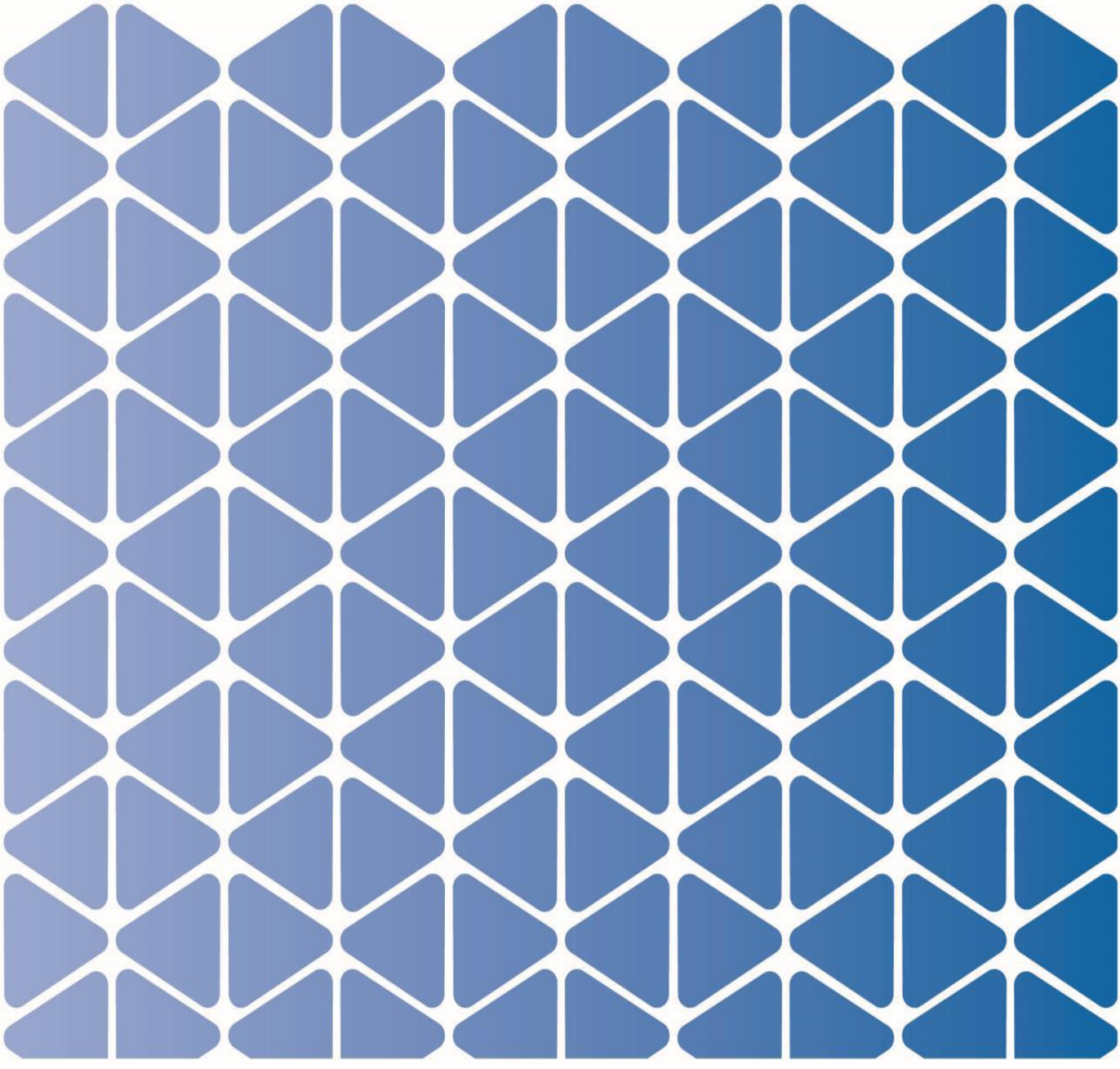
PATIENT INFORMATION

Worcestershire Acute Hospitals NHS Trust

GOING HOME ON OXYGEN

WORCESTERSHIRE NEONATAL COMMUNITY OUTREACH SERVICE



Going home on oxygen.

Your baby is almost ready for home; however they still require nasal prong oxygen. This is usually because they have a condition called 'Chronic Lung Disease'. Every baby with this condition requires differing amounts of oxygen for varying lengths of time; this can be 3 – 12 months or longer and it is important that they receive the correct amount of oxygen for their growth and development.

It is natural for you to feel anxious but the Neonatal Community Outreach Team (NCOT) on the unit will help you prepare for your babies discharge home and will ensure you feel confident in caring for them with oxygen.

They will:

- Discuss with you about home oxygen and what this involves.
- Liaise with the Nurses, Consultant, GP and Health Visitor to facilitate this.
- Provide you with all the necessary equipment.
- Ensure you complete the *'Parent Competencies'*
- Teach you 'Basic Life Support' and discuss how to reduce the risk of 'SIDS' (Sudden Infant Death Syndrome).
- Arrange a home visit prior to ordering the oxygen
- Arrange with you and Baywater Healthcare a suitable date and time for installation of oxygen.
- Arrange 'Open Access' to the Children's Ward in case of re-admission.
- Arrange Disability Living Allowance.
- Visit you at least once/twice a week at home to support you in the care of your baby.
- Liaise with your baby's Paediatrician to discuss progress and reduce oxygen.

First steps: When a joint decision has been made for your baby to go home on oxygen following discussions with you, they will have an overnight sleep study performed. This will involve attaching an oxygen saturation monitor to baby's foot and recording the oxygen levels for 10-12 hours. We can then work out how much oxygen is needed at home.

Next: The NCOT will arrange a suitable date with you for a home visit to complete a home safety assessment. Once this is successfully completed the oxygen can be ordered and delivery arranged.

Oxygen in the home is provided using oxygen cylinders or concentrators. We normally arrange to have 1 cylinder each in the lounge and in the bedroom with a couple of spares. These are fitted with the micro-flow valves as on the Neonatal Unit. We will also arrange for 2 - 3 small portable cylinders which you can carry in a backpack or on the pushchair when away from home.

The Baywater engineer will visit your home and set up the equipment and talk you through its use.

To re-order cylinders contact Baywater on: 0800 373580

Oxygen cylinders are safe provided you:

- DO NOT subject them to extremes of heat or cold – Keep 5ft away from a heat source
- Cylinders must be 10 ft away from an open fire
- DO NOT smoke, use e-cigarettes or naked flames near the cylinder
- Turn OFF cylinders when not in use.
- DO NOT use oil or grease on the skin ie: Vaseline, petroleum gel
- ALWAYS use a firebreak
- Ensure cylinders are firmly secured and cannot be knocked over - lie flat when in use
- Store away from flammable, oil based products

The Fire service will provide smoke detectors if not already fitted

Preparation: From when the decision to go home has been agreed there will be a period of time to plan all the arrangements with you and for you to be supported to become confident in your baby's care. If you would like to chat with another family who have a baby go home on oxygen please ask the NCOT who will try and arrange this.

You will be taught:

- Use of the cylinder and changing the flowmeter
- Changing and securing of nasal prongs
- Oxygen saturation monitoring and use of apnoea alarm
- Basic life support
- How to assess baby for any breathing difficulties.
- Storage and giving of medicines

You will need to:

- Inform your house insurer/landlord of home oxygen
- Inform your car insurance provider
- Apply for Blue Badge parking on the Worcestershire.gov website
- Contact Fire Service for FREE fire safety check on your home. www.fireservice.co.uk

You will be offered the opportunity to spend at least 2 nights in the Transitional Care Unit before going home, where you can care for your baby alone to build your confidence.

You will be provided with an *apnoea alarm*. This will monitor your baby's breathing and be loaned until they are off oxygen or 6 months old. You will also be loaned an *oxygen saturation monitor* for the first 2 weeks at home so you can perform 'spot' checks. The NCOT will arrange this and teach you how to use the equipment.

Home ward bound:

On the day of discharge a member of NCOT will aim to visit you at home to provide support and guidance during the first few hours at home. They will continue to visit daily for the first week then reduce visits to twice weekly, then fortnightly as required. The visits will continue until your baby does not require oxygen supplementation. If your baby is still requiring oxygen at 6 months it may be more appropriate for their care to be handed over to the *Orchard Service – Children's Community Nursing team*. This will be discussed fully with you beforehand.

Weaning your baby off oxygen:

Your baby will commence a programme of weaning approximately 4 weeks after discharge if stable and gaining weight. You will be fully informed and supported to do this by the NCOT.

You will be asked to do an overnight sleep study at home in a lower amount of oxygen as instructed by NCOT which will have been agreed with your baby's Paediatrician. This will involve attaching an oxygen saturation monitor to your baby's foot which will record the oxygen levels for 10-12 hours overnight. NCOT will collect the monitor and assess the data with your baby's Paediatrician and a decision will be made on the amount of oxygen required.

Overnight sleep studies will be repeated every 4 weeks until baby is in air. Once 2 satisfactory studies in air are completed your baby will be discharged from NCOT and the oxygen will be removed from the home.

Assessing babies breathing:

You will need to know what your baby's normal breathing rate is when awake and asleep. Your baby may breathe faster during and after a feed, crying or when active which is quite normal. However if they have an increased breathing rate when asleep it may be a sign of being unwell. Look at the way the chest moves, you may see the spaces between the ribs being drawn in (this is called recession) and could indicate your baby is unwell or there is a problem with the oxygen.

Breathing sounds: Listen carefully to the sounds your baby makes, is there any grunting or wheezing, have you noticed a cough?

Colour: If your baby goes dusky or pale:

- Check that the prongs are in place and they are not twisted or blocked.
- Check the oxygen tubing for any kinks (Briefly turn the oxygen up to 1 litre and listen for the 'hiss' in the nostrils). If in doubt change the prongs.
- Check the flowmeter is set correctly, that the cylinder is ON and is not empty.
- Check the flow through the flowmeter from the cylinder. If you can't feel oxygen then change to another cylinder.

IN AN EMERGENCY CALL 999
Cylinder problems call BAYWATER 0800 373580

If you are anxious about baby and it is not related to oxygen equipment call the NCOT on 01905 760661

Nutrition

Babies with chronic lung disease may have special nutritional needs; this is because they can use more energy for breathing than other babies. It is therefore important that your baby receives the correct balance of nutrients.
Your baby may have received human milk fortifier given alongside breast milk feeds to support their growth and development, this will continue at home if required. Sometimes babies require a preterm milk formula called Nutriprem 2 to aid growth. This will be available on prescription to 6 months of age.
Your baby's weight will be monitored weekly at home initially. If you are concerned about feeding or weight gain you can get advice from NCOT or Health Visitor.

Immunisations

Your baby may have already received their first immunisations at 8 weeks and should continue the programme at 12 weeks and 16 weeks. These will be given at your local GP practice.

Your baby will also be offered the Respiratory Syncytial Virus (RSV) injection on discharge to reduce the risk and severity of an infection to the lungs called Bronchiolitis.

Some baby's may be given the flu jab if they are 6 months old.

Appointments

You will receive an appointment to see the Paediatrician 6 – 8 weeks after discharge from hospital and then every 3-4 months.
You will also receive an appointment to be seen in the Chronic Lung Clinic soon after discharge.

General Information

Your baby is going to remain vulnerable to coughs and colds in the first year of life and trying to avoid infections will be advantageous.

Environment.

Getting out of the house is essential, however try and avoid crowded places such as schools and supermarkets.

Contact

Young children are most likely to pass on coughs and colds. If your baby has older brothers or sisters encourage them to wash their hands before touching the baby. If you have friends or relatives with school age children ask them not to visit if the child is unwell. (Be aware of candles if attending Birthday celebrations)

Avoid cigarette smoke and e-cigarettes

One of the most important things you can do is NOT smoke in the house – ideally consider 'quitting'.

Smoking increases inflammation in the lungs, worsens lung function and increases the risk of catching lung infections.

Babies exposed to cigarette smoke are at an increased risk of *'Sudden Infant Death'*.

Smoking around oxygen cylinders is a fire hazard.

Bathing and skin care

Your baby will enjoy bath time but be careful to avoid bath oils or bubble bath which contain oil whilst baby is on oxygen.

Avoid using oils, creams and ointments (which contain petroleum or oil) on babies skin, this includes cradle cap treatment and sun cream so check the ingredients carefully or speak to a pharmacist.

If attending baby massage classes only use WATER based products.

Financial advice

As your baby is home on oxygen they are entitled to Disability Living Allowance. NCOT will arrange for an application form to be sent to your home and can assist you in completing your claim if needed.

Travelling

Oxygen cylinders should be stored securely in the car, either behind the front seat or fastened with a seat belt in the rear seat. Extra cylinders should be stored in the boot.
NEVER use oxygen in a fuel station

It is advisable to inform your vehicle insurance company that you will be carrying oxygen cylinders; this should not affect your premiums.

Buses – you are able to use oxygen cylinders on a bus, but it is worth checking with the bus company prior to travelling.

Holidays
It is possible to travel and go away from home while dependent on oxygen, however please discuss your plans with NCOT.
If you are travelling away from home anywhere within the UK, the oxygen you need will be provided to you free of charge by Baywater.

Firstly contact your destination to obtain permission for your oxygen equipment to be delivered and stored at your accommodation.

Then if you require the same oxygen equipment at your destination as you have at home then contact Baywater with your holiday details

Cylinders

Large cylinder

Flow rate	Duration (approx.)
0.1 Lpm	14 days
0.2 Lpm	7 days
0.3 Lpm	4 days

Lightweight portable cylinder

Flow rate	Duration (approx.)
0.1 Lpm	4 days
0.2 Lpm	2 days

Contact Phone Numbers.

Neonatal Community Outreach Team
(7 days a week, 08.00 – 16.00)
01905 760661

Mobile: 07834 172337

Worcester Neonatal Unit
01905 760661

Baywater Healthcare
0800 373580

Riverbank Childrens Ward
01905 760588

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.