

TRAVELLING WITH CYSTIC FIBROSIS

THINGS TO REMEMBER

If you are travelling with little ones....

If your child needs special formula as an infant or toddler, have it shipped directly to your destination. Your medical supply company will usually ship free of charge anywhere. Call ahead to the hotel for their shipping address, any instructions for shipping & that you will have a package delivered. I have found all hotels to be very accommodating.

Bring all medications & equipment with you as a carry on. At the security check point all will need to be removed & checked by security personnel. It is convenient to have one bag with all medication & equipment to keep it organized and not worry where something is or "hiding". Depending on the size of your medication, you might need to be wanded, patted down & possibly swabbed on your hands as part of the security check.

Security check can be time consuming in general and usually longer with special needs like a nebulizer, feeding pump, IV pole, etc. In my personal experience, keep your cool & don't worry about the people waiting in line behind you. Be courteous but speak out if they don't let you take any of your medical needs, they don't know what you need, you do. I have asked for a supervisor & explained the need for my 3 year old to have 16 cartons of a specialized formula (which they looked at as drink boxes) for tube feeding in great length, it's not your everyday & they are doing their jobs. Make sure you are respectful but voice your need for your child's or own medical well being.

Also, if all your medications & equipment are in one bag, usually this one can be just opened that once at security & then stowed in the overhead on the plane. There are no restrictions on medicine, medical equipment or general baby equipment on airlines.

As a bonus, travelling to theme parks is made easier when your CF center sends along a letter asking for expedited waits in lines, etc. Disney World gave us a free refrigerator when we stated we needed it to store medication for a child.



Traveling with Cystic Fibrosis may require a bit more planning than usual, but it is always best to be as prepared as possible. We've traveled to many destinations and have had many wonderful experiences. Here are some important tips to consider when planning a trip:

1. Choose a destination that has access to medical care and is "CF Friendly". We booked a room on the beach and had no idea that a "red tide" was present. It seriously affected our son's breathing and we sought emergency care at the local emergency room which was only 1 mile away. Fortunately we were able to enjoy the rest of our vacation, just not on the beach. We try not to vacation in remote areas where access to medical care is limited. Ensure communication with your CF center if the need arises.
2. Check with your health insurance carrier to see what coverage you have at your particular destination. It may be wise to purchase trip insurance with medical coverage.
3. Check with your airline carrier etc. for their policy on travelers with special/medical needs. Obtain documentation necessary to ensure your child's medical and other needs are met. Usually that includes a letter from your CF center, documenting the need to carry your equipment and medicines with you on the plane.
4. Check with your airline carrier or other mode of transportation to ensure proper storage of your medical equipment. Minimize chances of damaged or lost equipment. Keep your compressor AND vest with you. We didn't bring the Vest with us on trips when our son was younger, we just did manual PT. Now that he is older and will probably travel independently, we obtained the smaller Vest system which conveniently fits in a carryon bag.
5. Keep all medications with you. Do not store with luggage as they can get lost or be exposed to poor storage conditions. Keep refrigerated items in a small cooler. Also bring extra medication, inhalers, etc. in case of any malfunctions or trip delays. Many CF medications are not available in local pharmacies or there may be insurance issues when trying to obtain extra meds away from home.
6. Bring extra food and beverages with you when traveling.
7. Bring medications in anticipation of a potential health issue. For example, bring antibiotics to treat a sinus infection if that is something your child is susceptible to.
8. Ensure accommodations are air conditioned and bring any electrical adapters to ensure your medical equipment can be used.
9. Have a great trip!!!

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Traveling Internationally with CF....

Traveling internationally with CF requires a bit more organization and planning ahead. Our 18 year old daughter has visited 31 states including Alaska, and has visited Canada, Mexico, Costa Rica, Iceland, Sweden, Finland and Spain. She went with her classmates and teachers to Spain for 2 weeks without accompanying family members and lived with a Spanish host family.

For the Spanish exchange, we rented an international traveling ABI vest from Hill-Rom. It is a smaller device and comes with a carry-on sized suitcase. This model has the internal AC/DC converter and will work with ease on the different voltage. However, it is *imperative* to bring along the proper plug adapter. The plug is a 2 pronged North American type plug, and different countries in Europe have different shaped plugs. We purchased these adapters at Radio Shack and Circuit City. It is also important to note that voltage converters may make appliances and compressors work less efficiently, making treatment times longer.

You might also want to ask your CF center for other chest physiotherapy options to bring along with you (acapella, aerobika) in case the vest does not work abroad.

Additionally it is important to travel with medication in their labeled bottles. However I would not advise bringing more medication than 1.5x the duration of the trip, and leave most of the medication at home. This may require saving empty Rx bottles in advance to the trip so medications can be portioned out in labeled bottles.

Another practical travel tip is to scan important documents and email them to yourself. Therefore if the documents are lost, you can access them on email for customs officials.

