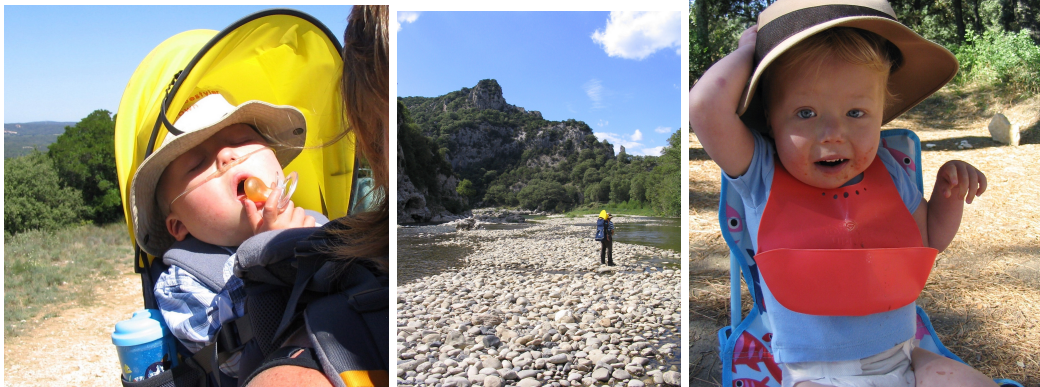


## Taking oxygen dependent children abroad

### Advice from Sonya Pettigrew, a parent who's been there, done that and bought the T-shirt

Last year my husband and I decided in a moment of madness to take our son Alexander on a holiday. We decided to go camping in the south of France for two weeks. I should explain that my son, who was two and a half at the time, was born with complex congenital heart and lung defects requiring him to have home oxygen when he sleeps. It was surprising how easily we made the decision to go on the holiday without realising the consequences of that choice. The following two weeks prior to the holiday I frantically tried to organise oxygen supply in France and insurance to cover us for any medical emergency. It was a complicated and frustrating process full of pitfalls however on a bright Saturday in August we set on our adventure from Dover on the ferry to France. We spent two glorious weeks walking, swimming eating and drinking, living out of a tent. We even devised an ingenious way of strapping the oxygen to the bottom of the back carrier, enabling us to take an epic walk through the Gorge de l'Ardeche, a seven hour round trip into the wilderness. It felt like a huge achievement to be on a camping holiday despite Alexander's extra needs. It was refreshing to be in such a different environment from the clinical stench of the hospital with which we had become so familiar.



Travelling with oxygen can be intimidating but with proper planning it can be achieved comfortably and safely. You don't have to give up the adventure of travel you just have to make your arrangements well in advance and be willing to take the extra time to confirm details thoroughly prior to your trip. Make sure you leave yourself a period of three to six months starting with a visit to your child's local paediatric consultant. You will need doctor's certificates for any public

transport such as airlines and ferries. Make sure your doctor mentions your child's flow requirements and how long they need to be on the oxygen (i.e. for intermittent periods or continuously).

Once you have decided on where to go you need to think about how you are going to get there and who is going to provide an oxygen supply for your stay.

## Getting there

Ferries, cruises, trains and flights are all prepared to take oxygen dependent passengers as long as they have doctor's letters permitting them to travel. It's essential to check with the company before making any booking as each have their own criteria you need to adhere to.

### Flights

Taking a flight with a child on oxygen needs a considerable amount of planning. High altitudes will cause the partial pressure of oxygen to naturally fall. Healthy people are largely unaffected but if your oxygen levels are low at sea level then flying can have serious implications. You may be instructed by the doctor to adjust the level of your child's oxygen during the flight to take this into consideration. Department of Health and some airline guidelines say you will not be troubled by cabin pressures if you can walk for 50 meters on level ground at a steady pace without getting breathless (difficult if you have a baby who cannot walk yet).

Certain airlines may also request you to fill in a MEDIF (medical information form that you and your doctor need to complete). Most airlines will not permit you to carry your own supply onto the plane however it's worth calling to find out their individual policy. Airlines generally prefer to provide their own oxygen cylinders at a cost of between £80n and £100 per leg (ie if you change planes you will get charged twice so try to take a direct flight). The maximum flow rate provided by airlines is generally not more than 4 litres per minute. Low flow meters are hard to come by so it's worth checking what the lowest flow is that they can deliver.

A nebuliser can be carried onto the plane as hand luggage however it cannot be operated during takeoff and landing and must be battery operated as there are no mains connections available. If you have to change planes you will need to arrange oxygen supply in the airport of your transfer with the country you are landing in.

Before booking, contact the airline as far in advance as possible to check the following:

- What documents do they require?
- What is the charge for providing/carrying oxygen on board?

- Find out what flow they can deliver and if they provide mask or nasal cannula
- Confirm arrangements 48 hours prior to flying
- Arrive early for check in (at least an hour and a half) on domestic flights so that complications can get ironed out well in advance of take off.

## Cruises and ferries

Cruises do not supply oxygen but are happy for you to bring your own supply on board with the appropriate paperwork. Ferries also will permit you to carry oxygen on board (and in your vehicle if you are on a car ferry). P&O will allow six size F cylinders (or smaller) which is a total of 60 litres of oxygen along with a doctors certificate. We travelled by SeaFrance last year, who have no specific policy regarding carrying oxygen in your car and didn't even require a doctors certificate (we took one with us just in case).

## Eurostar

Eurostar permit you to carry on a small cylinder (no specific size was mentioned) as long as you declare it upon check-in and produce a doctor's certificate. Eurotunnel permits you to carry 50 kg of oxygen cylinders in your car (with a small portable taken into the carriage). Be careful when booking the Eurostar as they are pretty awkward at the moment about taking cylinders onboard their trains. Most countries request that you declare any cylinders you have with you through customs upon entering and leaving the country, including Britain.

## Driving

If you decide to drive to your holiday location there are a few things that you need to know. If you are going to transport the concentrator, which is only an option if you are in the UK as you are not permitted to take it abroad, it must remain upright in the boot of your car, or restrained on the backseat. Remember to store oxygen cylinders securely in the car - we put all the spare cylinders in the back with a small cylinder for the journey secured under the passenger seat. If you travel abroad in the EU (this includes the UK) and have oxygen in your car you are meant to carry a TREM card (transport emergency card) displayed in your window screen however you need to buy these at a cost of £10 or more and need specific information about the oxygen you carry which is complicated. In the end we settled for displaying a green compressed gas sticker and the ferry company were happy with that

## Your stay

As of 1<sup>st</sup> February 2006 all UK oxygen suppliers have a duty to enable you to get oxygen abroad. However, on calling Allied Respiratory (the supplier for this area) the only advice they gave me was to call the embassy of the country I was

travelling to. Allied Respiratory are only able to arrange oxygen supply in the UK, Scotland and Northern Ireland. You are not legally allowed to take their oxygen cylinders or concentrator out of the country.

In theory if you travel within the EU you can arrange for oxygen to be delivered to you at your point of entry into the country by contacting the relevant embassy in London before you go. You will be charged the total cost of this, however it is possible to claim 70% of this money back from the Overseas Division for Medical Benefits (0191 218 1999) upon your return to this country. So, make sure you get receipts for any oxygen you buy overseas. If you purchase oxygen privately in this country you cannot claim this money back. I found that in reality this was a nightmare to organise in the time I had. I don't speak 'medical' French and in the end it was much easier to buy oxygen from a private supplier in this country to take with us.

Locally we have an excellent supplier called Advanced Air Medical (01273 308176) who will provide cylinders for you to take abroad in your car. If you fly then you will need to arrange supply to be delivered to your airport destination from a supplier in the host country (a full list of suppliers worldwide is available from myself or amaze). I found Oxygen Worldwide an expensive but reliable company ([www.oxygenworldwide.co.uk](http://www.oxygenworldwide.co.uk)) that were willing to deliver cylinders wherever we wanted (even to our campsite!)

Hotels, B&B's self-catering apartments and campsites need to be notified when you make your booking. When making bookings remember that you are going to have to carry all that oxygen along with your luggage to your room or site so make sure they have a lift or request a ground floor room with easy access.

## Insurance

It is essential to get proper insurance cover when travelling with a child with extra medical needs. Within the EU we are meant to receive reciprocal care. However you may find that without insurance you have to pay the hospital bill and then claim it back upon return to the UK. Make sure you carry an EHIC (E111) card with you which entitles you to reduced cost and sometimes free medical treatment. You can pick one of these up from the post office or apply on line at [www.ehic.org.uk/Internet/home](http://www.ehic.org.uk/Internet/home).

The US has private medical care so even a short stay in a hospital can cost thousands of pounds. Most hospitals stateside won't let you through the door of an A&E department without evidence of either a valid insurance document or a credit card so it's worth making sure you have adequate cover. Getting insurance for your child can be tricky especially if they are waiting further procedures or have ongoing issues with their health. Insurers are really only interested in the stability of your child's condition so expect long telephone calls with lots of questions. Make sure you know the exact medical name of your child's condition

and always take a note of who you speak along with the date and time of the call. There are many specialist insurance companies that cover people with complex medical needs however they are can be very expensive and by shopping around a cheaper alternative can often be found on the high street. Makes sure you tell the insurance company all the details of your child's condition, any information you withhold about your child's condition can invalidate the policy.

There are various travel agencies that cater for disabled passengers needs but we found it cheaper and easier to organise it ourselves. It just needs time, patience and planning. It was an important step for us to take this trip and let ourselves not feel defeated by Alexander's condition. It was an unforgettable and invaluable experience for us as a family, one I would repeat readily. We are currently in the process of planning our next camping trip abroad. This year I am delighted to say that Alexander is off the oxygen, however he now has a gastrostomy fitted requiring a battery/mains operated feeding pump overnight, which at first I thought this was going to put a stop to our little adventures but in reality it has made us all the more determined to make it happen!

**Sonya Pettigrew – May 2008**

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### Useful numbers :

British Lung Foundation	0845505020 <a href="http://www.lunguk.org">www.lunguk.org</a>
Department of Health (provide numbers for foreign embassies in London)	0207 210 4850
Overseas Division for Medical Benefits (Claim back a percentage of your oxygen bills from EU through this department)	0191 218 1999
NHS Home oxygen	<a href="http://www.homeoxygen.nhs.uk">www.homeoxygen.nhs.uk</a>
Allied Respiratory (supplier for South East)	0500 823 773
Advanced Air Medical (provides oxygen privately for UK and continent)	01273 308 176
Oxygen worldwide	(00 34) 96 688 28 73 <a href="http://www.oxygenworldwide.co.uk">www.oxygenworldwide.co.uk</a>