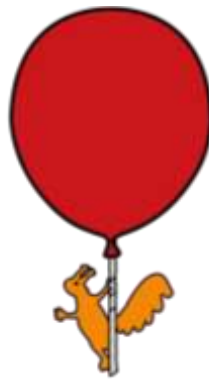


Respiratory Department

Home Oxygen Therapy Manual



Information for parents and carers

Introduction

Dear Parents and Carers

The oxygen team at Alder Hey Children's NHS Foundation Trust are available to support you whilst your child has oxygen at home.

This manual gives you information about taking your child home on oxygen. We will discuss the oxygen equipment, oxygen safety and our role in caring for your child in the community.

You may feel very anxious about taking your child home on oxygen. Please be reassured that although the equipment and oxygen safety information sounds complicated, it isn't, and once installed the equipment is very easy to use.

Our contact details are:

Oxygen.nurse@alderhey.nhs.uk

Email is preferred method of contact however telephone number as below:

Mob: 07976208705

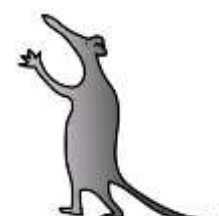
Monday to Friday 9-5pm

Liverpool Women's Hospital

If your child is born prematurely and discharged home from Liverpool Women's Hospital requiring oxygen therapy, their consultant will be **Prof Sinha**, Consultant in Paediatric Respiratory Care.

Alder Hey Children's NHS Foundation Trust

If your child is discharged home from Alder Hey Children's Hospital requiring oxygen therapy, their Respiratory Consultant will either be Dr Grime, Dr Halfhide, Dr Mayell, Prof Sinha, Prof McNamara, Prof Semple, Prof Southern or Dr Thursfield.



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Baywater

In the North West, home oxygen equipment is provided by a company called 'Baywater Healthcare'. They are an established company who provide home oxygen both in our region, and across other regions in the UK.

Baywater Healthcare

0800 373580

The Healthcare helpline can be contacted every day 08:00-18:30. Emergency calls can be made 24hours a day.

Home Oxygen Equipment

Baywater Healthcare has a variety of different oxygen equipment available. This will be discussed with you prior to ordering and the most appropriate equipment will be put in place. If anything changes, please contact either myself or your local community nursing team to discuss. Pictures of some of the equipment can be found later in the booklet.

Baywater Healthcare will:

- Install oxygen equipment within three working days (next day delivery if a hospital discharge) of the order being placed.
- Provide an emergency backup cylinder to your home (if using an oxygen concentrator).
- Carry out a risk assessment of your home, installing oxygen cylinders in the safest places
- Provide user guides for all oxygen equipment
- Reimburse your electricity costs (if using an oxygen concentrator), and service the equipment every 6 months
- Inform the fire service that oxygen equipment has been installed in your home
- Provide required consumables e.g. nasal cannula, oxygen tubing, face masks etc.
- Provide a carry bag for portable oxygen cylinders



You will be asked to sign a consent and IHORM form (Step 1) and then your Respiratory Team can complete a 'Home Oxygen Order Form' (HOOF) (Step 2). Baywater Healthcare will contact you by phone to arrange installation (Step 3).

Step 1

Sign a consent/ IHORM form allowing your child's information (name / DOB/ address/ diagnosis to be shared with Baywater

Step 2

Your respiratory team will complete the Home Oxygen Order Form (HOOF) and send to Baywater. Your GP will also be informed.

Step 3

Baywater will contact you by phone to install the appropriate oxygen equipment in your home.

Oxygen Concentrators

➤ What is an Oxygen Concentrator?

An oxygen concentrator is a machine operated by electricity, weighs approximately 25kg (55lb) and are 50-70cm (19.5 – 27.5ins) high. The machine draws in air from the room atmosphere, separates the oxygen from the other gases in the air and delivers oxygen to your child. It is simple and easy to use and needs to be plugged into the mains when being used (not an extension lead).

The concentrator will be serviced by a Baywater engineer at three months then every six months. Between these service dates parents are asked to clean and change the air filter on the machine (standard / low flow concentrator only). The filter should be washed weekly in warm water, allowed to completely dry before replacing in the machine. You will be given a spare filter and the engineer will explain what you need to do.

The concentrators are:

Airsep NewLife Elite will provide oxygen requirements between 1 – 5L/min only

Airsep NewLife Elite (low flow) will provide oxygen requirements between 0.1 – 2L/min only

Airsep NewLife Elite (high flow) will provide oxygen requirements between 2 – 8L/min only

The concentrator is serviced every 6 months by Baywater Healthcare, they will contact you to make arrangements for this to be done.

FireBreaks

Along the tubing on the concentrator and static cylinders will be firebreaks, on them is an arrow which should always be pointing to your child. Also you can ask for small piece of tubing and firebreak for your portable cylinder, as a safety aspect when outside with your child.

Emergency Backup Service

Baywater Healthcare will provide an emergency back- up oxygen cylinder with a concentrator. If there are any problems with the concentrator, parents are asked to connect their child to the back-up cylinder, by opening the valve on the side (**please see separate sheet**) and setting it at the correct oxygen flow and ring the company for advice.

Some problems can be resolved with advice over the telephone; however the company do guarantee to call out if the problem persists and before the back-up cylinder runs out.



Ambulatory (Portable) Oxygen Cylinders

➤ What are portable oxygen cylinders?

If your child requires oxygen at night and during the day they will require portable oxygen cylinders so that you can go out. Baywater Healthcare provide different portable oxygen cylinders and also provide a carry bag for these cylinders. Cylinders which have the open valve on will need to have the valve open when in use for the patient (**please see separate sheet**).

Leaks

- Any leakage of oxygen from a cylinder will be evident by a hissing noise. Slight leaks may not always be obvious therefore regular checks of the contents gauge need to be made.
- Leaks most commonly occur at points where attachments are connected to the cylinder.
- Never use any kind of sealing compound or sticky tape to fix a suspected leak
- Never attempt to repair a cylinder.
- **In the event of a leak, do not use the cylinder.** Transfer the cylinder to a safe well-ventilated area, generally outside and open the valve to empty cylinder. Ring Baywater Healthcare to collect the cylinder, ensuring that they know the cylinder is faulty.
- **Use the spare oxygen cylinder.** Ensure that your child continues to receive supplemental oxygen. Make arrangements for the spare cylinder to be replaced.

Liquid Oxygen

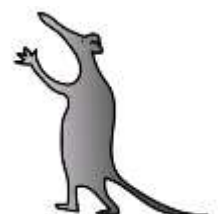
Used when patients are on high flow oxygen and require cylinders to last longer. Patients have base unit which holds up to 60L of Liquid oxygen at a temperature of -183C and then the Portable Unit is refilled from the base unit.

Associated Consumables

Including nasal cannula, face masks, tubing etc.

Risk Assessment Visit

These are completed every 6 months and Baywater Healthcare will contact you to make arrangements for this to happen – it is important you allow Baywater Healthcare to carry out these risk assessments when required.



Nasal Cannula

➤ What are Nasal Cannula

Nasal cannulas are used to deliver a low to moderate concentration of oxygen and are easily applied as long as your child's nasal passages are open. Eating, talking and coughing are all possible. As long as the tubes remain clear and unblocked, it is advised to **change the nasal cannula every seven days**. The small tubes should be soft and pliable and to avoid soreness around the nose they should be inspected regularly. If they do become blocked with mucus, become hard or discoloured they should be discarded and a new set used. The use of petroleum based creams (eg. Vaseline) around the nose should be avoided, as these react with oxygen and may cause soreness. Water based creams such as KY Jelly can be used if required.

Nasal cannula are not available on prescription but are **supplied by Baywater Healthcare**. When the oxygen equipment is installed the company will leave enough nasal cannula with you until the engineer visits again. If you run out of nasal cannula please ring Baywater Healthcare on the customer service helpline to order more and they will send them out to you by post.

Securing Nasal Cannula

The nasal cannula will need securing onto your child's face to ensure that the tubing does not become dislodged.

For children requiring continuous oxygen the tapes used are called Duoderm (extra thin granuflex) and Blenderm (clear tape) or Mefix (white gauze tape). Duoderm is available as a 7.5cm x 7.5cm square sheet and will need to be cut into small rectangular pieces approximately 1cm x 2cm. Duoderm is applied directly to the skin under the nasal cannula tubing to provide some cushioning and must be renewed weekly at the same time that the nasal cannula are changed. The nasal cannula are then correctly positioned on the child's face with the prongs into each nostril and secured with the Blenderm or Mefix. The Duoderm is left in place and the Blenderm or Mefix can then be changed as frequently as required without pulling the tape directly off your child's skin (Figure 3).

For children who require intermittent oxygen or overnight oxygen only, the nasal cannula can be secured with Mefix only. When removing the Mefix from the child's face, thoroughly wet the tape with warm water using either a tissue or cotton wool, so that it can be removed easily without pulling your child's skin.

Some older children may not need the nasal cannula securing with tape, as the cannula tubing can be looped over their ears and the toggle pulled taught but comfortably behind their head.

If your child has sensitive skin there are alternative tapes that can be used. Tendergrips are small round stickers, which can be used if your child has very sensitive skin, eczema or any allergic reactions to the other tapes (Figure 4). These are not available on prescription or from local chemists. Please contact Baywater Healthcare for the Tendergrips.





Figure 3. Duoderm and Blenderm (clear tape) or Duoderm and Mefix (white gauze tape)
Available from GP on prescription

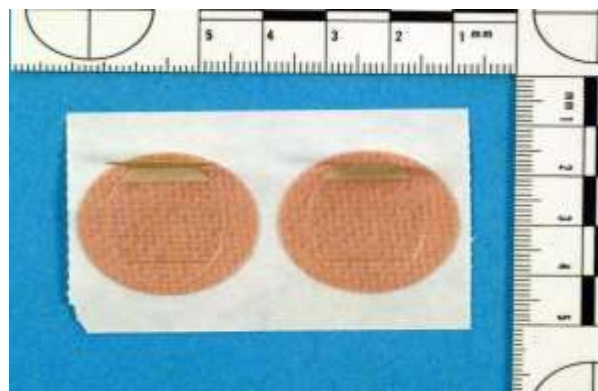


Figure 4. Tendergrip stickers

Safety

- Ensure the nasal cannula is well secured to your child's face especially at night when you will be asleep.
- If your child starts to pull the nasal cannula off then ensure the tapes are secured nearer to their nose (so that there isn't a gap between their nose and the tapes), rather than on the middle of their cheeks or near their ears. **Put mittens on your child at night.**
- As your child gets older they become more active. At night they may wriggle more, therefore the oxygen tubing needs to be checked to ensure that it doesn't become wrapped round them. To help prevent this problem thread the tubing down through their babygrow or pyjamas at the side, so they are not lying on the tubing at night and the tubing comes out by their feet and out to the oxygen supply at the bottom of their crib or cot.
- Overnight saturation studies can be performed at home to assess your child's oxygen requirement. When performing these studies at home the probe is generally applied to your child's foot or toe. The probe will therefore come out at the bottom of their crib or cot and connect to the monitor.



Oxygen Safety



Oxygen is a colourless and odourless gas, which is slightly heavier than air. The presence of oxygen within a building can increase the risk of fire. Oxygen itself is not flammable but may support and accelerate combustion and cause substances to ignite more easily and burn more fiercely.

Here are a few simple precautions that are needed when using oxygen at home.

- DO NOT SMOKE** NEAR ANY OXYGEN EQUIPMENT. This includes the use of e-cigarettes.
- DO NOT** charge e-cigarettes or other personal re-chargeable electronic devices (particularly ones with lithium batteries) anywhere in the vicinity of oxygen equipment.
- DO NOT** use the equipment near a fire or naked flames, this includes candles, gas cookers.
- DO NOT** use grease or oil to lubricate or to come in contact with the oxygen cylinders, liquid oxygen, valves or fittings.
- DO NOT** handle equipment with greasy hands.
- DO NOT** store oxygen cylinders in the same place as paint, petrol, and paraffin, heating gas or other flammable materials.
- DO NOT** let children play or untrained persons tamper with the oxygen equipment.
- DO NOT** hang clothes over the concentrator or oxygen cylinders.
- DO NOT** let the concentration of oxygen build up in a confined space (eg. by leaving Concentrator / cylinder on when not required).
- DO NOT** use petroleum based creams (eg. Vaseline) around the nose, as oil based products may react with the oxygen and can cause soreness/ redness even burns. Water based creams can be used if required.

- DO** open ON/OFF valve on cylinders with this feature OR ensure valve is ON
- DO** contact the local fire department requesting free fire safety advice and smoke alarms. Visit www.firekills.gov.uk for safety information.
(Baywater Healthcare automatically inform the fire service that O2 has been installed).
- DO** have a full understanding in the use of all the equipment before taking your child home and know who to contact if the equipment is faulty.
- DO** return defective equipment for replacement.
- DO** be careful that the oxygen tubing does not become kinked, blocked, disconnected or punctured.
- DO** check oxygen cylinders are stored securely where they cannot fall or be knocked over.
- DO** store oxygen cylinders away from heaters, radiators and hot sun.
- DO** ensure a spare cylinder is available for emergency use.
- DO** keep oxygen supplies at the lowest possible level required.



Alder Hey Children's Hospital NHS Foundation Trust

Alder Hey Children's NHS Foundation Trust
East Prescott Road
Liverpool
L14 5AB
Tel: 0151 228 4811
Web address: www.alderhey.nhs.uk

Respiratory Secretaries Tel: 0151 252 5777

- If your child is unwell please contact their GP and make an appointment for them to be seen.
- If your child has breathing difficulties, call 999. (See page 11)

Clinic Appointments

Chronic Lung Disease of Prematurity

Prof Sinha, Consultant in Paediatric Respiratory Care, will review your child at the Alder Hey Children's NHS Foundation Trust, Outpatients within approx. 4 weeks from discharge. Further appointments will be approximately every eight to twelve weeks whilst your child remains oxygen dependent.

The Oxygen Nurse Specialist will arrange to see your child in between appointments to review their oxygen requirement, and when safe, plan to wean the oxygen.

When their oxygen is discontinued they will continued to be seen in clinic every three – six months.

Paediatric Respiratory Patients

Your child will be reviewed in clinic by a Respiratory Consultant at Alder Hey Children's NHS Foundation Trust.



What to do if your Child has Breathing Problems

Is your child?

- chesty
- wheezy
- coughing more than usual
- and / or have a temperature

↓
YES
 ↓

Make an appointment for your child to see the GP

Does your child have any of the following?

- going 'blue' – do they look blue around their lips, nails or ear lobes
- short of breath or breathing a lot quicker than normal
- looking unusually pale
- 'tugging' when breathing - pulling in the muscles around their chest or neck
- sweaty and clammy
- a fast pounding pulse rate
- reduced consciousness or unusually agitated
- (in older children) confused and / or complaining of dizziness or headaches

↓
NO **YES**
 ↓

Stay calm and reassure your child

Check your child's airway

- Make sure your child's nose and mouth or tracheostomy is not obstructed with mucus

If there are any problems with the concentrator or oxygen cylinder then connect the back-up supply and contact Baywater Healthcare

Check your child's breathing returns to normal

Is there still a problem with their breathing?

Is the oxygen equipment working correctly?

Check

- the oxygen tubing is correctly connected
- the oxygen flow is set at the correct flow rate
- the tubing is mucus free and not kinked
- the concentrator is working or there is sufficient oxygen left in the cylinder

NO ←

YES →

Emergency procedure

Call 999 for immediate help and advice
 Increase the oxygen flow to your child, as instructed

Stay with your child and await the help of the emergency services

Is your child breathing?

YES ←

NO →

Start resuscitation procedure whilst waiting for the emergency services to arrive

RESUSCITATION TRAINING IS REQUIRED BEFORE DISCHARGE

Insurance Companies / Fire Service / Electricity Company

House Insurance

Inform your house building / contents insurance company that oxygen equipment has been installed in your home. The insurance company will make a record of this information on your insurance policy. Most companies will accept this information verbally by phone, however some companies may ask you put the information in writing. If a letter is requested then contact Gemma Murphy for a letter and keep a copy of the letter with your insurance policy.

Most companies will not alter the insurance premium, however if a family do not inform the company it could jeopardise any claims that you make.

Car Insurance

You are advised to tell your car insurance company that you will be carrying portable oxygen equipment in your vehicle. The insurance company will make a record of this information on your insurance policy. Generally most companies accept this information verbally by phone, however some companies may request that the family inform them in writing. If a letter is requested then contact Gemma Murphy for a letter and keep a copy of the letter with your insurance policy.

Most companies will not alter the insurance premium, however if a family do not inform the company it could jeopardise any claims that you make.

Secure cylinder in vehicle

You **MUST** ensure that the oxygen cylinder is secured during all journeys either in the boot of the car, behind the front seat with a secure fastening. You may need to purchase elastic luggage straps to secure the cylinder safely.

Travelling on Public Transport

You may need to ring your public transport supplier to enquire if you can travel on their service with an oxygen supply. Some companies may need you to carry a supporting letter.

The companies below allow transport with oxygen and do not require a supporting letter.

- Arriva 0844 800 44111
- Merseyrail 0151 702 2071
- Stage Coach 0151 330 6200

Fire service

Baywater Healthcare will automatically inform the local fire services and the fire department will record this information in case of any emergency calls. You are also advised to inform the fire services that oxygen equipment has been installed in your home and request a 'Home Risk assessment' and Merseyside Fire Services will visit your home, check the property, install smoke alarms and give fire safety advice free of charge.

Freephone number for: Merseyside is: 0800 731 5958
Lancashire is: 0800 169 1125
Cheshire is: 0800 389 0053



Electricity

Electricity costs

If you are using an oxygen concentrator, Baywater Healthcare will reimburse the electricity costs at the standard rate of electricity. The refund will preferably be a direct payment to your bank account or electricity company, therefore Baywater Healthcare will need the details of your electricity company or your bank details.

Electricity Supplier

You are also advised to inform your electricity supplier that your child needs oxygen and that the oxygen machine requires electricity to work. If there is a problem with the electricity supply you will need priority to be reconnected.

Moving House

If you are moving house, a new Home Oxygen Order Form (HOOF) will need to be completed with your new address details. Please update Baywater Healthcare as soon as you have a move date. Please contact the Oxygen Nurse Specialist informing them of your new address. You will not be able to order any oxygen supplies at the new address if a HOOF has not been completed.



Allowances

Disability Living Allowance (DLA)

If a child is oxygen dependent, the family can claim for Disability Living Allowance (DLA).

The 'Child Disability Living Allowance' forms can be obtained from:

- Contact DLA office on TEL: 0800 88 2200
- www.direct.gov.uk
- www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925

Scroll down to either:

- download a claim form to print at home (Disability Living Allowance form for people under the age of 16 PDF document 259KB)
or
- download a claim form to complete on your computer.

DLA is awarded at different levels depending on your child's illness and needs.

If your child is over 3 year old, the DLA will combine both a carers and a mobility component.

Carers Component

There are 3 different levels of carer's component:
Low/Middle/High

Mobility Component

There are 2 levels of mobility component: High level / Low level

If a child has previously been awarded DLA, the claim will be reviewed on a regular basis. If a family has any queries regarding DLA reviews, the office can be contacted on Tel no: 0845 712 3456 giving them your child's name and reference number.

The Blue Badge Scheme provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport. This enables badge holders to park close to where they need to go.

A parent of a child who is less than two years old may apply for a badge for their child if the child has a specific medical condition which means that they:

- a. must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty;
and / or
- b. need to be kept near a vehicle at all times, so that they can, if necessary, be treated in the vehicle, or quickly driven to a place where they can be treated; such as a hospital



Carers Allowance (CA)

- Carers Allowance is a social security benefit to help people look after someone who gets:
 - a) Attendance Allowance
 - b) Constant Attendance Allowance at not less than the full day rate
 - c) Disability Living Allowance at the middle or highest rate for help with personal care.
- Invalid Care Allowance is paid to the person who does the caring **not** the person being cared for.

For further information or an application forms contact:

Carer's Allowance Unit
Palatine House Lancaster Road
Preston
PR1 1HB
Tel: 01253 856 123



Stopping Supplemental Oxygen

Babies with Chronic Lung Disease of Prematurity

Weaning your baby off supplemental oxygen is a gradual process, which may be achieved over several months (occasionally it can take longer).

Following discharge from hospital your baby will initially be reviewed at home by the neonatal community team / Gemma Murphy. Infants with Chronic Lung Disease of Prematurity are seen by Prof Sinha (Consultant in Paediatric Respiratory Care).

Gemma Murphy will visit you at home following discharge to ensure you are happy and comfortable with the oxygen equipment and to address any questions you might have. Further home visits will be scheduled between clinic appointments, or when weaning this will be more regular depending on your child's progress. Assessment at each review is essential to ensure that your baby is well with no respiratory concerns. They must be gaining weight, and be clinically well before stopping oxygen is considered. Their oxygen saturation levels are monitored, ideally when they are awake, asleep and feeding, although this is not always possible.

- If they are receiving less than 0.5L/min the time (hours) off oxygen may be increased at each review, starting at one hour a day gradually increasing over several weeks/months to off oxygen 12 hours a day and on overnight oxygen only.
- If they are receiving more than 0.5L/min, an overnight saturation study will be performed and they will be weaned down to 0.5L/min before weaning off oxygen into air is considered.

When your baby is being weaned off their oxygen, you will be given instructions about what to do and advise if you have any concerns.

When your child has been off oxygen 12 hours a day for approx. 4 weeks, an overnight saturation study in air will be performed. This study can be performed at home whilst they are asleep. The information from the monitor is downloaded onto a computer. If your child's overnight saturations in air are within the normal reference range, then the oxygen will be discontinued.

When their oxygen is stopped they will continue to be reviewed in clinic by Dr Sinha (generally every three – six months) but home visits from the Oxygen Nurse Practitioner will be discontinued.

These are only guidelines to weaning your child off oxygen and obviously the time off oxygen is altered to suit the individual child and their ability to cope off the oxygen without any problem and may vary from child to child.



Stopping Supplemental Oxygen

Paediatric Respiratory patients

Weaning your child off supplemental oxygen is a gradual process, which may be achieved over several months (occasionally it can take longer).

Following discharge from hospital your child will be reviewed in clinic, by a Respiratory Consultant.

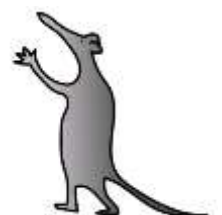
The frequency of these appointments and visits will depend on your child's oxygen requirement and respiratory problem. Your child's oxygen saturation levels should be monitored when they are awake, asleep and feeding although this is not always possible. Your child should be gaining weight, and be clinically well before stopping the oxygen is considered.

- If your child is receiving less than 0.5L/min the time (hours) off oxygen may be increased at each review, starting at one hour a day, gradually increasing over several months so that they are off oxygen 12 hours a day and requiring overnight oxygen only.
- If your child is receiving more than 0.5L/min, an overnight saturation study will be performed and they will be weaned down to 0.5L/min before weaning off oxygen into air is considered.

Whilst your child is being weaned off their oxygen, you will be given instructions and advice about what to do if you have any concerns.

When your child has been off oxygen 12 hours a day for approx. 4 weeks, an overnight saturation study in air will be performed. This study can be performed at home whilst they are asleep. The information from the monitor is downloaded onto a computer. If your child's overnight saturations in air are within the normal reference range, then the oxygen will be discontinued.

These are only guidelines to weaning your child off oxygen and obviously the time off oxygen is altered to suit the individual child and their ability to cope off the oxygen without any problem and may vary from child to child.



Holidays

• Holidays in England and Wales

If you are planning a holiday either to visit friends and relatives for a family holiday Baywater Healthcare provide a free holiday oxygen service in England and Wales. If you are going outside the Baywater Healthcare contracted area then they will contact the specific oxygen company for that area and oxygen can still be supplied. Be aware that if you are supplied by another oxygen company then the equipment may vary slightly.

What you need to do:

- You can contact Baywater Healthcare directly to discuss your holiday arrangements.
- Ensure you give plenty of notice (preferably four weeks).
- You will need to provide details of the holiday address including postcode, holiday dates, reference number, contact name and telephone number.
- Holiday Oxygen information leaflet is available from Oxygen Nurse at Alder Hey.
- Baywater Healthcare will contact you to confirm arrangements.
- If you are staying in a hotel, guesthouse or caravan you need to inform the owners of the holiday destination that your child is oxygen dependent (for insurance purposes) and tell them that oxygen equipment will be used.

• Holidays Abroad

Baywater Healthcare provide a holiday information service for advice if traveling abroad however there is a cost for oxygen provision abroad.

For further advice on traveling contact:

Baywater Healthcare on **0800 373580**

Or visit:

<https://www.baywater.co.uk/patient-carer-our-therapies/oxygen/holidays-withoxygen/outside-the-uk>

More information is available from the:

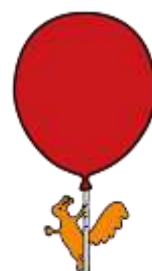
- Department of Health travel advice on 0800 555 777 or www.dh.gov.uk/travellers
- If traveling in EEA please contact DoH on 0207 2104850
- British Lung Foundation on 08458 50 50 20 or www.lunguk.org.

Ask for a copy of their booklet 'Going on Holiday with a Lung Condition'

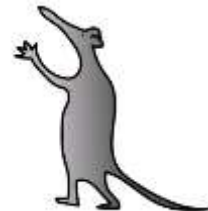


Equipment pictures

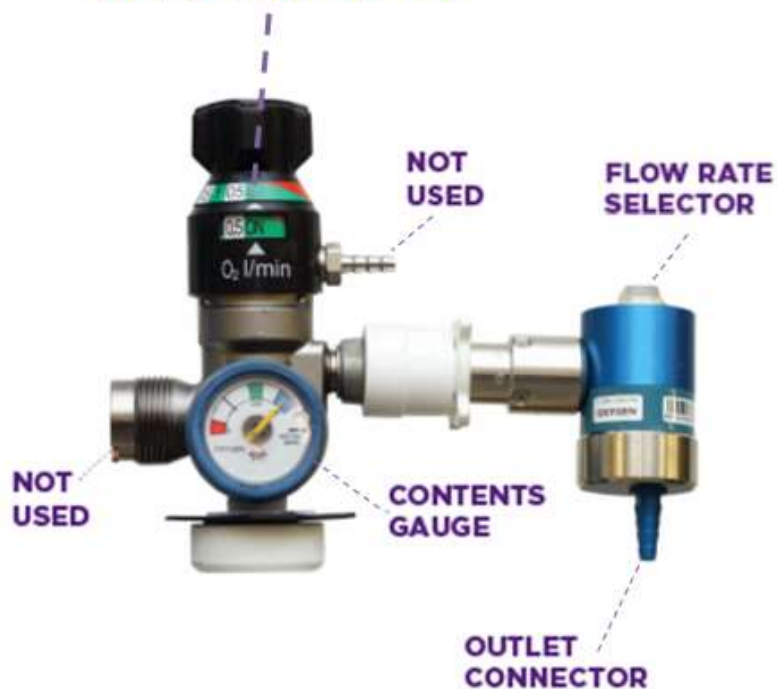
Depending on your child's need you may have different types of oxygen equipment at home, this will be discussed with you prior to discharge.



Setting the flow



**IMPORTANT –
NEEDS TO BE ON**



'Things To Do' List

You will be seen by the Oxygen Nurse Specialist and the oxygen equipment, oxygen safety will be discussed. She will arrange for the Home Oxygen Order Form to be completed and oxygen equipment to be organised for your home. **Once you have been seen** and the procedure explained, then the following checklist can be completed.

WHAT TO DO	TICK
1. Sign consent / IHORM form, so that your Respiratory Team can complete the Home Oxygen Order Form (HOOF) and fax your child's details to Baywater Healthcare, PCT and GP.	
2. Inform your house insurance company that oxygen has been installed at your property. If you rent the property, inform the landlord.	
3. Inform your car insurance company (If your child requires continuous oxygen and you intend carrying a portable oxygen cylinder in the vehicle).	
4. Ensure portable oxygen cylinders are secured in your vehicle.	
5. Merseyside Fire service will provide free smoke alarms and safety advice. Ring Freephone no: 0800 731 5958 and ask for a Home Risk Assessment.	
6. If using an oxygen concentrator, inform the electricity board ensuring you are priority for reconnecting, incase of any electricity cuts. If you are on metered electricity ensure you always have enough top up on your card to cover the electricity costs.	
7. In case of a power cut always have a torch handy. Ensure you are aware of how to use the back up oxygen cylinders and have a contingency plan incase of a prolonged power cut.	
8. Contact the DLA for Child Disability Living Allowance form and this will be sent or apply online www.direct.gov.uk (see p14).	
9. Resuscitation training has been completed, Resus link can be provided by the ward	
10. Before your child is discharged, check that the: <ul style="list-style-type: none"> • Oxygen equipment has been installed. • Portable cylinders have been delivered. • You will need to bring a portable cylinder (+/- low flow meter attached to cylinder) into the hospital, so that your child can be discharged home on the oxygen. • You are shown how to secure the nasal cannula • You are given a supply of Duoderm and Blenderm / Mefix to secure the nasal cannula. 	
11. A clinic appointment with a Respiratory Consultant will be arranged.	



Contact Address / Telephone Numbers

Respiratory Consultant:

Respiratory Unit

Alder Hey Children's NHS Foundation Trust

East Prescott Road,

Liverpool. L14 5AB

Tel: 0151 228 4811 (Alder Hey switchboard)

Web address www.alderhey.nhs.uk

Baywater Healthcare

0800 373580

www.baywater.co.uk

British Lung Foundation

73 – 75 Goswell Road, London EC1V 7ER

Tel: 020 7688 5555 Fax: 020 7688 5556

Internet: www.lunguk.org

E-mail: enquiries@blf-uk.org

Family Fund

PO Box 50, York, YO1 9ZX

Tel: 01904 621115

E-mail: info@familyfund.org.uk

Internet: www.familyfundtrust.org.uk

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust

Alder Hey

East Prescott Road

Liverpool

L14 5AB

Tel: 0151 228 4811

www.alderhey.nhs.uk

