

# Your baby's home oxygen therapy

## Information for children, families and carers

We have given you this factsheet because your baby needs additional help with their breathing and is due to go home from hospital on oxygen (this is known as home oxygen therapy). It explains what home oxygen therapy is and what it involves, so you know what to expect. We hope it helps to answer some of your questions. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

### What is home oxygen therapy?

Home oxygen therapy involves breathing in additional oxygen from a cylinder at home via nasal prongs.

### Why does my baby need home oxygen therapy?

Oxygen is needed for all the cells in the body to function properly. If your baby has a condition that prevents them from getting enough oxygen into their bloodstream, this can put a strain on their heart and lungs. Breathing in extra oxygen will help to reduce this strain.

Home oxygen therapy is usually prescribed for babies who have a condition called chronic lung disease (CLD). CLD (also known as bronchopulmonary dysplasia or BPD) is a breathing condition that is diagnosed when babies need ongoing help and support with their breathing after 36 weeks corrected age, or after they are 28 days old. Every baby will need a different amount of oxygen for a different amount of time. We will discuss your baby's individual home oxygen therapy plan with you in more detail.

### What happens next?

Before your baby can go home from hospital on oxygen, we will first perform an overnight sleep study (a non-invasive test that monitors the level of oxygen in your baby's body). For this test, we will attach an oxygen saturation monitor with a soft band to your baby's foot for 10 to 12 hours. This will help us to work out the amount of oxygen your baby needs at home.

After this test, we will arrange a suitable date for your baby to go home (this will depend on when the oxygen cylinders can be delivered to your home and when you feel confident to give your baby oxygen at home).

We will usually arrange for your baby to have two oxygen cylinders at home: one in the lounge area and one in the bedroom. The oxygen cylinders will be fitted with a low flow meter, as per the ones on the neonatal unit. We will also arrange for your baby to have three to four small portable oxygen cylinders, which you can carry in a backpack or in the pushchair basket when out and about.

Your baby's oxygen will be provided by a company called Vivisol. An engineer from Vivisol will call you on the morning of your baby's oxygen delivery to give you an approximate time of arrival. The first time Vivisol deliver oxygen to your home, they will explain how to use the equipment and answer any questions you may have.

## **Will I receive any support with home oxygen therapy?**

### **In hospital**

It is natural for you to feel anxious about your baby going home on oxygen. From the moment the decision has been made for your baby to go home on oxygen, we will support you and make sure you feel confident caring for your baby while on oxygen.

Before you leave hospital with your baby, we will:

- explain what home oxygen therapy is and what it involves in more detail.
- liaise with your baby's nurses, consultant, general practitioner (GP) and health visitor to arrange home oxygen therapy.
- complete a risk assessment to ensure it is safe for you to have oxygen in your home.
- provide you with all the necessary home oxygen therapy equipment and teach you how to use it safely at home (including how to use the cylinder, change the flow meter and change and secure the nasal prongs).
- support you to complete the home oxygen therapy competency checklist for parents and carers (for more information about this, please see page 7).
- teach you how to assess your baby for any breathing difficulties and who to call for help or advice.
- teach you how to perform 'Basic Life Support' (a set of basic life-saving first aid techniques).
- support you to apply for Disability Living Allowance (DLA) for children (for more information about this, please see page 5).
- visit you at home to support you with caring for your baby.
- liaise with your baby's paediatrician to discuss your baby's progress and whether their oxygen level can be reduced.

We can also try to arrange for you to chat with another family who have a baby at home on oxygen, if you think this would be helpful to you.

We will also give you the option to spend one or two nights in a room on the neonatal unit before going home. This will give you a chance to care for your baby alone, with support nearby, to help build your confidence before going home.

This is also a good opportunity for you to ask us any questions you may have before you go home. We have included a list below of some of the questions that you might like to ask us:

- If I have questions after my baby gets home, who should I call?
- Can I take my baby outside (for example, to see my friends, to go to baby groups or to go shopping)?

- Who will decide when to lower my baby's oxygen and how often might this be?
- Will my baby have any monitors at home?
- What happens if my baby needs to go back into hospital?

## At home

A member of our team will visit you soon after you go home, and then as much as you need for the first week or two until you feel confident caring for your baby. The home visits will then decrease to fortnightly (or as needed) until your baby no longer needs home oxygen therapy.

If your baby still needs oxygen three to six months after going home, we may pass their care over to the children's community nursing (CCN) team. If this is the case, we will discuss this with you in more detail and arrange for both teams to visit you at home to ensure a smooth transition.

## Important safety advice for home oxygen therapy

### Don't:

- smoke or use e-cigarettes or vapes near your baby's oxygen cylinders (indoors or outdoors).
- leave your baby's oxygen running when not in use, as there may be a buildup of gas in the room that could be dangerous.
- subject your baby's oxygen cylinders to extreme heat or cold, or place near any naked flames (including open fires) (always keep oxygen cylinders at least 5ft away from any heat sources).
- use flammable products, such as cleaning fluids, paint thinner, petroleum-based creams or aerosols, while your baby is on home oxygen therapy.
- use oil-based products, such as Vaseline and petroleum gel, on your or your baby's skin while they are on home oxygen therapy.

### Do:

- ensure oxygen cylinders are safely stored on their side, out of the reach of children.
- store oxygen cylinders away from flammable, oil-based products.
- inform your electricity supplier that your baby is using oxygen (if you have a concentrator). You will be put on a priority list for reconnection in the event of a power failure.
- inform your home insurance company. This should not affect your premium.
- inform your landlord (if applicable).
- inform your car insurance provider.
- have a smoke alarm in your home.
- apply for a Disability Living Allowance (DLA) for children and a Blue Badge (a badge that helps you to park close to your destination, either as a passenger or driver).
- contact UK Fire Service Resources for a free fire safety check on your home:  
[www.fireservice.co.uk/safety/home-fire-safety-check](http://www.fireservice.co.uk/safety/home-fire-safety-check)

## When should I seek medical help?

While your baby is receiving oxygen at home, it is important that you know what your baby's normal breathing rate is when they are awake and asleep. This is so you can easily spot any changes to their breathing patterns. **You will need to check your baby's breathing on a regular basis for any changes.**

It is normal for babies to breathe faster during and after a feed, crying or when active. However, if your baby has an increased breathing rate when asleep, it may be a sign that they are unwell. To check if your baby is unwell:

- **look** at the way their chest moves. Your baby may be unwell or there may be a problem with the oxygen if you can see the spaces between your baby's ribs being drawn in (this is called recession).
- **listen** carefully to the sounds your baby makes when they breathe. Your baby may be unwell or there may be a problem with the oxygen if they are grunting, wheezing or coughing.

If you notice any changes to your baby's breathing, first check that:

- the flow meter is set correctly.
- the cylinder is on and is not empty.
- all tubing is secured and not kinked at any point.
- the nasal prongs are in place and not blocked. To check for blockages, remove the prongs from your baby's nostrils briefly and turn the oxygen up to 1 litre and listen for the 'hiss' sound. If you have any doubts, change the prongs. If you are confident that there isn't a blockage, you can turn the oxygen back to your baby's usual amount.
- the oxygen is flowing through the flow meter from the cylinder. If you cannot feel oxygen, change to another cylinder.

**If your baby is still showing signs of increased work of breathing (see below), increase your baby's oxygen to 1 L/min and immediately call either your Open Access number (this can be found on your baby's discharge summary) or 999 depending on the severity of your baby's condition. Do not reduce your baby's oxygen until they have been seen by a medical professional.**

Call **999** for an ambulance **immediately** if your baby:

- looks pale or blue/grey in colour
- shows any signs of increased work of breathing (chest recession, nasal flaring, breathlessness, or feeding difficulties)

## Will my baby need any follow-up care?

### Home sleep studies

Your baby will need to have a sleep study at home once a month while they are on oxygen. The paediatric sleep team will call you to arrange these studies as and when needed. The team will also inform you of where to collect the equipment for the sleep study from and make sure you are confident on how to use it at home.

The sleep study will involve attaching an oxygen saturation monitor with a soft band to your baby's foot to record their oxygen levels for 10 to 12 hours overnight. You will usually need to perform this study twice (over two nights). Please follow the advice given to you by the paediatric sleep team.

## Community support

We will monitor your baby's weight along with your health visitor. Your baby's weight will help us to see how well they are doing on the oxygen. We will encourage you to keep in contact with your health visitor, and once you have been at home a while and feel confident to do so, we may encourage you to attend the baby weighing clinics in your local area.

Our neonatal community outreach team (NCOT) are specialists in the care of newborn and ex-premature babies only. Once your baby has been at home for three to six months, we will transfer your baby's care to the children's community nursing (CCN) team. The CCN team will continue to care for your baby until they no longer need home oxygen therapy.

## Additional support

### Disability Living Allowance (DLA) for children

Disability Living Allowance (DLA) for children may help with the extra costs of looking after a child who:

- is under 16
- has difficulties walking or needs much more looking after than a child of the same age who does not have a disability

When your baby has left hospital and is over three months old, call the DLA for children helpline to get a form sent to you in the post.

Telephone: **0800 121 4600** (Monday to Friday, 9am to 5pm)

Once you have received the form, let your community nurses know and they can help you complete it. Your claim will start on the date you call the DLA for children helpline (as long as you return your completed form within six weeks).

You will usually receive a decision letter about eight weeks after returning your form. The letter will tell you when you will get your first payment.

For more information about DLA for children, scan the QR code below or visit:

[www.gov.uk/disability-living-allowance-children](http://www.gov.uk/disability-living-allowance-children)





## Home oxygen therapy competency checklist for parents and carers

Checklist	Parent or carer one			Parent or carer two		
	✓	Date	Sign	✓	Date	Sign
I understand why my baby needs home oxygen therapy.						
I am aware of how the NCOT will manage my baby's oxygen at home (frequency of visits, weaning oxygen, transfer to CCN team).						
I have received information about Vivisol and how delivery of equipment and oxygen will be arranged.						
I know how much oxygen my baby will go home on, and how to set this on the flow meter.						
I can confidently change the flow meter on the oxygen cylinder and know how to check the oxygen cylinder is turned on.						
I am able to change the nasal prongs.						
I know the signs of increased work of breathing to look out for.						
I am clear on the appropriate action to take if my baby needs medical help and what to do in an emergency (for example, contacting my GP or the NCOT, going to my nearest emergency department, or calling <b>999</b> ).						
I understand the importance of only leaving my baby with someone who understands how to use the oxygen safely and knows what to do in an emergency. I know I can contact the NCOT to provide additional teaching for family and/or friends.						
I have been told how and when I can apply for DLA and a Blue Badge.						
I understand the safety aspects of having oxygen in the home (safe storage and use, fire safety, naked flames, vapes and smoking).						
It has been recommended that I inform my car and home insurance, and landlord (if applicable).						



## Share your experience of our care

Your feedback helps us to celebrate what's working well and identify where we need to improve. We would be grateful if you would take a moment to complete our NCOT feedback survey. Your feedback is anonymous. Thank you.

To complete the survey, scan the QR code below or visit: <https://gthr.co.uk/f1ea>



## Contact us

If you have any questions or concerns, please contact us.

Neonatal community outreach team (NCOT)

Telephone: **07766 994816** (Monday to Saturday, 7.30am to 4.30pm)

Outside of these hours, contact Woodland ward on telephone: **023 8120 6553**.

## Useful links

[www.bliss.org.uk/parents/going-home-from-the-neonatal-unit/going-home-on-oxygen](http://www.bliss.org.uk/parents/going-home-from-the-neonatal-unit/going-home-on-oxygen)

[www.bliss.org.uk/parents/about-your-baby/common-infectious-illnesses](http://www.bliss.org.uk/parents/about-your-baby/common-infectious-illnesses)

**If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone 0800 484 0135 or email [patientsupporthub@uhs.nhs.uk](mailto:patientsupporthub@uhs.nhs.uk)**

**For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit [www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**

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