



Respiratory Health
Implementation
Group

child health

Noah's Ark

Children's Hospital for Wales
Ysbyty Plant Cymru

Paediatric Respiratory Medicine

Taking your child home on oxygen

Name

Hospital number

Respiratory Consultant

Useful help line numbers

Respiratory nurses	
C.A.U	
Health visitor	
District nurses	
General Practitioner	
Chemist	
Social worker	
Oxygen company	
Family support worker	

Useful organisations

BLISS, National office	0207 820 9471
Freephone parent support helpline	0500 618140
British Lung Foundation	0207 831 5831
Action for Sick Children	0208 542 4848
Family Fund Trust (benefits & grants)	01904 621 115
Family Holiday Association	0207 436 3304
Janet James/Sarah Byrne/Claire Briggs Specialist paediatric respiratory nurses Children's Hospital for Wales	029 20742116

Introduction

This information has been put together to help prepare you, and your family, for taking your child home on oxygen. If you have any questions about any of the information provided, please ask the respiratory nurses or ward staff to help.

Looking after your child on oxygen

Your child is stable and ready to go home on oxygen therapy. The respiratory nurses will ensure that you feel confident about managing oxygen at home. Sometimes before you go home from hospital, a meeting may need to be arranged to include yourselves and various health professionals. This may include the respiratory nurse, health visitor, social worker, Consultant, General Practitioner and ward staff. You will have the chance here to discuss any concerns and ask questions.

The length of time that your child will be in oxygen will depend on his/her's individual progress, needs and illness. The Consultant may give you an idea of how long your child is likely to stay in oxygen, and will monitor your child's condition so that he/she isn't in oxygen for longer than necessary.

Your Consultant will have told you the amount of oxygen that is required. It is essential to make sure that your child gets the right level of oxygen and that oxygen levels are only altered with the health professional advice.

An oxygen saturation monitor or pulse oximeter as it is sometimes called, uses an infra-red light to detect the amount of oxygen that the red blood cells are carrying around the body. It is not usual to take an oxygen saturation monitor home with you though your child will have been on one in hospital. If you need an oxygen saturation monitor then it will be provided for you.

Before going home, you will be shown how to assess your child's colour and breathing pattern as this is often a better way of telling how your child is than using a pulse oximeter. The respiratory nurse will arrange regular home visits to check your child's oxygen saturations and will sometimes perform an overnight trace so that they can see how things are going and whether the oxygen is still needed.

Asking for Help

Once at home, if you are at all worried about your child's breathing, you should contact the hospital for help. Never worry about asking for help if you feel that your child is working harder to breathe - it is important to let the health professionals know.

If you are worried, call the respiratory nurse or the C.A.U. Your child will have open access to this unit where the staff will have your child's details on file.

If worried overnight, please telephone the appropriate ward for your child;

- Ocean ward (< 1 year of age) 029 20743359
- Land ward (> 1 year of age) 029 20743276

Emergency dial 999

If you are worried that your child is not getting enough oxygen or is ill

How will the oxygen work?

You will be given oxygen safety guidelines by your oxygen supplier and these will need to be followed for everyone's safety.

Oxygen comes in three different ways; oxygen concentrators, oxygen cylinders and liquid oxygen

- **Oxygen concentrator:** This is for use within the home and run off electricity. It concentrates the oxygen from the surrounding air.
- **Oxygen cylinders:** A large static cylinder is provided for the home as back up for the concentrator in case there is a power cut. Small cylinders are provided for ambulatory use (getting around)
- **Liquid oxygen** is mainly used for those patients requiring a high flow rate of oxygen 24 hours a day and needs to be mobile for long periods throughout the day e.g. at school

The Respiratory nurse will organize appropriate oxygen for your child with the oxygen company – *BAYWATER HEALTHCARE*.

More about oxygen cylinders

The oxygen cylinders, which store the oxygen, are black with a white top and are made from cast iron (gas) or aluminium (liquid), with a flat bottom for standing upright. The oxygen is delivered through tubes linking the cylinder to your child. A flow meter attached to the head of the cylinder tells you the rate at which the oxygen is being delivered.

You will need to contact *BAYWATER* to replace your empty cylinders, which can take up to 3 working days. Therefore, please do not wait to run out of oxygen before telephoning. The weekends are kept for emergency deliveries only and so no replacements will be delivered at this time.

The number of hours a cylinder lasts depends on the amount of oxygen being delivered

Freedom 400 cylinder will last approximately:

- 14 hrs when delivering at 0.5L
- 7 hrs when delivering at 1L
- 3.5 hrs when delivering at 2L

Cleaning the equipment

- The oxygen company will advise you about the safest way to store and clean oxygen equipment.
- If the nasal cannula becomes blocked, you will need to replace them and you must contact the oxygen company directly on FREEPHONE 0800373580.
- If for some reason you are experiencing problems in obtaining this equipment then please do not hesitate to contact your respiratory nurse who will help you.
- It is always a good idea to keep a list of the items that you are running short of.

Oxygen in the home, car and on holiday

Who do I need to notify about this?

- If you live in rented accommodation or Local Authority housing, you need to advise the appropriate persons that you will be having oxygen in the house. If you have any problems with this, please ask your social worker for assistance.
- You will also need to notify in writing your gas and electricity suppliers and car and household insurance company. Ask for something in writing from them after you have notified them.
- The oxygen company will provide you with written information on the safety aspects of oxygen.
- If you have a baby on oxygen, your pram will need a sturdy tray underneath. You will not be able to hang the cylinder over the pram handles, as the weight will pull it over. A carry bag is provided by the company to ease the transporting of the cylinder.
- If you are transporting oxygen cylinders, it is safe for them to be placed lying down providing they are secured and are not rolling around the car. Make sure that the area in which you are carrying the oxygen, for example the boot, is clean and dry.
- If you intend to travel abroad while your child is on oxygen, it is best to ask the Consultant's advice. When planning your trip, talk to the tour operators, the airline or ferry company, and oxygen company. Remember this may take months to organise safely. When arranging travel insurance, ensure that you advise the insurer that your child is on oxygen. It is worth checking more than one company. It may be better for your child to postpone the trip if at all possible, until he/she is out of oxygen.

Additional information

Infections

Children and especially babies on oxygen are particularly prone to chest infections and practical measures should be taken to avoid exposing them to other people's coughs and colds.

Benefits

You may be entitled to Disability living allowance now your child is receiving oxygen therapy. Your health visitor/local practice nurse can help you complete the necessary forms. There are other benefits that you may be entitled to depending on your particular situation.

Telephone

It is essential that you have a telephone at home. If you do not have one, ask your health visitor/local nurse for help to sort this out. If you need to have the line repaired, please inform the company that repairing a line is a priority, because of contact with the hospital and ambulance service.

Clinic

Once your child has left hospital, you will have an appointment to attend a follow up clinic to assess

your child's health and development. If you have trouble with transport please inform your social worker well in advance of the appointment. It is essential that your child attends these clinics.

Sleeping positions for babies on oxygen

As for all babies, 'back is best'. FSID produces free leaflets on sleeping positions and avoiding cot death. Please telephone 029 20825840 for a copy. A helpline is also available by phoning 0207 233 2090.

Respite care

If it is possible, take a regular rest from looking after your child. Whoever is looking after your child when you do this will need to be confident about the care that they provide and have received appropriate training in the provision of oxygen. This can normally be organized by the company or the Respiratory Nurse. It is possible to install oxygen cylinders in a secondary address, for example, a person/family member who regularly cares for your child as long as they agree to follow safety precautions. Please also ask the respiratory nurse about any local organisations or charities that may provide a suitable respite service, for example, Ty Hafan or Barnados.

Smoking

If there are smokers in the house, then it is essential to know about certain aspects of caring for your baby on oxygen. It is also important to understand that a child on oxygen has fragile lungs and can become ill very quickly. **Never** smoke in the house or around your baby/child.