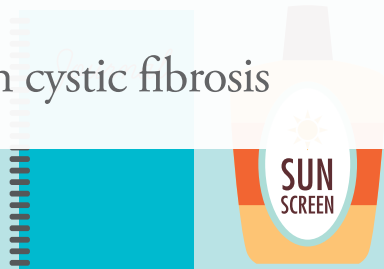
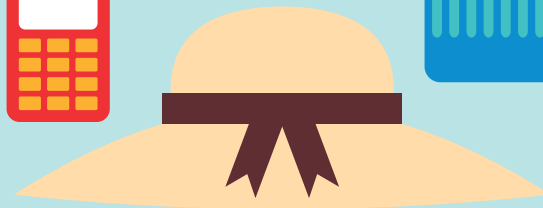


## *Travel Guide* for patients with cystic fibrosis





# *Travel guide*

## *for patients with cystic fibrosis*

We should all be able to enjoy travelling for business or pleasure, but for people with cystic fibrosis (CF) this can sometimes be daunting. Not only do you have to think about where to go and how to get there, you have to consider what medication to take, how to travel with it and where to go in an emergency. This booklet is for those people with CF who want to get away and enjoy themselves – a goal achievable through proper preparation and a little guidance.

Many thanks to Milly Dack,  
CF Adult Clinical Nurse Specialist  
at the Royal Brompton Hospital,  
for her expert guidance and help  
putting this booklet together.

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# *Before you go*

Tell your CF team you are planning a holiday as soon as possible. They can advise you on all the necessary documentation and equipment that you will need. They can also provide you with specific practical advice and help address any concerns you may have. They may recommend treatment – intravenous (IV) antibiotics, for example – to optimise your health before you go. There are certain conditions that may need to be stabilised, although they could prevent you from travelling if severe. Your CF centre will be able to advise you about fitness to travel. Your CF team can also help you to tailor your holiday around your health and capabilities. They will also be able to provide tips on how to avoid getting ill and how best to manage treatment while you are away. The CF Trust and the British Lung Foundation websites have factsheets on travelling which include oxygen policies and travel insurance that may be useful when choosing a holiday.

## *Examples of conditions that may delay travel*

- ✈ Coughing up blood (haemoptysis)
- ✈ Recent collapsed lung (pneumothorax)
- ✈ Gastrointestinal obstruction
- ✈ Acute chest infection

## Choosing where to go

Improved management of respiratory health for people with CF has not only provided opportunities for an active day-to-day life, but also increased the choice of potential holiday destinations and activities. Certain areas of the world are still best avoided, especially if there is potential risk of poor hygiene standards or medical care. Your CF team will be able to advise you of any specific diseases such as melioidosis (see box), associated with different countries and regions and how to avoid contact.

### ***Melioidosis***

- ➔ Potentially life-threatening infection
- ➔ Caused by *Burkholderia pseudomallei*
- ➔ Bacteria can be found in fresh water and damp soil in some areas of Asia and northern Australia
- ➔ A small number of cases reported in patients with CF
- ➔ Intensive antibiotic treatment required

*See CF Trust factsheet:  
Melioidosis and travel  
to tropical countries'*





## *Climate*

No specific climate is best suited for those with CF and individuals will have their own preferences. However, be aware that any change in climate could affect your breathing.

## *Terrain*

Whether the terrain is hilly or flat, sandy, stony or tarmac, ensure you are able to get around easily. Travel companies should be able to give you information when recommending hotels, but you may also be able to find details online or by calling the hotel directly. As differences in altitude can affect the levels of oxygen in the air, you should bear this in mind when booking trips; it may be that in the past you were able to cope with more extreme terrains and altitudes. Your CF team will be able to help you decide whether a particular destination is suitable for you.

If an excursion or trip involves changing altitude, ensure you have the correct equipment, which may include oxygen. Check with the travel company or your hotel for specific details of how you will be able to get about and what any excursions or trips might involve.

## *Accommodation*

It is sensible to discuss your specific needs with the hotel or travel company when arranging your accommodation. This includes wheelchair access, lifts, escalators and suitable entry to the restaurants, pool and facilities. Enquire whether non-smoking rooms and communal areas are available and if the hotel is able to cater for special dietary needs if required.

## *Power, pumps and plugs*

Don't forget that power supply varies from country to country. UK electrical appliances from hair dryers to travel irons will not work in certain countries – importantly, this includes your nebuliser.

You may be able to borrow a compressor from your CF team with a pump voltage suitable for the country to which you are travelling. Remember many countries have a different plug socket; plug adaptors are available at most travel shops or even at the airport.



## *Insurance*

Just because you have CF, it doesn't mean you shouldn't travel, you just need to be prepared for every eventuality. Travel insurance will cover you for anything from broken bones to lost luggage, but having CF means that you must ensure that you have a policy that covers travel with CF. A number of travel insurance companies will now cover people with "pre-existing" conditions. Although this may mean that the insurance is more expensive, you will be covered for CF-related treatment if you become ill over the course of your holiday. Shop around for the best deal and read the policy carefully to make sure you have the coverage you need. Give a copy of your travel insurance certificate to a member of the family or someone close to you in case they need to arrange treatment or fly you home.



## *European Health Insurance Card*

When travelling in the EU, apply for a European Health Insurance Card (EHIC). This entitles you to either free treatment or treatment at a reduced cost if you become ill when travelling in Europe. It will also cover treatment for chronic or pre-existing conditions.

The EHIC is NOT an alternative to travel insurance. It will not cover any private medical healthcare or the cost of things such as mountain rescue in ski resorts, repatriation to the UK or lost or stolen property. You can pick up an application form from your Post Office and some travel agents, phone the NHS Business Services Authority or apply online. It can take up to 21 days for the card to come through but it will cover you for 3–5 years.

## *Documentation you may need*

- Fitness to fly letter from consultant
- A letter detailing current medical condition and medication
- Travel insurance certificate
- European Health Insurance Card

# Flights

At high altitudes, air pressure and oxygen concentration are lower than on the ground. Although the pressure in an aeroplane cabin is altered to allow for this, the amount of oxygen in the air is still slightly reduced. While this may not affect most people, it can impact on those with lower blood oxygen levels due to lung diseases. For this reason it is advisable to speak to your CF team as soon as possible about whether you will need a “fit to fly” test. This involves breathing tests that show how you may react at altitude and whether a drop in blood oxygen levels will cause a problem. If the test shows that your usual blood oxygen levels could be affected by air travel, you may need to take oxygen with you on the aeroplane. Even if you have been advised on previous visits that your blood oxygen levels are high enough to allow you to fly, the tests may need to be repeated before each trip as levels may change over time.

## *If you need to take oxygen on a flight*

- ✈ Inform the airline you are travelling with of your requirements in plenty of time
- ✈ Be aware that airlines may charge an additional fee for carrying oxygen
- ✈ Speak to your doctor about providing the necessary paperwork



## *Oxygen, nebuliser and compressors*

As an oxygen user it is your responsibility to make your own arrangements – start organising sooner rather than later.

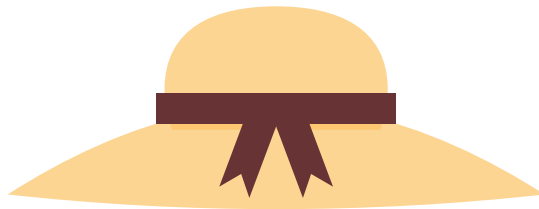
Each airline has its own policy on oxygen transport and in-flight usage; therefore, it is advisable that you contact the airline before you book in order to find out their policy. The British Lung Foundation has a list of airlines and their oxygen policies as well as contact details. The airline may need to know whether you require continuous oxygen during the entire flight or only once in a while. Their policy may depend on the duration of the flight, your route and whether you will be travelling alone or with a companion. Some airlines will provide oxygen either free of charge, or for a small fee. Budget airlines may seem the cheapest at the time but may charge extra for oxygen so may end up being more expensive. If you need oxygen, then you and your CF doctor will also need to sign a Medical Information Form (MEDIF).

Some airlines don't provide oxygen and you have to take your own (either compressor or cylinders depending on the airline policy) and some only provide it to a certain number of passengers. If you have to take your oxygen on board – ensure that the oxygen concentrator or cylinders comply with the airlines recommendations. Please check before booking your flight and get written confirmation from the airline or you may end up having to cancel it!

Airlines don't provide oxygen at airports so direct flights will be easier. It is also important to remember that there are often long distances to walk at some airports. UK airports are obliged to help people with reduced mobility from entering the airport to the departure gate but won't provide oxygen. OxygenWorldwide has an international network of oxygen suppliers and can provide oxygen at airports or abroad; however, you will have to pay.

## *Portable oxygen concentrators*

Some airlines allow portable oxygen concentrators on flights. They can run on both mains electricity and battery, so it is important to make sure that you have enough battery to cover your flight, as well as allowing for extra time in case of delays. They are available to purchase but remain an expensive piece of equipment. They can often be hired from the same companies who sell them.



## *Food and drink*

Dehydration caused by low cabin humidity or sweating may also affect you on the flight. Try to replace lost fluids by drinking plenty of water and eating salty snacks to replace salt lost from sweating. Dehydration can cause the blood to become thicker and more prone to clotting which in turn could increase the risk of deep vein thrombosis (DVT). Having a walk every hour or doing the exercises recommended in the in-flight magazine will help to decrease this risk.

On longer flights a meal may be provided; when booking your ticket inform the airline of any dietary requirements. If you would normally take medication around meal times – insulin or pancreatic enzymes for example – make sure you carry them in your hand luggage.

## *Deep vein thrombosis (DVT)*

DVT is a condition in which a blood clot forms in one of your deep veins, usually in your leg. DVT can cause pain and swelling and may lead to complications such as pulmonary embolism (blockage of lung vessels by a clot).



## *Medication*

As with any new medicine, it is important to check with your CF team whether you can receive vaccines with your current CF treatments. Some countries require you to have certain immunisations before you arrive. Specialist travel centres or your GP practice can provide advice on which vaccinations you may need. Your GP will also be able to tell you which vaccinations you have already received.

Suitcases can go missing; therefore, it is advisable to pack a separate set of medication in your hand luggage as well as in your suitcase. If you have more than one case, have a set of medication in each. Waiting at baggage collection for a suitcase that never turns up is frustrating for anybody, but it is a real problem if it contains your medication. Before you fly, check the baggage allowance; it may be that there will be an extra charge for more than one bag.

When you are packing to go on holiday, it is easy to think more about taking your new camera or that essential beach bag than taking spare medication; unfortunately, there's always a chance of becoming ill while you are away. If you have a regular routine for when you begin to feel unwell – taking oral or inhaled antibiotics for example – be prepared for this when you are on holiday.

Contact your airline before you fly to inform them you will be requiring medication on the flight. If medicines need to be refrigerated, you may have to carry a cool bag or vacuum flask on board; your pharmacist will be able to advise you on this. There will be no electrical supply on board so everything must be battery powered.

Most airlines will not allow the use of nebulisers during take-off or landing. When travelling abroad carry a letter from your doctor outlining all of the medicines and equipment which you need to travel with. This will help when you get to customs or deal with any security issues that may arise (see the previous section for documentation you may need before travel). Remember to pack enough medication for the flight and transfer time in your hand luggage, as well some extra in case of delay.

You will also need battery power to operate your nebuliser compressor during your flight. Aim to have 50 % more battery power than required for the estimated time of the flight, in case of delays or a stopover.

You may need to have a letter from your CF team if you need to take medical equipment in the cabin with you, e.g. nebuliser compressors.

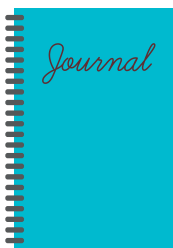




# *While you are away*

## *Risk of salt depletion*

Heat can cause excessive sweating which leads to dehydration, especially if you are exercising or walking around exploring. It's not just water that gets lost through sweating – salt does too, affecting the balance of salts in the blood. Even if you don't usually need salt tablets, it is advisable to take them on holiday. Drinking plenty of water (about three litres a day) along with taking salt tablets should help you to keep hydrated and regulate your electrolyte (salt) balance. The amount of salt required will vary from person to person. Salt can come in the form of a slow-release tablet or an oral rehydrant. Advice on which formulation and dose would be best suited for you can be found at your CF centre.



## *Planning activities*

Indwelling IV access devices (e.g. Portacath) are small devices inserted under the skin of the chest so IV medication can be given. If you have a Portacath there is no reason why you shouldn't swim or get it wet – as long as the incision has healed and is not currently in use.

There are no problems with public swimming pools as long as they are cleaned regularly. However, spa pools and jacuzzis can increase the risk of infection from *Pseudomonas aeruginosa* and should be avoided.

Some activities on holiday are not recommended. Discussion with your doctor about what you are planning to do will help to define your personal boundaries. Each person is different – if in doubt, sit it out.

## *Food and drink*

While on holiday excessive sweating, sunstroke and poor oral fluid intake can not only cause dehydration, but may also cause constipation or bowel obstruction. Be sure to keep hydrated at all times to help avoid this. People with CF who use a gastrostomy are often unwilling to take equipment and feeds with them. If this is your concern, work with your CF centre to maximise your nutritional state before you go and think about taking oral supplements with you.

In order to prevent food poisoning or other gastrointestinal upsets, try to avoid street-side food kiosks – it is difficult to know how long the food has been out for. Wash all fruit and vegetables, with bottled water if necessary. Guide books and travel centres can advise you further on cafés and restaurants and specific food types to avoid.

# *Dehydration*

Dehydration occurs when excess water is lost from the body. To prevent dehydration:

- Drink plenty of water
- Do not exercise excessively
- Try to stay out of the sun
- Limit the alcohol intake



Tap water in many countries is safe to drink, but if you cannot be sure then buy bottled water. This applies not only to drinking, but also to brushing your teeth, preparing food and using ice cubes. Contaminated water could cause vomiting and diarrhoea, which is not only unpleasant but could leave you very dehydrated and unwell. When dehydrated, you may need more than water alone. Oral rehydrants, which contain a variety of electrolytes including sodium chloride, potassium and bicarbonate, are helpful to prevent heat stroke and replace fluid and electrolytes lost from sweating, vomiting or diarrhoea.



## *Alcohol*

Drinking large amounts of alcohol, wherever you are, is not recommended.

Try to drink plenty of water if you are having alcohol, to maintain hydration levels. If you are diabetic, remember that alcohol can upset your blood sugar levels.

## *Medication*

Remember to store all medications in an appropriate place. If they need to be kept cool, check whether rooms at your hotel have fridges that you can use for this. If they don't, ask if you can hire one or if the hotel staff can store them for you. Put your medication in an identifiable bag or envelope and make sure that you are able to access it whenever necessary. Be aware of any side effects of your medications which may be made worse by different foods or climate. For example, the antibiotic ciprofloxacin can cause increased sensitivity to the sun. Going through the list of medication you are planning to take with you with your doctor will help to plan for any potential side effects.

If you are diabetic, you should be aware that your insulin requirements may change due to a change in your lifestyle, e.g. alcohol and different activity levels. If you forget your medication or require extra for any reason, you should only buy it under expert advice when abroad.

Don't forget to take a letter with you listing your medications and equipment, e.g. needles and syringes, for Customs. Also make sure you keep medication in the original boxes/containers not in dosette boxes so that they are easily identifiable.

## *Pancreatic enzymes*

The food you eat on holiday is likely to be quite different from what you're used to at home. You may need to adjust your dose of pancreatic enzymes to account for any change in fat intake. It may be useful to discuss with your dietitian the type of foods available in the country you are planning to visit. This will help to optimise your dose and reduce the risk of symptoms. Pancreatic enzymes need to be stored at room temperature (15–30°C).

## *Getting help if you are unwell*

Before you go, put together a list of CF centres or hospitals close to your destination that will be able to treat you if necessary. The Cystic Fibrosis Worldwide website and The European CF Society website both have a list of contact names and addresses and details for CF Associations for many worldwide countries. If in doubt, please ask your CF centre for advice and remember to take their contact details, including the emergency telephone number. If you begin to feel unwell while you are away and are unable to find the local doctor or hospital, contact the travel representative at your hotel if you have booked a package holiday. They usually live locally, can speak the local language and will either know where the nearest doctor or hospital is, or will be able to find out for you. Additionally, contact the number given in your medical insurance documents; your insurer will be able to provide advice on where to get help if you need it.

### *Things you need to know about your medication*

- ✈ What it is called
  - The generic name (active ingredient or chemical name)
  - The brand name
- ✈ What it is for
  - ✈ The dose you usually take

# *When you return*

When you return home, contact your CF centre if you have run into any problems. If you have any symptoms that persist for longer than a week after returning, get in touch with your team and they can advise you on the best course of action. Return borrowed equipment as soon as possible as there may be other people waiting to take it on their trip away.

## *Useful websites*

*[www.cfttrust.org.uk](http://www.cfttrust.org.uk)*

*[www.cff.org](http://www.cff.org)*

*[www.cfdreamholidays.co.uk](http://www.cfdreamholidays.co.uk)*

*[www.cf-holidayfund.org.uk](http://www.cf-holidayfund.org.uk)*

*[www.holidayaccessdirect.com](http://www.holidayaccessdirect.com)*

*[www.tourismforall.com](http://www.tourismforall.com)*

*[www.cfww.org](http://www.cfww.org)*

*[www.ecfseu](http://www.ecfseu)*

*[www.blf.org.uk](http://www.blf.org.uk)*

*[www.oxygenworldwide.com](http://www.oxygenworldwide.com)*

*[www.ehicuk.org](http://www.ehicuk.org)*

## *Before you go:*

- ✈ Tell your CF team
- ✈ Research your destination
  - Infection risk?
  - Climate and terrain
  - Accommodation and facilities
- ✈ Prepare for the flight
  - “Fit to fly” test
  - Organise oxygen, if required
  - Contact airline about special requirements
- ✈ Medications
  - Vaccinations
  - Spare supplies, hand luggage and hold luggage
- ✈ Paperwork
  - Travel insurance
  - EHIC
  - Doctor’s letter outlining medical condition and medication

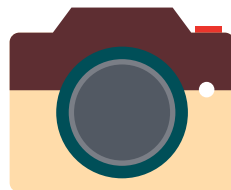


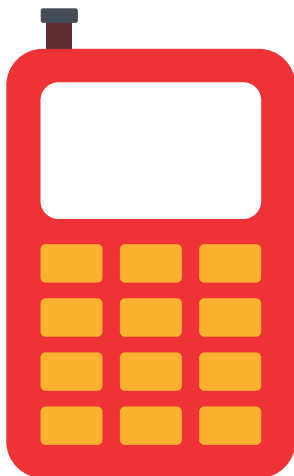
### *While you are away:*

- ✈ Keep hydrated
  - Drink plenty of water
  - Take salt tablets if necessary
  - Limit the amount of alcohol you drink
- ✈ If in doubt, stick to bottled water
- ✈ Store medication in the appropriate place
- ✈ Keep a list of medications you currently take
- ✈ Have important telephone numbers with you
  - Local doctor or CF centre
  - Medical insurance
- ✈ Ensure activities are suitable for you and your capabilities

### *When you are home:*

- ✈ Return any borrowed equipment
- ✈ Contact your CF centre if you have any problems
- ✈ Download those holiday snaps!





Contact details: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Your CF centre: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of consultant: \_\_\_\_\_

Contact number for the unit during working hours: \_\_\_\_\_

Contact number for out of hours: \_\_\_\_\_

Next of kin contact number: \_\_\_\_\_

List of medication: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I have diabetes: YES NO

I have a Portacath in situ: YES NO

(Provide details of where it is inserted) \_\_\_\_\_



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