useful in advising their patients on air travel issues.

This book aims to cover a range of issues related to air travel in general but especially the needs for those travelling with ventilator equipment. Ventilator users have different individual needs so you may find some sections of this guide apply to you more than others. We hope information here will assist discussion with a **local Respiratory Support Team, who should always be involved when considering long distance travel.**

The specialist team is particularly important with regard to the planning and implementation of care for those who are totally dependent on mechanical ventilation. Although many of the topics discussed here are relevant, a specific very individually tailored treatment plan is required for those totally dependent on their ventilator.

What changes with air travel?

The most important effect of flying is due to reduced air pressure in the aircraft cabin.

Air pressure in an aircraft cabin is lower than air pressure at ground level. Airplanes generally cruise at 30,000 feet, but the cabin pressure is adjusted to between 6,000 to 8,000 feet. This means that being in an aircraft cabin is like being at 6,000 to 8,000 feet up a mountain.

This lower air pressure causes blood oxygen levels to fall in everyone. Oxygen levels in the blood can drop between 5-20 percent below normal. The natural response is to breathe a little faster. Some people can therefore feel a little breathless, but in most healthy individuals this has no adverse effects on health.

You are more likely to be affected by this drop in air pressure if you already have a low blood oxygen level or are more sensitive to changes in oxygen levels due to a condition affecting your lungs. This extra drop in oxygen levels in an airplane might then potentially cause you to feel breathlessness and discomfort. If your respiratory muscles are already weakened or under strain, then you might find the effort of breathing faster is too much for you.

Other effects of air travel include an increased risk of becoming dehydrated as the air in aircraft cabins is very dry. Travelling is also tiring for most individuals and fatigue can make some breathing problems worse.

How travelling by air will effect your breathing depends on several factors:

- the type and duration of your respiratory condition
- how much your oxygen level is likely to fall during the flight – the greater the drop in blood oxygen, the more chance of adverse effects on the heart and lungs
- if you are 'tolerant' of some reduction in your blood oxygen level – some people who are 'used' to a slightly lower oxygen because of their condition do not react badly to a further reduction caused by altitude
- how well your breathing system can cope with the effort of having to breathe faster
- if you have problems with your heart or other health issues which make you more vulnerable to changes in your blood oxygen level.

Because of these particular medical aspects of flying, in addition to general travel considerations – **planning is required**

First steps

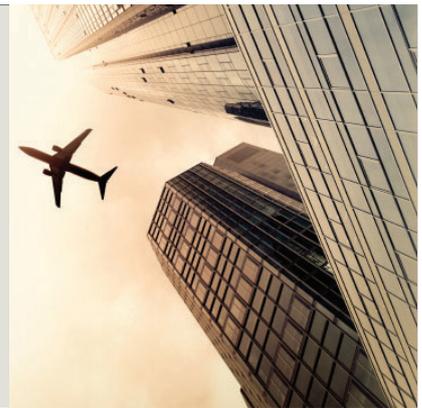
The importance of planning ahead

Although this guide focuses on the particular issues of respiratory care in relation to air travel, the authors' experience is that mobility and personal care aspects [wheelchair/hoists, transfers, toilet arrangements] influence the success of a trip more than anything else .

Attention to the general demands of travelling, including skills and confidence of your travel comparison, cannot be over emphasized.

Before you travel consider:

- travel companion[s]
- wheelchair [comfort & transport]
- transfers [e.g. on to plane, toilet access , at destination]
- food and drink [plus medication]
- respiratory equipment [use]
- respiratory equipment [storage].



Planning air travel

Ventilator users can enjoy travel by air, and many ventilator users report that air travel can be straightforward. However, preparation is key.

- First, ask your doctor whether you can travel by plane. This may involve discussing your plans with your respiratory specialist and Respiratory Support Team. You may also need some extra breathing tests.
- It is important to have appropriate travel insurance that covers your pre-existing medical conditions – this will be covered in the section Arranging insurance. It can be expensive so do look into travel insurance before you book a trip abroad.
- Consider how your destination may affect your health.
- Book flights well in advance and inform the airline representatives of your ventilator.
- Always take your ventilator in your hand luggage. It may be damaged or lost if placed in the aircraft hold.
- Consider how you are going to power your ventilator either on the flight or abroad.
- Consider taking a back-up ventilator and/or battery you may require.
- Consider what to do if something goes wrong while you are away.
- Remember to take important documents with you – this will include any paperwork from your doctor and insurance details. Make a list of important numbers to carry with you – this might include your insurance company and Respiratory Support Team.

The remaining sections of the guide will cover issues in more detail.

HINT

While reading this book it may help to make a 'to-do' list of issues you think apply to you – this will then help you tick off tasks as you organise your trip.

How do I know if I am fit to fly?

Limited research has been done looking at the effect of air travel on ventilator users, but essentially anyone can fly if enough equipment and trained personnel are available – for example when an individual requires medical repatriation from abroad. Of course this level of resources and medical care is not practical in most routine travel settings.

For routine travel, you can travel by air as a ventilator user once an assessment of your individual risk has been completed. Discussion with a respiratory specialist who is familiar with your case is essential. This will include a clinical assessment complemented by additional tests particular to each individual.

The aim of the pre-flight medical assessment is to:

1. Determine the degree of risk for acute medical difficulties
2. Determine whether providing oxygen and/or use of your ventilator during the flight would compensate for the effects of altitude on your breathing system. Unfortunately, even with oxygen and/or use of your ventilator it is not possible to guarantee 100 percent safety for your flight
3. Advise regarding general measures to 'protect' lung health during air travel
4. Advise regarding the level of trained and untrained assistance required to travel safely.

What medical assessments might be needed?

Whether you require to use your ventilator and/or oxygen on the flight will be a decision made by yourself and your doctor, taking into account your specific case and condition.

Your respiratory specialist will ask you questions about your general health, breathing and any previous air travel you have undertaken. He/she may also undertake a physical examination. In general, your respiratory condition should be stable and you should not be recovering from any recent exacerbation before embarking on air travel. The British Thoracic Society's recommendations for 'Managing passengers with stable respiratory disease planning air travel' [Thorax 2011 ;66; supplement 1] provides authoritative advice for health professionals in assisting your aims.

Your respiratory specialist will likely organise some further tests to help decide on your requirements during the flight, including any necessity for oxygen therapy. These include measuring your blood oxygen levels [pulse oximetry] and a flight altitude simulation test – described in more detail below.

Pulse oximetry

Pulse oximetry is a small probe placed on either your finger or ear-lobe. This gives an indication of the amount of oxygen in your blood. If your oxygen levels are low at rest, your doctor may recommend you use oxygen on a flight.

Flight altitude simulation test

The 'hypoxic challenge test' is the easiest way for doctors to recreate the aircraft environment and assess how this might affect your breathing. Although it can be a useful test, it does not reproduce all aspects of the in-flight environment.

The test involves breathing a mixture of gas that is similar to the oxygen levels available in an aircraft cabin. The test lasts up to 30 minutes. During the test you will be monitored for any change in your oxygen levels (usually via a probe on your finger or earlobe) and any symptoms you develop. A blood test is also often taken to accurately measure how much oxygen is in your blood.

The doctor may then also repeat the test giving you an extra supply of oxygen. This will help establish if your oxygen levels and symptoms might be improved by an extra supply of oxygen during a flight.

Other tests

A heart check may be requested.

Considering your destination

To get the most out of your holiday or travel, you should consider if your chosen destination is going to present any challenges to your breathing and general health. Remember, whilst the medical assessment of fitness to fly relates to the early effect of breathing in the aircraft environment, a long-haul flight is more challenging in relation to comfort, access to toilet facilities, and for the duration of 'stress' on your heart and lungs.

Consider:

- **If your destination is at high altitude** - similar to the effects of being on a plane, being far above sea level can cause increased breathlessness and low oxygen levels. This may cause your breathing to become more difficult and you to feel uncomfortable, but in severe cases altitude sickness can develop and be potentially dangerous.
- **Whether you have access to good medical care** - this is particularly important if you are prone to sudden changes in your health that may mean you need emergency medical treatment while away.
- **The weather at your destination** - very hot and sunny destinations might lead to dehydration if not careful. Think about how you will tolerate heat and humidity.
- **Terrain** – if your destination is hilly, this could affect your ability to get around comfortably. Further information on this can be provided by guidebooks, looking on the Internet, or via your travel agent.
- **Wheelchair access and transport availability** – if you have mobility problems, you should consider re-searching provisions for this at your destination. Guidebooks, your travel agent or hotel can provide more details (also see Appendix 5 - **Other Useful Sources of Information**).
- Like all travellers, you will need immunisations specific to your destination.

REMEMBER

If you are totally dependent on oxygen in your day-to-day life, then you will also have to secure a supply of oxygen at your destination.

The main oxygen distributors can often supply oxygen internationally. There is usually a charge for this service. Your tour operator should be able to help. Alternatively the British Lung Foundation (see Appendix 5 – Other Useful Sources of Information) may be able to give advice.

An informed travel companion

Many ventilator users travel successfully alone. However your ability to do so will depend on a number of factors, including your general health and mobility. There are advantages to having an informed travel companion with you. They may assist in getting through airport procedures, dealing with unfamiliar or unexpected situations and helping with the extra baggage you will be transporting.

Medical verdict

Will I need to use my ventilator during the flight?

For most ventilator users and especially during short flights, you may not need to use your ventilator at all. This will depend on your individual situation and you will be guided by your Respiratory Support Team or respiratory specialist.

If you use your ventilator only while asleep, then you should usually use your ventilator during a long and/or overnight flight when you are likely to sleep. This includes individuals with obstructive sleep apnoea using a CPAP machine. If you suffer from obstructive sleep apnoea then you should also avoid alcohol and sedative medication before and during your flight, as this can make your sleep apnoea worse.

If you have been using your ventilator for some time, you may recognise when you need to help your breathing for a while. This may particularly be the case if you are understandably tired from travelling.

Ventilator users who have access to a finger pulse oximeter (which gives a reading of the percentage oxygen in your blood) may want to use it to monitor for drops in oxygen during the flight.

Will I need oxygen during the flight?

If you are using oxygen in any form at sea level, it is very likely that you will require to use oxygen when travelling and during flights. Commercial airlines can only supply [or allow] for oxygen up to a flow rate of 4 litres per minute. Individuals needing a higher flow rate of oxygen than this are considered unsuitable for air travel.

For most ventilator users who do not normally use oxygen, the question is whether the likely drop in your blood oxygen levels during a flight requires correction and whether you also need to use your ventilator in-flight to keep your condition stable. This requires an individually tailored decision by your specialist respiratory team. However, as a general rule for a person who uses their ventilator overnight only, and wishes to go on a flight lasting up to 4-hours, then it would usually be reasonable for them to use in-flight oxygen but not their ventilator. Alternatively for someone using a ventilator more than 12 hours per day, then they would usually need to use their ventilator in-flight and may also require oxygen as well.

Other considerations for during your flight

Nebulisers

If you use a portable nebuliser, check with your airline in advance that you can carry it into the cabin of the plane. Remember using an inhaler with a spacer is just as effective as using a nebuliser.

Taking medications abroad

If you take medications on a regular basis and so need them during your trip, there are a few points to consider:

- Take any vital medication in sufficient quantities for your whole trip
- For longer trips your doctor can give you up to 3-months worth of medications
- Always carry medications in their original containers with a copy of your prescription
- Similar to your ventilator equipment, try to carry medications in your hand luggage in case of lost baggage
- It can be helpful to take a letter from your doctor with you describing the medications you need to take and that they are for your own exclusive use. This is particularly important if you use certain medications, such as strong painkillers.

Hydration

The air on board an airplane is very dry so you can easily become dehydrated. Drink plenty of water during the flight to avoid dehydration. Try to avoid alcohol and caffeinated drinks.

Mobility

If you have mobility problems, consider where you would like to be seated before you embark on your flight. You can usually request a specific seat via the airline at booking or 24 hours before departure. If you have mobility problems you will usually not be able to sit at the emergency exit rows. Some travellers with mobility problems prefer a window seat so they don't have to move to let others in/out. Others prefer to be seated next to the aisle to allow them easier access to the toilet facilities.

Preventing deep vein thrombosis (DVT)

Flights increase the risk of suffering a blood clot in veins (deep vein thrombosis or DVT), mainly due to the effects of sitting still for a long time. Deep vein thrombosis (DVT) usually affects one of the deep veins in your leg. It can cause pain and swelling and may lead to complications such as blockage of lung vessels by a clot (called a pulmonary embolism).

Using compression stockings, taking plenty of non-alcoholic drinks and regular leg exercises/movement during the flight can help prevent blood clots forming.

The paperwork

Arranging insurance

European Health Insurance Card

If you are travelling within the European Economic Area and Switzerland you need to get a European Health Insurance Card (EHIC). If you are a UK resident, then the EHIC will entitle you to some treatment free or at a reduced cost when visiting a European Union (EU) country, Iceland, Liechtenstein, Norway or Switzerland.

The EHIC is provided free of charge and replaces the older E111. The E111 card became invalid from 1st January 2006.

Obtaining an European Health Insurance Card (EHIC)

You can apply for an EHIC card online on www.ehic.org.uk, by telephone on 0845 605 7070, or by obtaining an application form from the Post Office. It takes up to 21 days for the card to come through.

Travel insurance

The EHIC is however not a replacement for travel insurance. Travel insurance is essential when going abroad. You will need to check that the travel insurance covers medical treatment and does not exclude “a pre-existing medical condition”. Most standard holiday company insurance policies will not cover pre-existing medical conditions. However there are specialist insurance companies that will do so. Appendix

1 – Holiday Insurance & the EHIC card – provides a list of insurance providers who specialize in catering for travellers with a disability or pre-existing medical conditions.

Most companies will charge an additional fee for adding pre-existing medical conditions to your travel insurance policy. This can be expensive so it is worth looking into travel insurance before you book a flight/holiday. Shop around to find the best policy for you.

Allow plenty of time to organise your travel insurance, as it can take longer than usual because your insurance company may ask for further information about your medical condition. The insurance company will usually ask you to go through a medical screening process. Some insurers will require a written note from your doctor stating your fitness to fly. It is very important to disclose any pre-existing medical conditions as failure to do so may invalidate any claim you make. It is also important that your travel medical insurance includes the cost of returning by air ambulance if you became too ill while abroad to return on a commercial flight.

Keep your EHIC and a copy of your travel insurance certificate with you while you travel. Also consider giving a copy of your travel insurance certificate to a family member or someone close to you in case they need to arrange medical treatment for you or to fly you home.

Contacting the airline

Contact the airline to book your flight well in advance of your intended travel. Many ventilator users report that it is easier to contact the airline directly rather than go through a travel agent/company. However you will need to give similar information if you do book through a travel agent.

Ensure you get the name of any airline representative you speak to, and ideally a reference number, in case there are any problems at a later date. Keep a note of this information and take it with you to the airport.

Some people do not contact the airline to let them know about their ventilator in advance of the flight. The risk with this approach is that you may not be allowed on the airplane with your ventilator or even that you may not be allowed to bring your ventilator back with you on your return flight.

Regarding your ventilator

Let the airline know you are travelling with a ventilator and batteries at the time of booking the flight. You should emphasise that using your ventilator is not the same as using oxygen in-flight. Most ventilator users report that they were able to deal directly with the airline sales representatives. But if you are experiencing problems explaining your ventilator and requirements then you may be able to speak to the airline's medical specialist/department.

Be prepared with the following information:

- **The ventilator's name and model number**
- **The manufacturer's name, address, phone number and, if known, website address**
- When the ventilator was issued to you
- The purpose of your ventilator - including if you use it only to help your breathing during sleep or if you use it during the day
- The type of battery your ventilator uses – this information may be available in your Users Manual, from your ventilator manufacturer's website or via your Respiratory Support Team. The airline can often be more interested in the battery you intend to take on-board. Wet-cell batteries are not permitted on planes, although most modern ventilators don't use these. Remember to also inform them of any 'back-up' battery pack you will be taking with you.

The airline will not let your ventilator or batteries on-board unless they are satisfied that they are safe. An airline's medical and engineering departments may need to approve the use of your ventilator and batteries in-flight. If you are potentially going to use your ventilator during the flight then you will need to know if your ventilator will fit under the seat in front of you. If not, you will usually be asked to pay for an extra seat. Most of the newer ventilators are small enough to do this. If you don't intend to use it during the flight then you will be able to store your ventilator in the overhead lockers. You may want to use the in-flight power supply rather than use a battery in-flight – there are possible limitations with this (discussed in the Section Using your ventilator in-flight). If you do wish to use the in-flight power supply, ask if this is possible on your flight, as some airlines don't provide this service. Ask if there is a charge to use the airplane's on-board electricity supply.

Ask what documentation you will require (i.e. doctor's paperwork).

Ask what procedure you should follow at the airport.

Medical equipment does not count towards your baggage allowance, so you should not have to pay an extra supplement. If you are using two different airlines for your trip, then remember that you will need to make each airline company aware of your ventilator.

Regarding using in-flight oxygen

Keep in mind that not all airlines offer an oxygen service, or may not offer it on board all their aircrafts. There may also be a charge for using the oxygen supply during the flight. Fees for using oxygen vary from airline to airline – so it is worth contacting different airlines before you book.

Airlines will usually ask for a doctor's letter (from either your GP or respiratory specialist) and/or ask you to complete a medical form.

The doctor's letter will normally state what amount of oxygen (the oxygen flow rate) you need during your flight. This is usually available in either 2 litres per minute or 4 litres per minute. Airlines usually deliver this via nasal cannulae (prongs and tubing that sit under your nose and deliver oxygen while you breath).

You will need to contact the airline prior to flying to advise them that you require oxygen, what oxygen flow rate you require, and to get full medical clearance, although this tends to be a minor technicality. Airlines vary as to how much notice they need, but some require 7 days' notice. Remember also that they may ask for a doctor's letter – so leave enough time for this to be organised before your trip. Given this, it is actually best to contact your airline as soon as you know you will be using oxygen on the flight.

If you are using two different airlines for your trip, then remember that you will need to make each airline company aware that you need oxygen during the flight.

Taking your own oxygen supply

Portable oxygen concentrators are fairly new but are increasingly being allowed on flights. They are available to purchase but are an expensive piece of equipment. If you already possess a portable oxygen concentrator to use at home, you may wish to take this on your flight/abroad with you. You should let the airline know if you intend to take and use your oxygen concentrator on the flight. You will need to ensure there is enough battery power for the flight and any potential delays.

If you use oxygen at home, you may approach the airline to see if they will allow you to take your own small, full cylinder.

Other aspects of your flight

Inform the airline if you intend to take into the cabin and/or use any other equipment, e.g. a nebuliser or suction device.

If you intend to take a wheelchair on the flight with you, let the airline know at the time of booking your flights. They may wish to know details on the type of wheelchair it is, if it uses batteries and what type, and also what it weighs.

If you have mobility problems and/or use a wheelchair, ask about the availability of jet-aways to avoid steps to the airplane. Ask about arrangements for assistance at the airport. You may also be offered priority boarding if you have mobility problems, which means you can get on to the plane and settled in your seat before other passengers.

It may be useful to contact the airline again 48 hours prior to your flight to confirm all arrangements. If using oxygen during the flight, then alert the check-in desk on arrival so they can phone ahead to ensure the oxygen has been made available on-board your flight.

Frequent Traveller Medical Card (FREMEC)

If you are a frequent traveller, you can get a Frequent Traveller Medical Card (FREMEC). This is available from some airlines and gives the airline a permanent record of your specific medical information and needs. The card acts as a proof of medical clearance with the allocated airline. This means you won't have to fill in a form and make special arrangements every time you fly. The period the FREMEC remains valid for depends on the specific medical condition.

If you travel with a different airline from the one that issued your FREMEC card, you should check that they will accept your card.

Documentation

It is very useful, and often essential, to have a letter from your doctor stating your ability to fly and explaining your medical need for your ventilator.

It is also useful to have a letter stating your ventilator settings and a copy of your latest blood gas measurements. This will be useful if you have a problem with your ventilator or you become unwell while away.

Your Respiratory Support Team can provide you with such a letter(s). This can also be useful for airport customs and security. Examples are shown in Appendix 2 and 3.

When travelling internationally, you may want to have these documents translated into the language of the country you are going to (see Appendix 4 for a list of medical translation services). This will depend on your destination and is not always necessary.

HINT

Keep a copy of your insurance certificate and EHIC with you.

It is a good idea to take a duplicate copy of any important documents. Some ventilator users find it useful to keep a copy of these documents in the bag they transport their ventilator in – therefore ensuring a copy is always to hand.

The trip

Getting through airport security and customs

With strict new regulations and screening it is very important to allow extra time to clear security and customs. Security personnel are justifiably nervous about equipment they have never seen. You may need to explain what kind of equipment it is and why you need it. A reasonable precaution is to arrive at the airport one hour earlier than normally advised.

However, most travellers with ventilators don't report any problems getting through airport security and customs.

Remember to keep with you and be prepared to show:

- The letter from your doctor stating your fitness to fly and explaining your medical need for the device, as well as any other information letter(s) you have been given by your Respiratory Support Team (see Appendix 2 for an example).
- Any documents received from the airline regarding using or transporting your ventilator and/or a note of the airline representative you spoke to when booking your flight and any reference number provided.

All equipment will either undergo x-ray screening (similar to conventional hand luggage) or physical inspection, and explosive trace detection inspection. Ventilators, suction machines and dry or gel-cell batteries can go through the x-ray scanner at the airport without any problem. You may also be asked by the airport security staff to switch your ventilator on to demonstrate that it is working and not a bomb!

Transporting your equipment

Keep your equipment with you and take it into the passenger cabin as hand luggage. Do this even if you don't intend to use your ventilator during the flight. Baggage, including your ventilator, is more likely to go missing or be damaged if placed in the hold.

Protect your equipment. Ensure your equipment is safely packed if putting it in overhead lockers. In many planes you can store your ventilator under the seat. The bags supplied with ventilators are often well padded and include useful pockets to keep your masks/tubing safe.

Remember ventilators and other medical equipment and supplies should not count towards the carry-on limit on hand luggage.

Transferring from one airline to another

It is not unusual to have to walk long distances to get to and from the airplane, particularly if you have to change airplanes during your journey. Make sure you have allowed plenty of time between connecting flights. If walking is a particular difficulty for you or you use a wheelchair, it would be best to let your travel agent or airline know in advance. Extra assistance at the airport, such as wheelchairs and/or electric vehicles, can usually be arranged if you alert your travel agent or airline in advance.

If you are using two different airlines for your trip, then remember that you will need to let each company know about your ventilator or need for oxygen during the flight.

Using your ventilator abroad

Power supply

It is critical to consider how you are going to power your ventilator while away. This indeed applies to all your electrical medical equipment.

Worldwide, many different mains power systems are found for operating electrical appliances. The different power systems may differ in the voltage, frequency and plugs/sockets used. Electricity supplies not compatible with your ventilator can cause problems and even stop your ventilator working.

In Europe the electricity is supplied at 220-240V/50Hz, whereas in North America power is supplied at 110-120V/60Hz. Many ventilators now have an **internal converter**, which will mean that both types of power supply can be used with your ventilator. Check in your Users Manual or with your Respiratory Support Team if you don't know if your ventilator has an internal converter.

Older ventilators may not have a built-in converter and you will need to get an appropriate voltage converter to use with your ventilator.

Remember to take the appropriate plug adaptor for your country of destination. These are available from most high street electrical retailers. Remember that adaptors only change the shape of the plug. They don't change the voltage – you will need a converter for this.

In some countries the electricity supply may not be reliable. If this likely to be the case, or you are very reliant on your ventilator, then take an alternative power supply, i.e. a back-up battery, with you.

Take an extension cable as there may not be a convenient plug socket, for example, near your hotel bed.

Ventilator humidifier

Some people use their ventilator with a humidifier (to moisten the air breathed in via the ventilator). While abroad, you may not need to use this if the air is very humid in the country you are visiting. If in doubt, check with your Respiratory Support Team.

Staying in hotels

It can be worthwhile to let the hotel front-desk know that you will be keeping your ventilator in your room and request that it is not moved by the hotel staff. This will prevent it being accidentally damaged when, for example, your hotel room is cleaned.

What should I do if something goes wrong with my ventilator while abroad?

Before travel

Before travel, ensure that your equipment is in good condition – e.g. there are no cracks in your mask or damage to the tubing. Contact your Respiratory Support Team if you need a new mask/tubing.

Make sure you are happy with operating your ventilator. If needed, refresh your knowledge by reading your User Manual and/or discussing any concerns with your Respiratory Support Team.

It is worth researching the local area at your destination, for example where the local hospital is and if there are any ventilation services.

Your local respiratory support service should also be able to provide information on the relevant specialised healthcare facilities nearest to your proposed destination.

While abroad

If your ventilator breaks while you are away – firstly, don't panic.

You may be able to get assistance from a local hospital. This will depend on the expertise of the hospital and local services. Take with you to the hospital your ventilator, any documents provided by your Respiratory Support Team and your insurance certificate.

You may be able to phone your Respiratory Support Team in the UK to obtain simple advice. However they will usually not be able to provide you with a replacement ventilator.

If your ventilator cannot be fixed while you are away, you may be offered an alternative model of ventilator. There is no problem with your using this different ventilator for the short period you are away. Simply provide the medical services with your usual ventilator settings.

If you have access to a spare ventilator, it is useful to take this as a 'back-up'. Your Respiratory Support Team may be able to help you with this. Replacement parts, such as spare tubing and mask, may also be useful. Alternatively, gaffer or masking tape might be used to fix tubing damage for a short period.

If there is a power cut or you are unable to access a power supply for a few days while you are abroad – again don't panic. Unless you are very reliant on your ventilator, you will not suffer any long-term harm if you are unable to use your ventilator for a few hours or indeed for a night or so. It may however cause some daytime sleepiness and you should not drive or operate machinery if that is the case.

If you are very reliant on your ventilator and are unable to either get your ventilator fixed at your destination or obtain a temporary replacement ventilator, then you will usually have to make arrangements to return home.

What should I do if I get a chest infection abroad?

Any chest infection should be treated before you fly home. If you suffer frequent chest infections, then you should discuss with your doctor the possibility of taking an emergency supply of antibiotics with you. You should have medical approval before you fly home if you suffer a chest infection abroad.

If you are admitted to hospital for any reason while abroad, you should take your ventilator with you into hospital. Also take the documents provided by your Respiratory Support Team or doctor describing the reason for your ventilator and usual settings (see Appendix 2 and 3 for examples).

The flight

Using your ventilator in-flight

When you can use your ventilator

You are usually not allowed to use electrical equipment, including your ventilator, during take-off or landing. This is a short period of time and you can use it during the rest of the flight. This usually doesn't cause any problems for ventilator users. If you are concerned about not being able to use your ventilator during take-off or landing, discuss your situation with your Respiratory Support Team.

Powering your ventilator on the airplane

If you intend to use your ventilator during your flight, you will need to know how you are going to power it.

Some ventilators (e.g. the NIPPY3) have built-in internal batteries. Others, particularly CPAP machines, will be reliant on an external power supply. If your machine has no internal battery, you can obtain an external battery to power your ventilator – speak to your Respiratory Support Team about this.

Most airlines will allow dry or gel-cell batteries on-board. Wet-cell batteries are not permitted. Check what type of battery your ventilator uses and if it is flight-compatible. Your ventilator manual or ventilator manufacturer will be able to provide this information.

Some airlines will allow you to use their on-board electricity supply – but you will need to check if this is possible in advance with the airline and if there is an associated charge. The number of plug sockets on planes is often very limited. This can mean you are seated away from your travelling companion(s) in order to use the airplane's plug socket, but more importantly the power supply may only be sufficient for laptops etc., not medical devices. It is always advisable to have battery power with you in the cabin if you anticipate using your equipment, in case the on-board electricity supply malfunctions.

Battery life

Internal batteries in ventilators can generally only power the machine for 4-6 hours. Check the battery duration in your Users Manual.

It can also be worthwhile testing your battery in advance to ensure it keeps your ventilator operating for the duration of your flight. It's a good idea to have 50 percent more battery power than required for the estimated time of the flight, in case of delays. This may not be necessary if you are highly unlikely to need your ventilator on the flight.

Airline staff

Our ventilator users don't report undue problems using their ventilators during the flight. However cabin staff may ask you if you need to use your ventilator. Be prepared to explain that it is a necessary form of medical treatment. Keep your documentation with you and be prepared to show it to airline staff who question whether you are allowed to use a ventilator in-flight.

Using in-flight oxygen

On board the aircraft, oxygen will normally be provided to you via nasal cannulae. As you have arranged to use their oxygen supply with the airline in advance, there will be enough oxygen on-board to last you the whole flight. Remember to ensure that if you are using oxygen through your ventilator that you and travelling companions have the necessary connectors and are familiar with the set-up.

Remember that airlines will not provide supplementary oxygen in ground terminals, between connecting flights, or after the flight. If you require oxygen on the ground, then you will have to arrange this in advance separately.

What to do if something goes wrong during the flight?

You can't use your ventilator

If you find you cannot use your ventilator during the flight, perhaps because the electricity supply is not available or you have accidentally packed your mask in the hold luggage, don't panic.

In most cases, and particularly for short flights, you will not suffer any adverse effects. This is particularly the case if you use your equipment for obstructive sleep apnoea – simply avoid alcohol during your flight and if you suffer daytime sleepiness after the flight, avoid driving or operating machinery.

You feel unwell

Don't panic. Let a member of the airline staff know you feel unwell. It is useful to show them your medical letter. The airline staff will be able to provide you with emergency oxygen if this is needed. In the worst case scenario, where a patient is seriously ill during a flight, cabin crew have the ability to contact emergency medical support and make a diversion before their final destination.

Summary

Travel can be very enjoyable and most ventilator users can take advantage of air travel.

Some key points are:

- Plan ahead.
- Check with your Respiratory Support Team or doctor to ensure your fitness to fly and whether you need any further tests.
- Remember insurance to cover pre-existing medical conditions can be expensive – look into this early.
- Be prepared to answer questions about both your ventilator and your battery when contacting the airline.
- Always take you ventilator in your hand-luggage – never trust that it will be safe in the aircraft hold.
- Simple measures, such as obtaining the relevant medical letters and contacting the airline directly, can make passing airport security much easier.
- Think about how you are going to power your ventilator during the flight and abroad.
- Consider taking a spare 'back-up' ventilator and take a spare mask, tubing and battery. Travel is exciting and rewarding, but it is worth being prepared for the unexpected.
- Be flexible – you may find challenges along your journey but these can often be overcome – this is all part of the travel experience!

Appendix 1 – Holiday Insurance & EHIC card

Obtaining a European Health Insurance Card (EHIC)

If you are travelling within the European Economic Area and Switzerland, you need to apply for a European Health Insurance Card (EHIC).

You can apply for the card:

- By phone: 0845 605 0707
- Online: www.ehic.org.uk
- By picking up an application form from the Post Office

Travel Insurance

We cannot endorse any particular insurance company. However below is a list of travel insurance providers that specialise in catering for people with a disability or pre-existing medical condition. You may also be able to find further companies via an Internet search. It is worth shopping around to find the best policy for you.

Able2travel

Website: www.able2travel.com

Telephone: 0845 839 9345

All Clear Travel Insurance Services

Website: www.allcleartravel.co.uk

Telephone: 0845 250 5200

Chartwell Insurance

Website: www.chartwellinsurance.co.uk

Telephone: 0800 089 0146

Columbus Direct

Website: www.columbusdirect.com

Telephone: 0870 033 988

Cover My Travels

Website: www.covermytravels.co.uk

Telephone: 0800 389 5904

Freedom Insurance Services Ltd

Website: www.freedominsure.co.uk

Telephone: 01223 446914

Freespirit

Website: www.free-spirit.com

Telephone: 0845 230 5000

Insurancewith

Website: www.insurancewith.com

Telephone: 0845 230 7159

World First

Website: www.world-first.co.uk

Telephone: 0845 90 80 161

Appendix 2 – Example of letter stating fitness to fly and need for ventilator

Department of Respiratory Medicine

DR. ANYONE'S RESPIRATORY MUSCLE CLINIC

Any Hospital.
1234 Smith Road
Anytown, UK.
Switchboard: 0141 xxxxxx
Fax: 0141 xxxxxx

24/01/12

TO WHOM IT MAY CONCERN:

Mrs C.D. Smith, 22b Any Street, Anytown, G4X XXX
DOB: 20/05/1950

This is to confirm that the above lady requires the following equipment for the treatment of a chronic medical condition. She has been deemed able to fly. She may require to use the below ventilator during her flight and the equipment must stay with her.

The equipment concerned is a Nippy 3+ flow generator with associated tubing and face mask attachment.

Yours faithfully,

Dr. S. W. ANYONE
CONSULTANT PHYSICIAN

Appendix 3 – Example of medical letter

Department of Respiratory Medicine

DR. ANYONE'S RESPIRATORY MUSCLE CLINIC

Any Hospital.
1234 Smith Road
Anytown, UK.
Switchboard: 0141 xxxxxx
Fax: 0141 xxxxxx

Clinic:
Dictated:
Typed:
Your Ref:
Our Ref:
Enquiries to:

16/06/12

TO WHOM IT MAY CONCERN:

Mr A. B. Smith, 22b Any Street, Anytown, G4X XXX
DOB: 28/06/1954

This patient attends the Respiratory Muscle and Assisted Ventilation Service at Any Hospital with an underlying diagnosis of progressive idiopathic cerebellar ataxia / sleep disordered breathing.

He is currently receiving non-invasive ventilation overnight via a VPAP III ST ventilator at the settings below:

Mode: PSV
IPAP: 14cm H₂O
EPAP: 10cm H₂O
Backup Rate: 18 bpm

Recent capillary blood gas sample on 17/05/12 breathing room air:

pCO ₂	5.3 kPa
pO ₂	10.8 kPa
pH	7.46 nmol/L
Bicarbonate	24.4 mmol/l
Resting oxygen saturation:	98%

Yours sincerely,

Dr. S. W. ANYONE
CONSULTANT PHYSICIAN

Appendix 4 – Medical Translation Services

We cannot endorse any particular company. However below is a list of translation services that specialise in medical translation. You may also be able to find further companies via an Internet search.

Transmedi

Website: www.transmedi.com

E-mail: office@transmedi.com

Telephone: 01162 337 640

Doctor Babel

Website: www.doctorbabel.com

E-mail: support@doctorbabel.com

Telephone: +47 988 34 946

Appendix 5 – Other useful sources of information

Tourism for All

Tourism for All is a charitable organisation that provides information and advice to adults and children with disabilities and their carers. It provides information on accessible accommodation, transport, special interest holidays, insurance and respite care.

7A Pixel Mill
44 Appleby Road
Kendal
Cumbria
LA9 6ES

Website: www.tourismforall.org.uk

E-mail: info@tourismforall.org.uk

Telephone: 0845 124 9971

International Ventilator Users Network

Provides general information on ventilator-assisted living, including education resources and newsletter.

Website: www.ventusers.org

Muscular Dystrophy Campaign

Provides a range of free factsheets, including information on planning a holiday; using public transport, specialist vehicles, assessment centres and mobility organisations; and insurance.

Website: www.muscular-dystrophy.org

Telephone: 020 7803 4800

The British Lung Foundation

Provides a range of advice for individuals living with a lung disease. Includes online advice on travel insurance and going on holiday with a lung condition. They also run a helpline service that offers free, confidential and impartial information and support on a number of subjects including travel and transport and oxygen therapy.

Website: www.lunguk.org

Helpline: 08458 50 50 20 (Monday to Friday 10 am to 6 pm) calls charged at your local rate

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