

Taking Your Baby Home with Oxygen

Paediatric Department

If you need this leaflet in a different language or accessible format please speak to a member of staff who can arrange it for you.

اگر به این بروشور به زبان دیگر یا در قالب دسترس پذیر نیاز دارید، لطفاً با یکی از کارکنان صحبت کنید تا آن را برای شما تهیه کند.

Jeśli niniejsza ulotka ma być dostępna w innym języku lub formacie, proszę skontaktować się z członkiem personelu, który ją dla Państwa przygotowuje.

Dacă aveți nevoie de această broșură într-o altă limbă sau într-un format accesibil, vă rog să discutați cu un membru al personalului să se ocupe de acest lucru pentru dumneavoastră

如果您需要本传单的其他语言版本或无障碍格式，请联系工作人员为您安排。

إذا احتجت إلى هذه النشرة بلغة أخرى، أو بتنسيق يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

Taking your baby home in Oxygen

Introduction

As your baby is nearly ready to go home but he/she needs to go home in oxygen therapy. We do not know for sure how long your baby will need this extra oxygen, however it is essential to help them grow and develop healthily.

Your baby has Bronchopulmonary Dysplasia or (BPD) also known as Chronic Lung Disease of prematurity (CLD). We have an active home oxygen programme designed specifically for babies with Chronic Lung Disease. A member of the paediatric respiratory team will co-ordinate the discharge plan following referral by the Consultant Paediatrician who is looking after your infant.

There is no doubt that you and your baby will be more relaxed at home away from the clinical environment, and I am sure it will be nice for you all to return to normal family life. The stimulation needed for your baby's development is also of great importance you, your family and friends can best provide this.

When your baby is stable and the decision is made, to plan for your baby's discharge from hospital, there will be a period of time to plan all the discharge arrangements before actually going home. This takes approximately 5 working days but this can vary depending on what your baby requires. Once the decision that your baby can go home has been made, a detailed teaching and discharge programme will begin.

This booklet is designed to help answer the many questions you may have.

If you are worried about any aspect of taking your baby home on oxygen therapy, and you have other questions to ask, please do not hesitate to ask any member of the nursing or medical team involved with your baby's care.

Your Nursing and Medical Team is as follows:

Consultant Paediatrician.....

Paediatric Respiratory Nurse

Health Visitor.....

General Practitioner.....

Social Worker.....

Bronchopulmonary Dysplasia (BPD) or Chronic Lung Disease of Prematurity (CLD)

Chronic Lung Disease of Prematurity (CLD) is a condition that develops in babies who are born premature and therefore have immature lungs. If your baby has CLD, they may have had a condition called respiratory distress syndrome (RDS) shortly after they were born. As babies with RDS have lungs that are immature, treatments used to treat RDS can cause changes to the lungs. This includes ventilation and oxygen delivered at high pressure. If your baby has been put on a ventilator for a long time, they are at a higher risk of developing CLD. In CLD the changes in the lungs make them stiffer than normal and less efficient. These babies need extra oxygen for several weeks, sometimes many months, which will allow the baby to grow and develop new and healthy lung tissue. It is not clear why some ventilated babies develop CLD and others do not. (BLISS; March 2021).

As for all babies we recommend that you follow all the guidelines (provided in the national leaflets) to reduce the risk of cot death.

How is CLD treated?

Supplementary oxygen and good nutritional support help your baby develop healthy new lung tissue and possibly help repair some of the damaged lung tissue. On discharge your baby will go home on the amount of oxygen he/she has been in at the hospital. As you will be aware your baby receives the oxygen via a small tube placed in their nostrils called a cannula. The oxygen your baby needs at home will be provided by an oxygen cylinder. Small portable oxygen cylinders will be provided so that you can go out of your home during your usual family activities.

It is important to monitor your baby's height and weight at regular intervals. If your baby is not gaining weight adequately then that may suggest that your baby is not having enough oxygen for their needs. Growth is a very good indicator of how well your baby is coping. Very often babies with CLD may need regular transfusions of blood (often called 'top-ups') and their blood levels are checked as required.

The oxygen will be continued over weeks/ months until your baby has been reduced to the smallest possible amount. If your baby is growing and developing well for example, gaining a steady weight, does not have any respiratory symptoms i.e. no cough wheeze or difficulty in breathing and is not on any diuretics (to relieve water retention) we will wean your baby off daytime oxygen. For the following week your baby will just have oxygen to sleep and then an overnight oxygen saturation study will be done whereby your baby will have had no oxygen all day and you leave it off at the night-time. Please note it is not our usual practice to wean infants off oxygen and diuretics at the same time.

Throughout your baby's care both in hospital and at home we will monitor overnight oxygen levels at random intervals by using an oxygen saturation monitor like the one used on the neonatal unit. Hospital at Home (HAH) will usually drop off/ collect the oxygen saturation monitor following requests from the respiratory nurses. It is the results from this monitoring which will give the respiratory nurse and the consultant in charge of your baby's care the information they require to make changes to your baby's treatment.

On initial discharge from the neonatal unit your baby will be monitored by the Hospital at Home Team (HAH) for approximately 7 days or until you are feeling confident in general care and management of your baby. Once HAH have discharged your baby, the respiratory nurses will make home visits weekly whilst baby is on oxygen. Any changes in treatments or management will be shared with the relevant professionals involved.

Up until the age of 2 years your baby will be followed up at regular clinic appointments. The Respiratory nurse is available for help and advice Monday to Friday between the hours of 9am – 5pm but **not** to provide emergency care or review acute illness episodes. **If your baby is unwell outside of the hours above, you should use the open-door policy to obtain medical advice and review. In an emergency an ambulance must always be called.**

Occasionally your infant may have other medical problems these are outlined here:

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Nutritional Requirements

Babies with CLD have special nutritional needs. This is because they use up more energy than other babies do with the extra effort they put into breathing and they get tired easily.

Because your baby was born early, they do not have the normal stores of nutrients in their body. To compensate for the loss of energy it is very important that they have a diet high in calories. You may be given a high calorie baby milk or calorie supplements to add to your baby's feeds such as Duocal. A high calorie diet, along with additional oxygen, will help your baby grow new lung tissue. The weight of your baby will be regularly checked by your respiratory nurse and consultant paediatrician during your follow up arrangements after leaving hospital.

Please note; If special milk or additives are required these are provided for your baby on prescription obtained from your GP. The paediatric dietician will coordinate feeding regimes with you.

It is important to wean your baby onto solid food as usual if you delay then they may find it more difficult to accept solids and cope with lumpy foods. You should start offering your baby solids from about 6 months (i.e. 26 weeks) of age if they have gained head control. Start slowly and gradually build up the intake, introducing one food at a time. Ask your health visitor or dietician for advice. On occasions we may suggest you wean your baby earlier than 26 weeks if this is needed this will be discussed with you. This is usually helpful if the baby is not putting on enough weight on a regular basis or the baby has significant gastro-oesophageal reflux.

Medications

Additional treatment may be required for your baby such as medicines. One may be a diuretic medicine, which will help your baby pass urine (wee) and remove any excess fluid that maybe collecting in and around their lungs. Sometimes steroids are also given, these help speed up the healing process in the lungs. All premature babies are put onto folic acid and iron supplements such as Sytron. Multivitamins are also given as Dalivit / Abidec routinely. It is important that the prescribed amount is given until your baby is about one year old and eating more of a variety of solid foods. The dietitian/ paediatric consultant will advise when these can be stopped.

Some babies have persistent vomiting (gastro-oesophageal reflux), and you may be advised to use a feed thickener such as Carobel or Infant Gaviscon. The dietician and nursing staff will direct you how to use these products if necessary.

Very often premature infants may develop asthma like symptoms such as wheeze and cough. If so, they may be treated with inhaled therapy. These symptoms usually resolve as your baby gets older. However, they may not and it may be that your baby will be troubled with asthma like symptoms for quite a long time.

You will be given a supply of medications on discharge from hospital all subsequent supplies should be obtained from your GP on regular repeat prescription. If you do not understand any of your medications always ask a member of staff to explain them to you.

Your infant's medications are as follows:

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Oxygen Equipment

Baywater is the company who provide the home oxygen service for your baby. Once the respiratory nurses have completed the required order forms and you have consented for the respiratory nurses to share your baby's details with the oxygen company. Baywater will contact you direct to arrange a date to install the equipment.

Baywater will teach you and your family how to use and maintain all the equipment during this visit, therefore it is preferable that one or both parents are around for this installation. **The type of home oxygen equipment will depend on your baby's oxygen needs.** For most babies, no concentrator is required as they are on a very low flow of oxygen therefore babies are usually just provided with oxygen cylinders.

Nasal cannulas and Rose buds (tender grips) are provided by Baywater, they can be requested via telephone when you order your oxygen.

Portable oxygen

You will be provided with as many portable oxygen cylinders as you will need to allow you freedom out of the home as per your usual lifestyle. These are provided by Baywater, a carrying bag will also be provided for ease of mobility.

It is important to inform your home insurance and car insurance you have oxygen fitted in your house. Please note there should be no extra charge to premiums for both home and car insurance. **It is your responsibility to inform your insurance companies.** The respiratory nurse will request a free home fire safety check from the fire brigade.

It is important that you, your family and all visitors adopt a NO SMOKING POLICY IN THE HOME FOR SAFETY PURPOSES this includes electronic cigarettes due to the risk of combustion.

Processing of the 'oxygen order' depends upon the baby being registered with a local GP. If you have not yet registered your baby then please do so as soon as possible to avoid any delay in discharge.

Parents should note that not all public service vehicles allow oxygen equipment to be carried in their vehicles. It is wise to check with your usual bus or taxi service just in case.

Once the Consultant and the respiratory nurses are happy that your baby is stable, all the criteria needed for safe delivery of home oxygen has been fulfilled and all equipment is set up (discharge checklist completed), a discharge date can be made. Referral to Hospital at Home (HAH) will be made prior to discharge. Discharge will usually be on a weekday and not over a weekend.

Action by parents

Ensure adequate contact numbers are available for the oxygen company.

On the day of discharge, you must remember to bring the portable oxygen cylinder with you so you can take baby home along with a suitable car seat if travelling in a car.

Parents must watch the BLISS resuscitation video available on the neonatal unit or on YouTube.

Getting out and about

You will be able to do most of the normal day to day things despite needing a constant supply of oxygen. Always check you have enough oxygen in your cylinder before going out for long periods of time.

It is safe to have your oxygen in a car provided it is well secured and not in danger of falling. It is worth avoiding public transport due to the restrictions mentioned earlier but also because they may be crowded.

If you are coming to clinic to see your consultant and you do not have any form of suitable transport, a taxi should be organised for your journey.

Vaccinations

It is important that your baby receives their full immunisation programme. This is usually carried out at the same time as for full term babies. The neonatal unit will ensure you are up to date where your child is up to with their immunisation, and they will inform your health visitor and GP when any follow up immunisations are due.

If your child is discharged over the winter period, a vaccination called Synagis (Palivizumab) may be offered. This consists of an intramuscular injection given every month throughout the RSV season. It gives added protection against the RSV strain of Bronchiolitis which is the most common strain of Bronchiolitis that can make premature infants very unwell. This vaccine will be discussed with you if your consultant feels it is appropriate.

Financial Advice

There may be funds and benefits which you may be entitled to. The main benefit for families with an oxygen dependant baby is Disability Living Allowance, (DLA) your respiratory nurse will advise you accordingly.

DLA is tax-free and non-means tested. Payment can start once a child reaches 12 weeks of age, but it can take 6-8 weeks to process. Your respiratory nurse will request a DLA form for you as part of the discharge package if the family agree.

The Disability Allowance is supported by the respiratory team to help families pay for the extra cost of travel to appointments. The respiratory nurse will support you in completing the application

Social Services or Citizens Advice Bureau can also provide extra financial advice and support if required, please contact your local office.

Support Groups

BLISS (Baby Life Support Systems) offer an array of parental support, please visit their website at www.bliss.org.uk for more information. They also offer a range of leaflets and information sheets on subjects that are of interest to parents of babies who have required special care.

Open door policy

As your baby has a long-term illness/disease he/she has been placed on the open door file for the paediatric unit at Whiston Hospital. This scheme enables you as parents to ring the ward for advice should your child have a medical problem.

If you are concerned about your baby please ring:

3F on 0151-430-1616

or

4F on 0151-430-1627

and ask to speak to a senior nurse. He/she will then go through a series of questions about your baby's problem. After assessing all the information, the nurse will give you instructions on how to proceed which can be one of the following options:

- See your GP
- Come directly to the children's ward for review
- Go to the Accident & Emergency department or
- Dial 999 for emergency services.

OPEN DOOR access can not be used as an emergency service; in the event of an emergency situation please DO NOT contact the ward or the respiratory nurse but immediately dial 999 as you would normally do in such circumstances and your child will be taken to the Accident and Emergency department for treatment.

Below are some useful contact numbers should you need to speak with another member of your baby's medical team:

Dr.Chilukuri/ Dr Prasad Consultant Paediatricians Secretary (Glenda) 0151-430-1453

Sarah Southern Respiratory & Allergy Nurse Specialist Direct line 0151-430-1938 or Mobile 07584143785

Danielle Davies Respiratory Nurse Specialist 0151-430-1938 / 07584143785

Emma Saunders Paediatric Respiratory Sister 0151-430-1938

Amy Griffiths (Dietician) 0151-430-1201

Care Plan For Baby on Home Oxygen

<p>Parent / Carer advice</p> <p>Observe for breathing difficulties</p> <ul style="list-style-type: none">• Fast Breathing.• Coughing episodes.• Changes in skin colour (paleness).• Poor handling.• Irritability.• Tummy muscles working hard (e.g. stomach drawing-in under the baby's rib cage).• Wheezing.	<p>Contact your Respiratory Nurse or Open Door if any of the following occur</p> <ul style="list-style-type: none">• If your baby is breathing very fast and is unable to feed as usual.• Coughing episodes are causing concern, e.g. loss of colour or continued vomiting.• Any in-drawing of tummy muscles.• Baby getting tired because he/she is having difficulty breathing. <p>If your baby is having severe breathing difficulty or is blue at any time dial 999 and call for emergency services. Start resuscitation if required until help arrives.</p> <p>Do not contact Open Door or your Respiratory Nurses in emergency situations always dial 999.</p>
<p>Monitor feeding</p> <p>Observe general feeding regime. Observe the amount of milk your baby is taking on a daily basis.</p> <p>Observe for any vomiting or positing (the regurgitation of small amounts of feed).</p> <p>Feed your baby as per the guidance of your dietician/nurse/health visitor.</p>	<ul style="list-style-type: none">• Not tolerating at least two thirds of their normal feeds.• Your baby is more lethargic (tired) or looks pale and floppy.• Your baby is vomiting and has not kept fluids down for the last 6 hours.• Your baby has not had a wet nappy for the last 6 hours.• Your baby continues to posit on a regular basis.

Care Plan For Baby on Home Oxygen continued..

Ensure Comfort & Safety

Ensure the nasal cannula is not too tight and causing any discomfort or injury to the face or nose.

Always fix the cannula as shown using the tender grips (rose buds) / duoderm/ tegetherm.

Change nasal cannula as little as possible to prevent skin damage.

Never use any Vaseline or other lubricant on the nose if sore.

If skin around the nostril is sore apply a little KY jelly only.

No Smoking / Naked flames / Electronic cigarettes around oxygen equipment.

- Ring Baywater if you require extra supply of nasal cannula/ tender grips (rose buds).
- Ring Baywater if any problems with the oxygen concentrator or portable cylinders.

General Monitoring

Monitor your baby's general behaviour; if your baby is irritable check all oxygen tubing to ensure there are no leaks or breaks in the tubing.

Always provide a comfortable position for your baby. Sitting up in a baby chair allows for easier breathing once they are old enough. At night you may elevate the head of the cot by **placing pillows under the mattress.**

If your baby has a cold (URTI= upper respiratory tract infection) the secretions in the nose may block the nasal cannula. Monitor this throughout the illness and change the cannula more frequently if required. Clean around the nose carefully using cotton buds.

If you require any advice on any aspect of your baby's care, please refer to your booklet or contact your respiratory nurse or your health visitor.

Out of hours or at night you may contact either ward 3F and 4F at Whiston Hospital for advice.

Respiratory Nurse
0151-430-1938 /1453

Hospital at Home
0151-430-1542

Ward 3F
0151-430-1616

Ward 4F
0151-430-1627

Please remember your baby is on the **OPEN DOOR Policy** for any problems please ring 4F/3F, advising of the problem and inform the nurse that your baby is on open door. The nurse will give you appropriate advice on any action to take. Whilst on HAH your child is classed as an **in-patient** and under the responsibility of your Consultant Paediatrician not your GP.

Date.....

Time.....

Signature of Nurse Providing Care Plan.....

Signature Parent/ Carer.....

Whiston Hospital
Warrington Road,
Prescot, Merseyside, L35 5DR
Telephone: 0151 426 1600

St Helens Hospital
Marshall Cross Road,
St Helens, Merseyside, WA9 3DA
Telephone: 01744 26633