

Travel Guide for People with Cystic Fibrosis



"Travel Guide for People with Cystic Fibrosis" has been compiled to assist you, your family and travel advisers. It is not intended to replace any advice you may receive from your doctor. Whilst every effort has been made to ensure accuracy the Cystic Fibrosis Association of New Zealand can accept no liability whatsoever for any matters in any way connected with or arising out of this information.

Travel Guide for People with Cystic Fibrosis

The information contained in this guide is published and distributed by:

The National Office,
Cystic Fibrosis Association of New Zealand,
PO Box 8241 Riccarton, Christchurch 8440.

The booklet is NOT intended to be an exhaustive checklist of things to do and take, but to raise some of the more important points to be considered before travelling overseas.

A note from Vicki Kennedy who helped us to compile this guide: *“Having a love of travel I have been most fortunate to have the option over the years to visit many countries. My first trip was in 1990 when I left New Zealand for the first time. Not on a short trip mind you! We left in April and returned in September. I was fortunate to have quite good health and only had to seek assistance on one occasion as I ran short of antibiotics.*

Looking back on the trip, I did not keep as well as I would have liked, and on a few occasions I had to muddle through, which I’m sure you know from having a chronic illness, can be difficult at times.

On my return, I made the decision to keep the trips short and I travelled every 2nd year for 10 days.

In the year 2000 my best friend Sheena was living in England and we jointly made the decision that I would return with her in January after her visit home for Xmas. So I went for my usual tune up in hospital and it was on this visit I asked a few questions re hospitalisation in the U.K. Needless to say the information available was in short supply and not altogether correct. So with this in mind I decided to compile as much information as possible with the aim of providing it in a manual.

I hope you all enjoy your travels and I would like to thank the health professionals who put forward some suggestions.”

Regards,

Vicki Kennedy

Before You Go

Do not plan to travel alone unless you are sure you will not need assistance from anyone.

Hotel staff, travel representatives, couriers and others may be helpful, but it is not their responsibility to assist travellers with special needs.

Where to?

Learn as much as possible about the area you plan to visit, for example, temperature, humidity, altitude and the health requirements/risks of your prospective destination.

Climate

No specific climate is best suited for those with CF and individuals will have their own preferences. Be aware that any change in climate could affect your lung function.

Climate also needs to be considered if it will increase the risk of infection, for example: Melioidosis and *Burkholderia pseudomallei* are far more prevalent in Northern Australia and Thailand during the monsoon season.

These bacteria can cause sepsis and can be hard to get rid of, so extra care should be taken in wet areas. It is now generally accepted advice that people with CF should avoid these areas during the wet season where possible.



Terrain

Whether the terrain is hilly or flat, smooth or rough, ensure you are able to get around easily. Travel agents should be able to give you this information when recommending hotels, but you could find these details online or contact the hotel directly.

Altitude can vastly affect the level of oxygen in the air, and you should bear this in mind when planning a trip. Your CF centre will be able to help you decide whether a particular destination is suitable for you in your current health.

If a trip involves changing altitude, ensure you have appropriate equipment, which may include having oxygen available.

Note from Vicki: *Whilst travelling in England, Scotland & Wales it was noted that the wheelchair access is appalling in these countries, particularly in major cities.*

Stairs are abundant in London and the old buses (and there are many of these) do not cater for wheelchairs. They allocate one day a week in suburbs between certain times (usually off peak) that they service the route with a more modern bus for people with disabilities. The time is listed on the board at the bus stands. But this time is not set in concrete and can change. Lifts in the underground are usually not going and on the new Jubilee line you have to press a button which alerts the guard in the office who will then check the area by viewing with the camera to see if you need to use the lift i.e. have a wheelchair. He will then potter down at his pace and activate the lift!! In the four months I spent in London, I was able to use two lifts in the underground; the others at the particular stations I frequented were broken.

Travelling through Europe, I found Holland and Vienna to be excellent for wheelchair-friendly facilities, France not so good, but not as bad as London.

Current information leads us to believe every bus now has wheelchair access. Visit www.tfl.gov.uk/gettingaround/ : Transport Accessibility, for more information on London's transport services.

Accommodation



It is sensible to discuss your specific needs with the hotel or travel agent when arranging your accommodation. Points include wheelchair access, lifts, escalators, suitable entry to restaurants, pools and facilities.

Check that the various hotels or other places you are visiting have an in-room refrigerator for medication (if required).

Flights

At high altitudes, air pressure and oxygen concentration are lower than on the ground. Although the pressure in an aeroplane cabin compensates for this, the amount of oxygen in the air is still slightly reduced. While this may not have any effect on most people, it can impact on those with decreased blood oxygen levels due to lung conditions.



For this reason it is advisable to speak to your CF team as soon as possible about whether a drop in blood oxygen levels could cause you problems when travelling by air. You may need to take oxygen with you on the plane.

Oxygen

If you require oxygen, a medical certificate and prescription can be completed by your doctor. This medical certificate and prescription (including O₂ flow-rate) issued by a doctor shows you are eligible to fly, and means the airline should provide an in-flight oxygen service. As this is an extra service, airlines will probably charge a fee, or it may not be available on all aircraft. Check with the travel agent at the time of booking.

Some hospitals have a department/service co-ordinator who can help you make enquiries with the airlines. Usually they have contacts at the airlines and may be able to arrange this service.

If the airline cannot provide in-flight oxygen the alternatives are bottled oxygen, or an oxygen concentrator.

Bottled oxygen is sometimes provided by the airline, but application and approval must be completed at least two weeks prior to travel if possible.

Portable oxygen concentrators are becoming more common and are preferred by airlines over bottled oxygen. These expensive machines are lightweight, portable and can be battery powered, but only approved makes/models are accepted. These are usually available for hire. Your CF team should be able to assist sourcing one.

Whichever oxygen method is the one for you, it must be approved by the airline prior to travel. Ensure this paperwork has been completed well in advance or they won't let you fly. Ensure that you have made arrangements for the return flight as well.

Your CF team and the airlines will be able to assist in finding the best option for your travel.

Airports can be VERY LARGE. Consider asking for a wheelchair to be made available at your destination.

Vicki's note: Travelling can be very tiring and I was, on many occasions pleased to see the wheelchair assistance – especially as in some airports the distances were huge to get to the required destinations (eg Hong Kong, LA, Heathrow)

In-Flight Food & Drink

Dehydration caused by low cabin humidity may affect you on the flight. Have a drink (avoid alcohol) at least once each hour and try to eat some salty snacks. Ensure you carry sufficient snacks and enzymes for the journey and inform the plane staff when you arrive on the plane, of your extra needs.

Dehydration can increase the risk of deep vein thrombosis (DVT), attention to food & drink, and having a walk every hour or doing the exercises in the in-flight magazine will reduce the risk.

When booking your ticket ensure that you specify any dietary requirements, and phone at least one week before departure to confirm with the airline that they have been advised. Airline meals are quite small, so asking for two meals is quite a good idea. If they are unable to supply two ensure you take plentiful snack foods or supplements with you.

In-Flight Medication

Carry any medications required during the flight in your hand luggage and pack an extra supply in case of delays. Take a letter from your doctor explaining what medications and equipment (such as nebulisers, syringes) you carry and why.

If you will need to use your nebuliser during the flight, this will need to be approved prior to travel, along with your need for oxygen.

Approved nebulisers will need to be battery powered, and you should ensure that the battery has 50% more battery life than the estimated duration of the flight, in case of delays or stopovers.

General

Discuss your requirements with your travel agent at the time of booking, as often they can help if you have special needs.

If you require the use of oxygen abroad, your travel agent can often help, if informed at the time of the booking. They may be able to arrange for an oxygen supply to be waiting at the airport or at the hotel.

Many coaches are not able to carry oxygen cylinders, but will make space for a concentrator - check at the time of booking.

DO NOT leave informing your airline or overseas travel operators of your need for oxygen until you check in!

All airlines and most travel operators need adequate notice that you will need supplementary oxygen. Each airline has different regulations regarding this, so please check with your airline BEFORE you book.

Vaccinations / Immunisations

You should consult your doctor well in advance (3-5 months) of your departure for advice and to arrange any necessary immunisations.

Medication

When you are off on holiday it is easier to think of the camera or beach bag rather than spare medication. But a bit of pre-planning can save you many hassles whilst away.

Medication should be carried in a correctly labelled (original) container as issued by the pharmacist and stored in a suitably robust outer container.

Divide your supply of medication between your hand luggage and your main luggage. Lost luggage can be frustrating to anyone, but it causes real problems if it contains your medication.



If your medications need to be refrigerated you may have to carry a cool bag or vacuum flask on board, check with your Pharmacist for advice.

When travelling abroad, carry a letter from your Doctor outlining all the medications and equipment which you need to travel with. Refer to 'Paperwork' section.

If your medications can produce side-effects, ensure you have this controlled. Such as 'sun-sensitivity' – take sunscreen and sunglasses.

Spare Supplies

Pack an additional two weeks supply of medication, particularly enzymes; In case variations in your health/diet mean you consume more medication than normal.

Take sufficient syringes and needles; and an empty official "Sharps" bin in which to bring back used needles for proper disposal. These can be obtained from the hospital and small sizes for holidays are available.

Emergency Supplies

Ask your Doctor to help you prepare a stand-by supply of antibiotics in case of an infection. Ensure all dosages for your less-regular medications are clearly marked.



Equipment

Nebulisers

Your nebuliser should be carried on as hand luggage, preferably in a robust travel case for protection against damage.

The new portable nebulisers, which can be run on battery, should have a nickel-cadmium battery. This type of battery is accepted for use on most international airlines. If in doubt, please phone the airline and check.

Carry any extra parts for your nebuliser, particularly those that are easily damaged or blocked.

Pack sterilising tablets for cleaning your nebuliser.

O2 Concentrators

Refer to comments in the 'Flights/oxygen' section.

Power / Batteries / Plugs / Adapters



Check the power supply standard in the countries you want to visit. The voltage may vary from that in New Zealand.

Carry suitable plug adaptors or transformers for each piece of equipment. Plug adaptors are available from most electrical, hardware, and travel stores.

Paperwork

Ensure that you have a valid passport and, if necessary, any visas required.

You should allow ample time when making visa applications and check before departure for any changes in visa/passport/health requirements that a country may have implemented.

In countries where a visa waiver can be obtained, ensure you have checked that it has been approved before you travel.

Travel Insurance

Insurance is essential if you are travelling overseas.

DO NOT TRAVEL WITHOUT SOME FORM OF TRAVEL INSURANCE.

Many insurance companies will not cover Cystic Fibrosis. It is recommended, however, that you consider the need for supplementary medical insurance regardless of any reciprocal arrangements New Zealand has with other countries.

Although travel insurance can be difficult to obtain for people with CF, it is possible in certain circumstances through the travel insurance company "Mike Henry". Visit www.mikehenry.co.nz

Please ensure that the company abroad you are booking your holiday with i.e. tour operator/travel agent does not exclude people with "pre-existing medical conditions"; Either generally or conditions that are relevant to you. Many package holidays include insurance cover, but you should check the clauses carefully to ensure that nothing prevents the policy applying to you. If your child is going on a school trip, check that the school's travel insurance covers them fully.

You must disclose all medical history or other factors that may affect the policy; otherwise this may result in the policy being void.

You may also need to check that there is adequate cover for equipment or other property you will be taking with you. If a travel agent cannot fully answer your questions, contact the insurance company. In particular, many companies will not cover electrical equipment that has been placed in 'checked in' luggage.

PLEASE NOTE: Some insurance companies do not cover the loss of medication. You should carefully read the insurance policy, which will give full details with emergency telephone numbers.

Other companies will include medication within their baggage policy. If in any doubt, please ask the company you are dealing with.

WARNING! If you happen to be admitted to a hospital overseas (for exacerbation of your CF) when you're not eligible for medical insurance and not covered by the reciprocal agreement, the cost to you as a traveller can be HUGE!



The cost of a hospital stay in New Zealand is approximately \$700 A DAY – this DOES NOT include medical treatment. Overseas it can be even more!

Reciprocal Agreements

Reciprocal agreements with foreign countries DO NOT COVER PRE-EXISTING CONDITIONS. Routine checks for existing conditions won't usually be provided for under the agreement.

If the treatment relates to an existing medical condition, then a medical specialist must agree that it is needed to stop the condition getting seriously worse, if it is to be provided under the Reciprocal Health Agreement Act. However if a new condition arises (for example, if your appendix needs to be removed) then the medical specialist must agree that you require the treatment promptly. In both cases the need for treatment must arise during your visit.

New Zealand only has reciprocal arrangements with the United Kingdom and Australia. This means that you are covered for emergency care only and not for ongoing chronic conditions that need regular management.

Medical Certificate / Letter detailing condition & medications

Obtain a letter from your Doctor or Specialist explaining why medication is carried and a list of the medicines you have in your luggage. This is required for customs.

Establish whether or not you will need a medical certificate. Some airlines and insurance companies, require a medical certificate completed by your doctor.



When transporting medicines of different types, you will need to know if there are any restrictions on taking them in and out of New Zealand. A letter from your GP or Specialist stating the quantity required and why, who it is for and the fact that it is required for your general well being is usually sufficient for customs. If in doubt, phone Customs on 0800 428786 to confirm the above requirements.

List of Medications: generic/brand name/ingredient, purpose, dose

If you need to take prescribed medicines whilst abroad you should check on their availability in the country you are visiting, because your doctor can normally only prescribe a limited quantity under the health system in New Zealand.

Be aware that medications may be packaged differently in other countries or go under a different name - discuss this with the hospital pharmacy or a pharmacist and ask for trade names that medicines might use in the country you are visiting.

Compile a list of your medications, their generic name, brand name, active ingredient, purpose and dosage. This will assist an overseas doctor/pharmacist in selecting the correct product for you.



Places To Get Assistance: CF Associations /Medical Contacts.



If you are unlucky enough to get unwell whilst away, some hassles can be alleviated by knowing where to go for assistance.

Compile a list of contact details for the CF Associations in the countries you are visiting. This information is available on both the CF Worldwide website (www.cfww.org) and the European CF Society website (www.ecfs.eu). Each

of these Associations will be able to assist you in finding a clinic or hospital near you.

Also ask your doctor for any contacts that they may have in the countries you are visiting.

Remember to include the contact details for the supplier of parts for your nebuliser and other equipment. They may be able to put you in contact with a local supplier, or it may be simpler to have parts express couriered to you.

***Vicki's note:** While in Holland I could not use my nebuliser for 2 days. I took all my medication, side stream drug container and coiled duratube down to the accident and emergency department at the local hospital and asked to use their nebuliser. They were more than happy to help.*

While Away

Planning

Food & Drink / Dehydration and Salt Depletion / Pancreatic Enzymes

Keeping yourself well nourished can be difficult while you are travelling. Eating and drinking can be expensive, so try and visit supermarkets to buy your snacks and drinks.



Always carry snacks and drinks with you as sometimes it is hard to access food (that you want to eat) at tourist destinations. Good snack ideas include chocolate bars, muesli bars, biscuits, packaged cheese and crackers and crisps. Read the nutrition labels of unfamiliar foods to work out how many enzymes to take.

The food you eat on holiday is likely to be quite different from what you are used to. You may need to adjust your dose of pancreatic enzymes to account for any changes in fat intake. Remember to store the enzymes at room temperature (15-30°C)

Unless you know for sure that it is safe to drink the water, boil it before drinking or better still – have only bottled water.



If you usually take gastrostomy feeds or nutritional supplements (Ensure, Fortisip or Resource) remember to take them with you. It is sensible to work out how much you need and how much this will weigh. You may be able to access powdered supplements instead so discuss this with your dietitian and make sure you take a good ‘shaker’ to mix it in. Talk to your airline to find out how much it will cost to take your supplements with you, it may be cheaper to ship them overseas a couple of months beforehand.

Remember to take adequate giving sets, syringes and extensions for your gastrostomy feeds. You will need to carry your feeding pump on the plane as hand luggage to prevent it from being damaged.

Other countries charge for nutritional supplements, so it is not a good idea to rely on purchasing them overseas – there are more exciting ways to spend your money. However if you haven't got anything with you and are losing weight, check out the supermarkets and pharmacies for Complan, Carnation Breakfast and other such products.



Overall, enjoy the change in cuisine while you are away, and if you hate the food you will find most items on the McDonalds menu taste the same as they do here!

Always consult with your nutrition team before you go: considering climate, ability to carry foods etc as increased problems can come with hotter climates. Always carry salt tablets in hotter climates.

Make sure you keep your hydration up according to the climate. As a guide mix 2 litres of non-caffeinated drink with 1 sachet of gastrolyte OR 1 tsp of salt OR 4 salt tablets.

Increase your fluid if you are not taking any enteral feeding and always make sure you are drinking safe water. A 'camel' pack that you can fill is a great idea. If you experience cramps/excessive fatigue or a loss of appetite you will need to increase your salt intake for 24 hours to 3 – 4 times your usual amount. Use a combination of salt tablets, extra salt on food and salty foods. Take a salt shaker with you or souvenir salt sachets from restaurants and cafes.

Avoid raw or poorly cooked food. Eating from street-side vendors in some countries is not a good idea so be sensible about the likelihood that food has been cooked hygienically.

Peel fruit – you don't know where it has been or if it has been washed

Make sure hot food is VERY hot and cold food is VERY cold!

Use bottled water when brushing teeth

Activities

Holidays outside the peak months generally cost less and crowds at resorts are thinner. Also, major attractions are quieter and the waiting time in queues is not as long. Standing for too long can make you tired.

Theme parks: Wheelchairs are available in all major parks for a small fee. If you plan to be there all day, do obtain one (wheelchairs also tend to go to the front of the queues). Don't attempt to visit two parks on consecutive days. Have a rest day between visits.



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.

Medication

Remember to store your medications in an appropriate place, eg the refrigerator, or dark cool places.

If your room does not have a refrigerator and you need cold storage for medications, make arrangements with the hotel kitchen. Put your medications in an easily identifiable bag. Ensure that you can have access whenever necessary.

Getting Help

If you begin to feel unwell whilst away, act early. Use your contacts list to find a local doctor or hospital to assist you.

Alternatively your insurance company contact should be able to assist you to find appropriate help.

Driving

International Driver's Permit: The New Zealand Automobile Association Inc. (AA) issue International Driving Permits. Application forms are available at AA centres nationwide.



STDs

Sexually transmitted diseases are very prevalent overseas. Be careful and be protected.

TIPS FOR THE LONE RANGER

Whilst travelling alone is not recommended, some people do prefer to travel this way, here are a few tips to help. Most of these points are applicable to all travellers.

1. Join a bus tour of the city, it's a great introduction to your new surroundings and you're bound to meet other solo travellers.
2. If you are not comfortable eating alone in the evening, have your main meal at lunchtime when even the finest eateries offer their specialities at more reasonable prices.
3. If you are going to an out-of-the-way place for the day, leave a note in your room explaining where you're going. If you run into trouble, at least there'll be clues for the authorities to follow.
4. Carry a business card from your hotel or bed-and-breakfast. If you get lost in a place where you can't speak the language it will help you get back.
5. You are less vulnerable if you travel light; a single piece of luggage is best.
6. Be attentive on the streets and don't discuss travel plans with strangers.
7. Try to arrange to be met at the Airport by your Hotel or Hostel.
8. Develop a secure presence. Act self-assured, and don't appear weak, lost, or give the impression of being vulnerable. Stay in control of your body language, voice and activities. You don't need to look tough, just confident.
9. Leave key documents in your hotel safe if possible. If not, carry a body-fitted bag with all key documents and valuables. If you have a pack – try to get a front-facing one and also one that is slash-proof. Be aware of cities where pickpockets are more prevalent (Spain, Portugal, Russia and Eastern Block countries)
10. Consult a travel agent about safety concerns and read the travel advisories on the Department of Foreign Affairs and Trade Website, www.dfat.gov.au/travel.

Note from Vicki:

While in major cities like London, Glasgow, Edinburgh, and Paris I went on bus tours - excellent value for money especially if you are on a time limit. If you use the same bus tour in each city they give you a great discount. They tour all the major sights. An extra bonus with these tours is that you can get on and off at the major sights to suit yourself and they arrive every 15 to 20 minutes, plus they give you a commentary about the history of the major sights.