Supplementary Oxygen Care – Information for Parents and Carers

Signature of care givers

Name (printed)	Signature	Designation

The aim of this leaflet is to ensure that parents/carers will feel safe and confident in giving supplementary oxygen care to their child/young person.

Before you take your child home the staff will:

- Give you appropriate information about your child's condition. You will be given a care plan to take home with you for the professionals involved in your child's care to record care given
- Ensure that you and anyone involved in caring for your child has adequate training in how to manage oxygen

Introduction

As a result of modern medicine, children with complex problems are now being routinely discharged home from hospital and cared for at home (Boosfield and O'Toole 2000). Many of these children have respiratory problems, requiring long-term oxygen therapy (Table1 on page 5) and home oxygen has resulted in infants, children and young people being discharged home much earlier. Previously these infants, children and young people had to remain in hospital on neonatal and paediatric wards, which had major effects on social interaction and normal family life.

Respiratory System

The main function of the respiratory system is to provide the body with a supply of oxygen and excrete carbon dioxide. Oxygen is transferred to the blood from the air, carbon dioxide is removed from the blood to the air and the exchange of these gases is called respiration. Effective and efficient exchange depends upon all parts of the respiratory system and any chronic or acute disease of these parts may impair gas exchange.

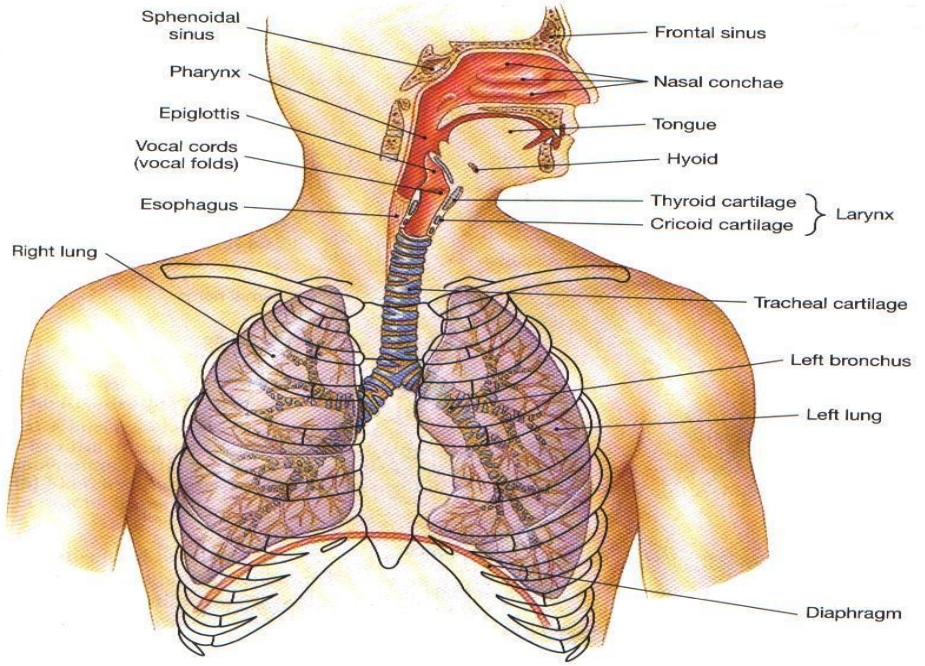

Figure 1. The Respiratory System

In the **upper airway**, air enters the lungs through the **nose** and **mouth**, to reach the **pharynx** [back of the throat], passes through the **larynx** [voice box] and into the **trachea** [windpipe].

Air is warmed and humidified and large particles of dust are filtered out as it passes through the nose. Mucus that comes from the tissues that line the airways will become dry, hardened or thickened causing a blockage if it is not warmed and humidified.

In the **lower airways**, the trachea divides into two main bronchi, and then subdivides into smaller bronchi. This division continues until bronchioles end in alveoli and this is where gas exchange takes place. The alveolus is only one cell in thickness and in contact with the blood, so oxygen can diffuse from the alveolus to the blood and carbon dioxide from the blood to the alveolus.

The **diaphragm** and **intercostal muscles** are the main muscles used in breathing. When the diaphragm contracts it pulls down and air enters the lungs. The intercostal muscles are attached to the ribs and increase the capacity of the chest by pulling the ribs upwards and outwards.

The **heart** pumps blood to the lungs and the body. If a child has heart problems, gas exchange may be inadequate and therefore supplemental oxygen may be required.

Disorders affecting the Respiratory System

Diseases may affect any part of the respiratory system, causing poor gas exchange and below are some common examples.

1. Disorders that affect the upper airways:
   - Abnormalities of the larynx, trachea or bronchi e.g. stenosis [narrowing], blockage [tumour/ swelling] or abnormal floppy airways
   - Structural abnormalities of the oral or nasal cavities e.g. cleft palate, coanal atresia [blocked nasal passages]

2. Disorders that affect the lower airways:
   - Asthma
   - Cystic fibrosis, which causes increased amount of thick mucus in the lungs and airways
   - Swelling, scaring and other structural blockages

3. Disorders that affect the alveoli:
   - Bronchopulmonary dysplasia
   - Pneumonia
   - Pulmonary toxicity from chemotherapy treatment

4. Disorders that affect the respiratory muscles:
   - Degenerative muscle disorders e.g. muscular dystrophy
   - Spinal cord injuries

5. Disorders that affect the stimulus to breathe:
   - Brain damage from trauma e.g. drowning, suffocation, birth problems
   - Certain neurological diseases

Table 1

Principle Paediatric Conditions requiring Long Term Oxygen Therapy (LTOT)
Chronic Neonatal Lung Disease (Bronchopulmonary Dysplasia)
Other Neonatal Conditions (e.g. Pulmonary Hypoplasia)
Congenital Heart Disease with Pulmonary Hypertension
Pulmonary Hypertension secondary to pulmonary disease
Interstitial Lung Disease
Obliterative Bronchiolitis
End Stage Cystic Fibrosis and other causes of severe bronchiectasis
Obstructive sleep apnoea syndrome and other sleep related disorders
Neuromuscular conditions requiring non-invasive ventilation
Disorders of the chest wall (e.g. Thoracic dystrophy, severe kyphoscoliosis)
Palliative Care for symptom relief

Reference: Balfour-Lynn IM, Primhak RA, Shaw NJ (2005).
Home oxygen for children: Who, how and when? Thorax: 60, 76-81

Supplemental Oxygen

Oxygen reduces the workload on the heart and relieves shortness of breath. When caring for a child requiring supplemental oxygen it is important to be aware of their underlying condition and the possible problems associated with the condition and their treatment. The carer requires a knowledge of all the equipment used, oxygen required [l/min], oxygen safety, infant/child/young people's baseline observations including colour, pulse and respiratory rate and what to do in an emergency situation is essential.

The Importance of Oxygen

Oxygen is vital for a number of reasons, including:
1. To prevent tissue damage, as prolonged low oxygen levels (hypoxia) can result in cell death, leading to brain or heart damage
2. The need to grow and develop
3. To encourage premature babies to grow new lung tissue

Oxygen Equipment

Baywater is the company providing oxygen in the North West area.

Baywater have a variety of different oxygen equipment available, including:

- Oxygen concentrators
- Static and portable cylinders with integrated valves
- Liquid Oxygen
- Associated consumables (nasal specs / masks etc)

BAYWATER

0800 373 580 - Freephone Homecare Helpline

Office Hours: Monday– Friday 08.30 am – 6.30 pm
Line is 24 hours

Why provide oxygen at home?

There are many conditions which require treatment with oxygen therapy. These include:

- Bronchopulmonary Dysplasia (BPD) in babies
- Chronic lung disease
- Severe chest infections
- Children with cancer
- Terminally ill children

Previously this has required extended stay in hospital causing stress to your child and family. It is now widely accepted that oxygen therapy can be provided in the home environment for those children who have a long term need for oxygen.

Administration of oxygen

Administration of oxygen is a lifesaving intervention but it can often be difficult to do in infants, children and young people, as they do not tolerate oxygen equipment well. There are three main ways of administrating oxygen to children:

1. Via a face mask
2. Using nasal cannula
3. In a head box

Face mask – Unless the infant, child or young person is old enough to understand the need for oxygen, they will not tolerate a mask being held over their face. Careful explanation to the parents/carers/child or young person will help to maximise co-operation. Careful explanation of the equipment involved is also important to minimise anxiety by reducing the fear of the unknown.

Nasal cannula – The advantage of using the nasal cannula is that they are usually well tolerated by most children of all ages and carbon dioxide rebreathing does not occur. Humidification is also not necessary as the oxygen is entering via the nasal passages where it is warmed and moistened in the usual way.

The disadvantages are that the child mouth breathes, the oxygen concentration is diluted and also high flow oxygen can cause some discomfort and dry the nasal mucosa.

Headbox – The advantages of this type of device is that they give effective oxygen delivery in a completely non-invasive way which minimises the infant, child or young person's anxiety and fear. It is important that the supply is warmed and humidified prior to administration. It is only suitable for the smaller baby, as it is not well tolerated in babies over the age of about one year old.

Important point:
Oxygen should be treated like a drug and a Doctor should always prescribe the delivery of oxygen therapy. In any infant, child or young person, the oxygen should be delivered at the lowest concentration level possible and for the shortest time possible.

Oxygen saturation levels

To prevent the long-term risks of hypoxia, it is suggested that the infant, child or young person's oxygen level may be better kept above 94% saturation, with a baseline of between 96-98% for as much time as possible.

How is oxygen supplied at home?

There are two ways of supplying the oxygen:

1. In the form of large cylinders which can take up a lot of room at home
2. The most commonly used method and most economical is the oxygen concentrator. This is an electrically operated device that draws in room air, separates the oxygen from the other gases in the air, and delivers the oxygen at high concentrations to the child

Observations whilst using oxygen

An infant, child or young person requiring oxygen should be monitored closely and carefully. The use of a pulse oximeter is of use, but the parent/carer should also observe for physical signs of deterioration in the infant, child or young person's condition. The signs to watch for are:

- Increased respiration rate
- Cyanosis
- Increase in respiratory effort

Care of the infant, child or young person needing oxygen

The infant, child or young person who goes home on oxygen is usually well who just requires a set prescribed amount of oxygen to maintain their oxygen levels at the optimum level. There are certain ways to ensure that they receive the best care to maintain a good standard of living.

- Children and young people with respiratory problems may benefit from being nursed upright, well supported with pillows
- Infants may benefit from being placed in a baby chair to expand their lungs properly
- Ensure that the nostrils remain free from dried mucus using warm water to clean them as required
- If the skin around the nose becomes sore, use a water based cream such as E45, avoiding a petroleum based cream which can react with the oxygen causing the soreness to increase
- Do not use oil or paraffin based emollients or creams as these can soak into clothing and bedding, increasing risk of flammability.

- Take care when using heat generating appliances such as irons, hair driers and hair straignteners, do not use these or leave them near to the oxygen source.
- Ensure that the cannula is well secured to the infant, child or young person's face so that they cannot pull it off

Home Oxygen Paediatric User Guide

You will received the 'Home Oxygen Paediatric User Guide' when the Baywater engineer visits your home to install the equipment

The oxygen company will:

- Install the 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)
- In the event of a concentrator machine breakdown they provide an emergency call out service and guarantee to be at your home within eight hours of the call out
- Reimburse your electricity costs (if using an oxygen concentrator)
- Inform the fire service that oxygen equipment has been installed at the infant, child or young person's address
- Provide nasal cannula, oxygen tubing, face mask, etc
- Provide a carry bag for portable oxygen cylinders

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

Step 1	**Step 2**	**Step 3**
Sign a consent form allowing your infant, child young person's information (name / DOB / address / diagnosis) to be shared with Baywater	Your Respiratory Team will complete the Home Oxygen Order Form (HOOF) and send to Baywater via the Baywater portal. A copy is sent to the nominated Oxygen Lead for the CCG.	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 is 50-70cm (19.5 – 27.5inc) high. The machine draws air from the room atmosphere, separates the oxygen from the other gases in the air and delivers oxygen to your infant, child or young person. It is simple and easy to use.

Oxygen concentrators **are not generally used in schools** because:
1. They are noisy, therefore can disturb children in a classroom setting
2. The concentrators are installed in one room, therefore there are problems concerning trailing oxygen tubing and health and safety issues to be considered
3. Children in school move around for different lessons and activities therefore

concentrators are not practical and a portable oxygen delivery system is more suitable

If a child has high oxygen requirements then a concentrator in school can be considered, however liquid oxygen (see page 15) may be more suitable.

Baywater have various oxygen concentrators available:

- Standard flow 1– 5 l/min (max use 4l/min)

Figure 2. Baywater oxygen concentrator

The concentrator will be serviced by a Baywaterengineer at three months and then every six months. Between these dates, parents are asked to clean and change the air filter on the machine (standard concentrator only). The filter should be washed weekly in warm water and 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.

Emergency backup service

Baywater will provide an emergency backup oxygen cylinder with the concentrator. If there are any problems with the concentrator, parents/carers are asked to connect their infant, child or young person to the backup cylinder, setting it at the correct oxygen flow and telephone the company for advice.

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

Further information for parents and carers

1. The concentrator can be slightly noisy
2. It can warm the surrounding room air
3. The concentrator will only work if there is an electricity supply.
4. Be prepared for any electricity cuts in your area. If there is an electricity cut, use the backup emergency oxygen cylinder or your child's portable oxygen cylinder
5. If your child is in school and the electricity supply is off for a long period, the school will contact you to collect your child/young person

6. The engineer will take a reading from the concentrator at each service to calculate the amount of hours / electricity used. Baywater will then refund the cost, usually by direct payment
7. Switch off the machine when not in use

Static cylinders

Baywater provide static cylinders for infant, child or young person requiring less than 1l/min of oxygen. These cylinders have integrated values to allow for a micro flow and low flow regulator to be fitted to given oxygen requirements between 0.01l/min – 1l/min.

- B10P for low and micro flows cylinder
- B10 for standard flow cylinder

Ambulatory (portable) oxygen cylinders

What are portable oxygen cylinders?

If your infant, child or young person requires oxygen at night and during the day, they will require portable oxygen cylinders so that they can go out. Baywater provide different portable oxygen cylinders and also provide a carry bag for these cylinders.

Re-ordering Baywater oxygen cylinders

The quantity of cylinders required each week will depend on the oxygen flow and amount of time (hours) that the infant, child or young person is away from their home. It is important that the infant, child or young person has enough cylinders each week so that they can participate in normal activities, including attending school.

- Parents/carers need to ring Baywater on 0800 373 580 to order more portable cylinders
- Baywater will organise delivery of these cylinders within the **standard delivery time of three working days.**
- Baywater will collect the empty cylinders when delivering a new order
- Parents/carers will need to ensure that they do not run out of cylinders. They need to constantly check their supplies ensuring they ring before they run out of cylinders
- Spare cylinders can be ordered for school, using a secondary address. If the cylinder is used, it is the responsibility of the school to have the cylinder replenished

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 will 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 the cylinder. Telephone Baywater to collect the cylinder, ensuring that they know the cylinder is faulty
- **Use the spare oxygen cylinder.** Ensure that your infant, child or young person continues to receive supplemental oxygen. Make arrangements for the spare cylinder to be replaced

Procedure in the event of fire

In the event of a fire it is stressed that the safety of all people MUST be the first priority.

Do not take any undue risks.

- In the event of fire, the safety of everyone **must** be the first priority
- As soon as a fire is discovered, dial 999 asking for the 'Fire Service' and evacuate the building
- Ensure to warn the fire services of the presence of compressed gas cylinders or liquid oxygen
- The tubing is fitted with fire breaks in order to stop the fire travelling down the line to the cylinder however cylinders involved in a fire may burst due to excessive heat and therefore the immediate area must be evacuated.
- Do not attempt to fight a fire in which oxygen cylinders are directly involved

Associated consumables- Including nasal cannula, face masks, tubing, etc.

Nasal Cannula / Specs

What are Nasal Cannula/ Specs?

Nasal cannula are used to deliver a low to moderate concentration of oxygen and are easily applied as long as your infant, child or young person'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 each time you attend your infant, child or young person. If they do become blocked with mucus, hard or discoloured they should be discarded and a new set used. The use of petroleum based creams (e.g. 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 (the oxygen company).** 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 telephone Baywater on the customer service helpline to order more and they will send them to you by post.

There are different sizes of nasal cannula:

What to do if the infant, child or young person has breathing problems

If the infant, child or young person is:
- chesty
- wheezy
- coughing more than usual
- has a temperature

Do they have any of the following?
- going 'blue' – e.g., looking 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 → **Advised that the child may need a GP appointment for review**

YES

Stay calm and reassure the infant, child or young person

Check the infant, child or young person's airway
- Make sure their nose and mouth or tracheostomy is not obstructed with mucus

Is the oxygen equipment working correctly?
Check:
- is the oxygen supply working e.g. Is there sufficient oxygen left in the cylinder
- is the oxygen tubing correctly connected
- is the oxygen flow set at the correct flow rate
- is the tubing mucus free and not kinked

NO → If there are any problems with the oxygen equipment then connect the backup supply and contact the child's parents.

Check their breathing returns to normal

Is there still a problem with their breathing?

YES

Emergency procedure
- Call 999 for immediate help and advice.
- Increase the oxygen flow to the infant, child or young person, as per care plan.
- If your child has stopped breathing, start resuscitation procedure, if you are trained to do so whilst waiting for the emergency services to arrive.

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

Procedure for Administration of Lowflow Oxygen Therapy via Nasal Cannula

Aim: To safely administer oxygen and understand how to monitor the infant, child or young person to maintain their respiratory function.

Equipment:
Supply of oxygen
Suction machine if required.
Supply of oxygen tubing and nasal cannula.
Access to telephone.

It is very important that each infant, child or young person has their own care plan and is only given the prescribed amount of oxygen.
If there are any changes in the infant, child or young person's colour, breathing rate or delivery of the oxygen PHONE 999 - EMERGENCY HELP MUST BE OBTAINED.

ACTION	RATIONALE
Store oxygen as instructed by the manufacturer.	To maintain health and safety and prevent risk of fire.
Ensure that the appropriate size nasal cannula are correctly placed in the child's nostril and secured in place with non-allergic dressings.	Appropriate size nasal cannula will be more effective and comfortable. To prevent trauma to skin.
Connect tubing to the cylinder or oxygen concentrator.	To ensure connections are secure.
Follow the prescription and the pre-set levels (usually set by the company) to maintain correct oxygen flow.	To ensure correct flow of oxygen is delivered.
Monitor your child for breathing rate and breathing effort, skin colour and pulse. If any of these are not normal for your child seek medical help immediately.	To recognise problems quickly and obtain help.
Observe your child for appearance of oral/nasal secretions and if necessary maintain a clear airway by performing suction (procedure available).	A clear airway facilitates a more effective oxygen delivery.
If there is a problem with the electricity supply when using the oxygen concentrator transfer the tubing to the cylinder.	To ensure your child continues to receive their oxygen supply.
Inspect nasal cannula regularly; the small tubes should be soft and pliable. If they are hard or discoloured replace with new set. If your child has a cold check that the cannula is not blocked with mucus.	To avoid soreness around the nose.
If cream is required on the face use a water based cream such as E45, not Vaseline.	Petroleum based creams may react with the oxygen and cause soreness.
If your child becomes unwell or there are any sudden changes in their breathing or colour **PHONE 999 – EMERGENCY HELP MUST BE OBTAINED.**	To obtain immediate medical help if any problems.

Oxygen Saturation Monitoring - Guidelines for parents/carers

Pulse oximeter

AIM:
To monitor oxygen saturation levels to assist in the assessment of your infant, child or young person, and to be able to act on the results.

EQUIPMENT:

- Oxygen saturation monitor
- Correct size sensor (or probe)
- Tape
- Alcohol swab

REMEMBER: The main reason for monitoring is to detect any changes, before clinical signs become evident. Therefore if the machine alarms or records an abnormal saturation, first look at the infant, child or young person to see if they are well, then check that the machine is recording properly and that the sensor is in place.

CAUTION: If the circulation to their hands or feet is reduced (due to cold or shock) the readings may be inaccurate.

ACTION	RATIONALE
Plug monitor into mains electric supply.	To provide uninterrupted power.
Connect probe cable to monitor. Clean surface of the probe with 70% isopropyl alcohol (Sani cloth), insert the probe through the slots on the adhesive wrap, or apply finger clip.	To ensure probe is clean to detect the light.
Press and hold power switch on.	A diagnostic check will be visible on the screen. To check the machine is working correctly.
Check that alarm levels are set. If it is necessary to have different alarms to those on the monitor, the nurse will customise the alarms before monitoring begins	During routine monitoring to enable your child to sleep without unnecessary disturbance the alarm limits are set at limits which are unlikely to be reached. If your child is on oxygen the limits will need to be set for your child.
Explain the procedure to your child and select a warm, pink finger or toe. Place the probe on the child's toe or finger. The light source should shine through the skin from the top of the warm finger or toenail. Make sure the detector is directly	To reduce anxiety and select the best site for a good reading. To ensure that the sensor will detect a good light source to provide an accurate reading.

ACTION	RATIONALE
opposite the light source. Wrap the adhesive strap around the site and fasten carefully. If used overnight check the site regularly, and move sensor 4 hourly during the night. If necessary tape the cable approximately 10-15cm away from the probe onto the arm or leg. Make sure the excess cable is away from the child's head and neck.	To avoid restricting the circulation and causing damage to the underlying skin. To prevent entanglement of the lead and possible injury to your child.
Observe monitor – Perfusion index is displayed on the monitor and should be over 1. The nurse will discuss this with carers when the monitor is loaned	To ensure that the sensor is picking up a good signal.
Keep your child as still as possible with distraction therapy. Sometimes it is best to put the probe on after your child has gone to sleep.	The monitor cannot record accurately if there is excessive movement.
Alarms: The monitor will alarm if the probe is off your child – this can be silenced for 120 seconds by pressing the alarm button.	Alarms will alert parents/carers to the possibility of abnormal oxygen levels or pulse rates.
Overnight monitoring requires an average of 8 hours. When monitoring is complete remove the probe and turn off machine, by pressing the on off switch and holding for 2 seconds.	To give a good representation of your child's breathing pattern and oxygen saturation.

Stopping supplemental oxygen

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

Following discharge from hospital your infant, child or young person will initially be reviewed at home by the Children's and Young People's Home Care Team. They will be seen by their local Consultant between 0 – 8 weeks after discharge at Leighton Hospital.

After four weeks following discharge, the process of weaning an infant, child or young person off oxygen may be considered. Assessment at each review is essential to ensure that the infant, child or young person 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 is awake, asleep and feeding, although this is not always possible.

When the infant, child or young person is being weaned off their oxygen, you will be given instructions about what to do and advise if you have any concerns.

When the infant, child or young person has been off oxygen for 12 hours a day for a month, 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 infant, child or young person's overnight saturations in air are within the normal reference range, then the oxygen will be discontinued.

Your Health Care Nurse / Oxygen Nurse will arrange removal of the oxygen.

Allowances

Disability Living Allowance (DLA)

If an infant, child or young person 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 121 4600
- 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 the infant, child or young person's illness and needs.

If your child is over three years 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 an infant, child or young person 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 the infant, child or young person's name and DLA claim 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 an infant who is less than two years old may apply for a badge if their infant 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 difficultly;
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

'Things To Do' List

You will be seen by the Children's and Young People's Home Care Team. 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 Nurse will complete the following checklist.

What to do	Tick
Sign consent form, so that your Nurse can complete the Home Oxygen Order Form (HOOF) and fax your infant, child or young person's details to Baywater, CCG and GP.	
Inform your house insurance company that oxygen has been installed at your property. If you rent the property, inform the landlord.	
Inform your car insurance company (If your child requires continuous oxygen and you intend carrying a portable oxygen cylinder in the vehicle).	
Ensure portable oxygen cylinders are secured in your vehicle.	
Cheshire Fire service will provide free smoke alarms and safety advice. Ring Freephone no: 0800 731 5958 and ask for a Home Risk Assessment.	
If using an oxygen concentrator, inform the electricity board ensuring you are priority for reconnecting, in case 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.	
In case of a power cut always have a torch handy. Ensure you are aware of how to use the backup oxygen cylinders and have a contingency plan in case of a prolonged power cut.	
Contact the DLA for Child Disability Living Allowance form and this will be sent or apply online www.direct.gov.uk.	
Resuscitation training has been completed.	
Before your infant, child or young person is discharged, check that the: • Oxygen equipment has been installed. • Portable cylinders have been delivered. • You will need to bring a portable cylinder into the hospital, so that your infant, child or young person can be discharged home on the oxygen. • You are shown how to secure the nasal cannula. • You are given a supply of dressings to secure the nasal cannula.	
A follow up clinic appointment has been arranged with your Consultant.	

Glossary of Terms You May Encounter

AF Cylinder	*Large size of oxygen cylinder (1360 litre capacity)*
Apnoea monitor	*A device that monitors breathing and sounds an alarm if no breathing is detected for more than a pre-set time*
CPR	*Cardio-pulmonary resuscitation*
Cylinder valves	*Oxygen "on/off" tap*
Discharge planning	*Discussion and action about going home from hospital*
Flow meter	*Controls rate of oxygen coming out of cylinder*
Humidifier	*Device to add moisture*
Hypoxia	*Abnormally low oxygen in the blood*
Liquid oxygen	*Oxygen gas compressed to a liquid*
Low flow gauge cylinder head	*Supplies oxygen at a very slow rate*
Management plan	*A plan of care for the infant, child or young person's care at home*
Nasal cannula	*Tubes to deliver oxygen via nose*
Named nurse	*Nurse responsible for child's care*
Oxygen saturation	*Percentage of oxygen in the blood*
Oxygen supplier	*Company which produces oxygen*
Oxygen tubing	*Plastic tubing delivering oxygen between delivery system and mask/nasal cannulas*
Parameter	*An upper and lower limit*
PD cylinder	*A small size oxygen cylinder*
Portable cylinder	*A small size oxygen cylinder that is easier to transport than a regular cylinder*
Respiratory pattern	*Breathing characteristics*
TREM Card	*Transport Emergency Card (Road). Sign displayed in vehicle to highlight carrying of oxygen with advice on what to do in an emergency situation*
Valve outlet	*Part of oxygen cylinder head (top)*
Valve seat	*Part of oxygen cylinder head (top)*
Valve spindle	*Part of oxygen cylinder head (top)*

Useful contact details

Children & Young People's Home Care Team
Leighton Hospital
Crewe
CW1 4QJ
Telephone: 01270 612071

Baywater Home Care
Wulvern House, Electra Way, Crewe CW1 6GW
Freephone: 0800 373 580

Baywater can provide oxygen information in other languages and formats if requested

British Lung Foundation
73 – 75 Goswell Road, London EC1V 7ER
Tel: 020 7688 5555 Fax: 020 7688 5556 E-mail: enquiries@blf-uk.org
Internet: www.lunguk.org

Family Fund
PO Box 50, York, YO1 9ZX
Tel: 01904 621115
E-mail: info@familyfund.org.uk
Internet: www.familyfundtrust.org.uk

This information pack only gives general information. You must always discuss the individual treatment of the infant, child or young person with the appropriate member of staff. Do not rely on this information pack alone about the infant, child or young person's treatment. This information can be made available in other languages and formats if requested.

Certificate of Instruction

Child & Adolescent Unit **Children & Young Peoples Home Care Team**

Patient's name…… DoB……..

I agree that I have received written guidelines and been instructed how to:

……..……
……

and now feel confident and competent to carry out this procedure/treatment.

I understand what problems may arise and what to do if they occur.

Parent / legal guardian / patient's signature: (print & sign)

……..

Date ……
Signature of registered nurse assessing competency: (print & sign)

……..

Date …… Date for review ……

Review Date	Parent / legal guardian	Nurse assessor
……..	……	……
……..	……	……
……..	……	……

To request a copy, please telephone 01270 612071.

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