



Travel advice for patients with CF

Just because you have CF doesn't mean you shouldn't travel; you just need to be well prepared.

In this information leaflet, we have tried to address some common questions and problems facing people with CF when they travel abroad. If you still have questions after reading this - just ask! Alternatively, there is a list of useful websites at the bottom of the sheet.

The first thing to do before you start to plan a holiday is to have a chat about it with the CF team, and not just to make us jealous while it's raining back at home! We can give you practical advice on documentation and travelling with medication, tailor your holiday around your health and give tips on how to avoid getting ill while you are away.

1. General advice

We always want to encourage people to live as normal a life as possible, but there are some conditions that prevent or delay travel, and some reasons for avoiding certain destinations, forms of transport or activities while on holiday. Often these are very individual, another reason for talking to us about your plans. It may also be recommended to have some treatment before you go or have some extra to take with you.

There are some conditions that would prevent you from travelling until you are better, such as coughing up significant amounts of blood, a collapsed lung (pneumothorax), bowel obstruction or an acute chest infection. Some people need a course of intravenous antibiotics before they go away to get their lung function as good as can be.

2.Planning your trip

Choosing where to go:

When planning a trip abroad as a person living with cystic fibrosis, lots of different factors are important, the type of travel involved, how long it will take to get there, how to travel with medication and medical devices, what the temperature will be, and not least, what the healthcare facilities are like if you needed them. Certain destinations are best avoided if you are susceptible to infection, especially if there is a risk of poor hygiene. Have a talk to your CF team to see how all this applies to you.

Depending where you are heading, you may need appropriate immunisations or anti-malaria tablets. Having CF doesn't stop you having these, but liver disease would prevent the use of certain drugs, and some tablets might interact with your antibiotics. Some vaccines have 'live' components (like oral polio, mumps, measles, rubella, BCG, and yellow fever vaccines) and cannot be given to people taking drugs that effect their immune system, such as people who are on medication after a transplant. Post transplant patients should seek advice from their transplant centre.

If you want to go somewhere hot, there will be a risk of getting dehydrated. Hot countries and heat can cause excess sweating, which can lead to dehydration and salt depletion. You are more at risk of this if you exercise or drink alcohol. Drinking plenty of water (about 3 litres a day) and taking salt tablets while on holiday keeps you hydrated. Salt tablets can be prescribed by your GP or the CF team. The amount of salt needed depends on the person and the place visited. Tablets are usually comes in a slow release form taken two to four times a day. We also understand that different people like to do very different activities on their holiday. Some may have health effects you haven't ever considered - diving and mountain climbing, for example, can affect your breathing in very different ways. A difference in altitude changes the amount of oxygen in the air, and may affect your breathing. This also applies during a flight.

How are you planning to travel?

Long journeys by train, coach, car or air, can make it difficult to keep mobile, do physiotherapy or keep yourself hydrated. It is important to keep as mobile as possible to reduce the risk of blood clots (deep vein thrombosis or DVT) and to drink plenty of clear fluids. If you would normally take medicines at meal times (e.g. pancreatic enzymes or insulin) make sure you have these with you. If you will need to do physiotherapy during the journey, let them know when booking and see if space could be made available.

On a flight, the changes in air pressure at high altitudes cause the concentration of oxygen in the air to fall. For the majority of people this is not a problem and the body adjusts for short periods, although it can leave you feeling tired. However, some people, usually those with low baseline oxygen levels or lung function of less than 50%, cannot manage at these lower oxygen concentrations and need oxygen during the flight. So some people who don't need oxygen under normal circumstances may need oxygen while flying.

A way of predicting who may need oxygen is a 'fit to fly test' or, to use its proper name, a 'hypoxic challenge test'. It is also helpful to know whether you have flown before, and if you felt unwell on any previous flights. The hypoxic challenge test involves breathing a lower concentration of oxygen in a supervised environment and testing blood oxygen levels to assess how your body copes. The lung function team at the hospital can organise this for you if the CF team think it is necessary, but there may be a bit of waiting list so please let us know about your holiday plans as far in advance as possible.

If it turns out that you do need oxygen on the aircraft, you will need to contact the airline to organise this. The cost of this varies significantly between airlines. Advice is available from the CF trust and the British Lung Foundation.

Documentation:

Paperwork is really important too. A letter from the CF team detailing your diagnosis, medication and equipment including syringes and needles helps prevent difficulties at customs. In Europe, make sure that you have an EHIC card which you use alongside valid travel insurance. It's free of charge and you can apply for it at the Post Office, (can take up to 21 days) or online at www.ehic.org, or ring the NHSBSA EHIC Application Line on 0845 606 2030. This entitles you to either free treatment or treatment at a reduced cost if you fall ill while travelling in Europe. But it does not replace insurance, and does not cover private medical care, getting you home in an emergency or lost or stolen property.

This makes travel insurance really essential too. We understand that it can often be hard or expensive to get full insurance cover, but it is very important. Shop around for a suitable comprehensive policy and get several different quotes. It is very important that you take out a comprehensive travel policy before any trip abroad, as otherwise you could be liable for expensive costs for any medical treatment required while you are away. Help and advice is also available from the CF Trust, who deal with many queries about travel insurance. It's also a good idea to leave a copy of your insurance certificate with someone back home, in case they need to arrange treatment for you or to fly you back. Be honest and declare everything.

3. Medication

It is a good idea to pack a set of medication in your hold luggage and a spare set in your hand luggage, just in case any baggage gets lost. This means you always have a spare set. It does also mean you will be taking medication through customs, and for this you will need a letter from your doctor listing what you take.

If you have problems with infections, or your lung function is low, it may be a good idea to take a spare set of emergency antibiotics with you, or even have a course of intravenous (IV) antibiotics before you go. Talk it through with the CF team to see what is right for you.

If you have medicines that need to stay cold (like insulin or pulmozyme) put them in a coolbag or wide mouthed thermos flask filled with ice for the journey. Keep your insulin in your hand luggage as the flight may get delayed and insulin could freeze in the hold.

Certain drugs need special considerations - for example, when travelling to hot climates it is important to remember that pulmozyme® (DNase) should be stored in a refrigerator at 2 - 8°C and protected from strong light. Tobramycin (TOBI®) is stable at room temperature below 25 degrees centigrade for up to 28 days. It is also worth taking a small sharps bin - these are available on prescription from your GP.

If you are taking doxycycline or ciprofloxacin your skin can burn more easily, so make sure you use lots of suncream.

Nebulisers and compressors

If you're planning to go abroad, don't forget that power supplies vary from country to country, and this will affect your nebuliser and other medical equipment. You may need an adapter for the plug, and possibly even a different nebuliser. You will also need to have the nebuliser battery charged if you want to use it during the flight.

Always take your nebuliser as hand luggage, and we will include this on your letter for customs.

Oxygen

If you normally need oxygen at home and are going on holiday in the UK, oxygen can be provided for your holiday for free. If you let us know where you are going (and give us plenty of notice, 4 weeks is a good idea) we can fill out a new temporary oxygen order form for your holiday address.

You can also take your own concentrator on holiday with you in the UK, but not if you are going abroad. We can give you general advice about transporting it and you can also contact your oxygen supplier for more information. Air Products can also supply oxygen to some overseas destinations. If you talk to your CF team in advance we can give you advice on the best way to organise oxygen abroad.

4. Getting help if you are unwell

Before you go, put together a list of CF centres or hospitals close to your destination in case you need them. Keep your paperwork to hand and your insurance documents where you can find them quickly. Contact the CF team if there are any problems when you get home.

5. Other places for advice

www.brit-thoracic.org - guideline on air travel

www.cf-holidayfund.org.uk - financial assistance for people up to 25 years with CF

www.lunguk.org - British Lung Foundation website

www.cfmedicine.com

CF Trust - Adult Forum:

<http://www.cftrust.org.uk/forum/viewforum.php?f=3&sid=8bbf8689037b6db4131558bb3ab1413f>

**With a bit of planning, you can have a safe,
stress free and healthy holiday!**