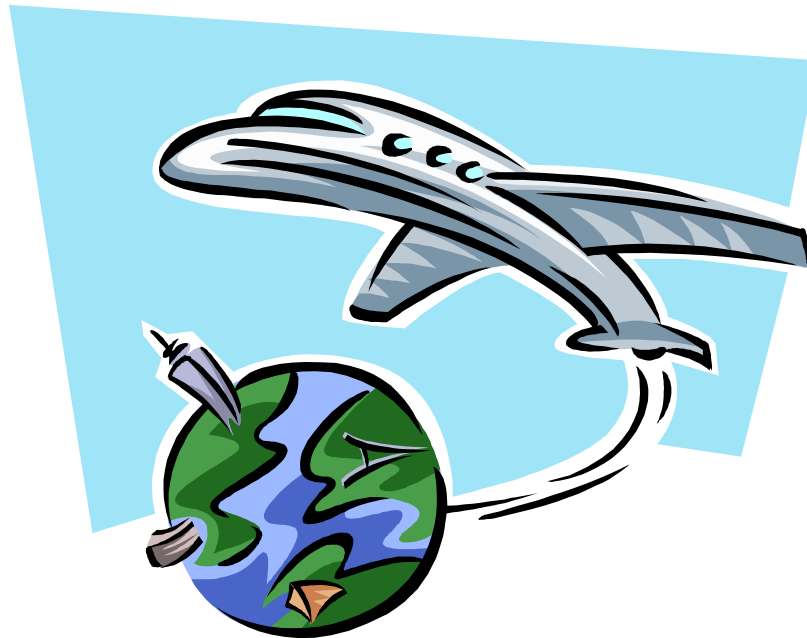


*Holidays & Travel Abroad*  
*Information Guide for People with Cystic Fibrosis*



*The information contained in this guide is published and distributed by the National Office, Cystic Fibrosis Association of New Zealand, P.O. Box 8241, Christchurch.*

*This booklet is NOT intended to be an exhaustive checklist of things to do and take, but points to some of the more important areas people need to consider.*

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*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 2<sup>nd</sup> 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 read the manual and put forward some suggestions."*

*Regards,*

*Vicki Kennedy*

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## BEFORE TRAVELLING

1. **It is your responsibility to ensure that you are in possession of a valid passport and, if necessary, any visa. You should also allow ample time when making visa applications and check before departure for any changes in visa/passport/health requirements that a country may make at any time.**
2. **Do not 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.**
3. Learn as much as possible about the area you plan to visit, for example, temperature, humidity, altitude and health requirements for your destination. Altitude is very important when assessing what your oxygen requirements may be.
4. You should consult your doctor well in advance of your departure for advice and to arrange any necessary immunisations. This is particularly important if you are travelling with children and they have not had their full course of childhood immunisations.
5. Establish whether or not you will need a medical certificate. Some airlines and insurance companies, require a medical certificate completed by your doctor.
6. 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 (approx. 3 months). Also be aware that they might 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.
7. 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 0800-428-786 to confirm the above requirements.
8. **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. New Zealanders are not eligible for GP subsidies or subsidised diagnostic and laboratory tests (other than in Hospital).
9. **RECIPROCAL 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.
10. Insurance is essential if visiting any other countries. **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.

## MEDICATION

- (a) Prepare sufficient medicines and nutritional supplements for the holiday, plus 2 additional weeks' supply
- (b) Prepare also a stand-by supply of antibiotics in case of an infection.
- (c) Mark all dosages clearly.
- (d) Consider carefully the time of year you should travel and obtain an adequate supply of salt tablets if necessary. 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.
- (e) Medication should be carried in a correctly labelled (original) container as issued by the pharmacist and stored in a Tupperware, or other suitably robust container. Medication should be packed in the main luggage - if travelling by air, divide the medication between more than one suitcase in case any luggage is lost in transit.
- (f) Nebuliser should be carried on as hand luggage (in a backpack) with enough medication to cover for a week in case luggage is lost in transit. (Think worse case scenario: if you lose your neb you have no way of treating yourself).
- (g) Pack sterilising tablets (for nebulisers).
- (h) 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.
- (i) If ciprofloxin is part of your medication, then sunblock will be needed. This medication makes you more sensitive to sunlight, and be aware while driving at night - it can affect your vision with the glare of headlights.
- (j) Ensure you take extra enzymes in case food is particularly high in fat content.
- (k) Any glass bottles should be carried in hand luggage.
- (l) Pack travel sickness tablets.
- (m) 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.
- (n) Check that, if required, the various hotels or other places you are visiting have a refrigerator.
- (o) If Pulmozyme (DNase) is part of your medication it's temperature must be between + 2°C to + 8°C. It can be stored in a cool bag with freezer block. Pharmacist issues this to you on receiving Pulmozyme. Pulmozyme will only last up to 24 hours out of the recommended temperature range.

- (p) **OXYGEN** - 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. Also available are portable oxygen units, which can be hired, or the cost of hiring financed through a local Cystic Fibrosis branch. Many coaches are not able to carry oxygen cylinders, but many make space for a concentrator - check at the time of booking. **DO NOT** leave informing your airline of your need for oxygen until you check in! Many airlines need several day's notice that you will need supplementary oxygen – after all it is a flammable substance! All airlines have different regulations regarding this, so please check with your airline **BEFORE** you book.

Also note that even if you do not require oxygen therapy usually, you may need to in flight on long-haul because you will be exposed to lower oxygen concentrations for long periods.

## INFECTIONS

In some countries, bacteria exist in more dangerous levels due to heat/ humidity etc. Things to be aware of in this regard are:

1. 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. Avoiding barefoot exposure to mud in the wet season in these countries.
2. Sexually transmitted diseases are very prevalent overseas. Be careful and be protected
3. If backpacking in low income countries, make sure you get all the appropriate vaccines

## NUTRITION

Keeping yourself well nourished can be difficult while you are travelling. It is a good idea to discuss your nutrition with your dietitian before you go. 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. 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! Also a McDonalds Shake is worth 580kcal so is a great snack if you can get it.

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.

Limit alcohol, 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 streetside 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

## NEBULISERS

Carry a suitable plug adaptor. There are universal ones available from hardware stores in New Zealand - Mitre 10 or Placemakers - approx price \$25.

New portable nebulisers, which can be run on battery, should also 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 an extra side stream drug container in case the jet holes get damaged. If parts are interchangeable, just the bottom half of the side stream drug container will be sufficient for a short-term holiday.

Have a contact phone number for the supplier of the parts to your nebuliser. Fisher & Paykel Healthcare sell a Freeway Lite Nebuliser and they have an 0800-503-553 number for phone and fax (NB: 0800 numbers can not be dialled from overseas) phone +64-9-574-0100 or fax +64-9-574-0158. Sometimes it is easier to have parts couriered over, as it is difficult trying to find a supplier in a strange country. Have a list of the code numbers for individual accessories available for your nebuliser. Some suppliers may have a contact phone number for suppliers in other countries.

***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.***

## AIR TRAVEL

Establish whether you will need oxygen on the plane. If you require oxygen, a certificate and prescription can be completed by a doctor. Having a certificate and prescription issued by a doctor shows you are eligible to fly, and means the airline should provide an in-flight oxygen service. They are entitled to charge and some airlines can refuse to supply it. Check with the travel agent at the time of booking, but bear in mind that airline policies may change before your departure.

Some hospitals have a department (outreach department) and a service co-ordinator that can help you make enquires with the airlines. Usually they have people they contact at the airlines on a regular basis and may be able to arrange this service 'NO CHARGE'. Airlines are entitled to charge for this service so I have included the cost.

The following gives an approximate idea of charges that airlines make for in-flight oxygen. Domestic: Air New Zealand charge \$25.00 per flight coupon (subject to change). Oxygen is available only on aircraft ATR5000 and 737/400/500/600. Flow rates vary for each aircraft. ATR5000 flow rate is 4 litres per minute; 737 flow rate is 2,4 or 8 litres per minute. If you are travelling domestic and they cannot supply oxygen, you may be allowed to use your own supply. Lightweight portable systems may sometimes be taken on the airline as hand luggage so long as they are disconnected. Check with the travel agent at time of booking the ticket.

International: Air New Zealand charge US\$75.00 per flight coupon (subject to change). The aircraft that can supply oxygen are 737, 767 or 747 and their flow rate is 5 litres per minute and the bottles are available in 2 or 7 litres. You will also require a medical certificate stating the required flow rate.

Also check when booking, that the airline concerned will allow a compressor to be carried. If it is allowed, take it as part of your hand luggage. Concentrators generally need to be insured if you are taking them abroad; this can be done separately or as listed items on your household or travel insurance.

Have a drink at least once each hour, letting the plane staff know when you arrive on the plane of your extra needs and carry sufficient snacks and enzymes for the journey. Ask for a seat at the front where there is extra space for physio.

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)**

If special meals are required, arrange at time of booking the ticket, 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 2 meals is quite a good idea. If they are unable to supply 2 make sure you take snack foods with you.

Planes can become very cold on long flights, so wear or take additional clothing such as a tracksuit. Also carry an inflatable neck pillow and eyeshades - this makes a huge difference to you being able to sleep.

Carry any medicines required during the flight in your hand luggage and take extra in case of delays. Take a letter explaining what medicines, syringes etc. you carry and why.

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

## DRIVING

International Licences: The New Zealand Automobile Association Inc. (AA) issue International Driving Permits. Application forms are available at AA centres nationwide; the cost is \$20.00 and the permit is valid for 12 months from the date of Issue.

The application must be accompanied by a current New Zealand Driving Licence (a photocopy is unacceptable) and one recent passport type photograph. If you take a passport-sized photo with you, you'll save having to pay another \$20 to have a photo taken there! An International Driving Permit cannot be issued to a person under 18 years of age or to holders of Learners, Provisional or Restricted Licences.

## CLOTHES

When choosing clothes it is sensible to bear in mind that the weather may be changeable. Try and wear only dark colours and make use of lightweight wind proof articles that are invaluable due to their quick drying times. Do a practice pack one week prior to leaving and then halve it. Keep the luggage to a minimum. **REMEMBER - YOU HAVE TO CARRY IT!**

## VISITS TO DISNEYLAND & THEME PARKS

Use the first aid stations for physio. Wheelchairs are available in all major parks for a small fee. If 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.

## CF CENTRES ABROAD

The CF Trust in England can provide addresses of National Associations and local clinics that are available in the country you may be travelling to. It is best not to rely on there being a CF Centre but check first with the Family & Adult Support Department, Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY, Phone +44-208-464-7211. NB: approx 12 hours behind New Zealand

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

*Stairs are in abundance 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 a certain time (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.*

## INSURANCE

It is generally known that insurance cover for the person with an illness or disability is more expensive and difficult to obtain. Many insurance companies or brokers will not cover certain disabilities, so 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 that is 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.

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 when you're not eligible for medical insurance for Cystic Fibrosis and not covered by the reciprocal agreement for a pre-existing condition, 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!*

## **TRAVELLING SOLO - TIPS FOR THE LONE RANGER**

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](http://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.***

"Holidays and Travel Abroad - Information Guide for People with Cystic Fibrosis" has been compiled to assist you, your family and medical 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 author and distributor can accept no liability whatsoever for any matters in any way connected with or arising out of this information.



## **Official Guide for Adults with Cystic Fibrosis traveling abroad from the Cystic Fibrosis Association of New Zealand**

The following guide is based on information provided by our affiliated CF Associations and Foundations around the world and gives care information for some of the most commonly visited countries by Kiwis.

### **First – information common to all countries and a guide to the basics you should have with you when you travel.**

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

Travel Insurance, although difficult to get for people with CF, is possible through the Travel Insurance company “Mike Henry”. Visit [www.mikehenry.co.nz](http://www.mikehenry.co.nz)

#### ***You should take with you:***

A letter of introduction from your Physician, outlining your condition – phenotype (if known), FEV 1 at last spirometry and a full list of the medications you routinely take to keep you well and all the equipment you need (nebuliser/ syringes etc)

A recent lab report showing you are free of MRSA and Burkholderia Cepacia if you can.

Enough medication for your whole trip if it is a short holiday and for at least three months if you are staying longer.

### **Regulations in Specific Countries**

#### **Australia**

Has a very functional and well resourced CF Association that is split into autonomous State organisations. Support types and levels vary but our Australian CF Association ‘cousins’ are very happy to hear from any New Zealanders coming to Aussie who want some support while they are there. See above for the reciprocal agreement. This means that should you need ongoing care for an extended stay you will be required to pay 100% of the cost of care and medication.

#### **Canada, USA, UK, Germany, France, Italy and all Asian countries**

Travelers must pay 100% for all services. No reciprocal arrangements are in place.