

# Taking your baby home on low-flow oxygen: information for parents and carers

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## **What to do in an emergency?**

Before you go home we will have had lots of discussions about what to do in an emergency, such as your baby is not breathing, is struggling to breathe or is seriously unwell. The main things are:

1. If you feel you need to **do not hesitate** to call an ambulance. The ambulance will have all the equipment on it to be able to deal with an emergency situation.
2. Make sure you know where your nearest paediatric emergency centre is, if it different from your usual hospital make sure you take your red book and the discharge letter that you were given upon discharge. However, these are not essential but can help give a new centre a bit of background information to your child's medical history.

## **A few quick things you can check before you call an ambulance:**

1. Are the oxygen prongs in the baby's nose?
2. Are the prongs blocked at all?
3. Is the oxygen cylinder turned on?

## Questions about going home on oxygen

### What is oxygen?

Oxygen is an essential gas that is required for the body to generate energy. The air that we breathe is 21% oxygen. The remaining air is made up of nitrogen (78%) and other tiny amounts of components such as carbon dioxide, methane and argon.

### Why does my baby need oxygen?

Your baby's lungs are not working well enough to extract enough oxygen from air. This may be because your baby has immature lungs due to prematurity, has had a birth incident such as a meconium aspiration, or has a heart condition.

The most common reason is from being born prematurely – the lungs are immature, less stretchy (to be able to expand to full potential) and unable to extract enough oxygen for essential brain and body growth and development. This is often given the term bronchopulmonary dysplasia (BPD) but you may hear it referred to as 'Chronic lung disease'. This is an umbrella term for anyone who has respiratory issues so don't get too hung up on the label for this diagnosis.

### How long will they be on oxygen for?

The length of time that your baby will be on oxygen completely depends on them. Some babies are on oxygen for a matter of weeks, some are on oxygen for a significant amount of time. Some babies come off of their low-flow oxygen quicker than other babies. Your baby is an individual so there is no comparison to other babies as their condition will differ slightly to your baby's condition. Your allocated children's community nurse (CCN) will assess your baby's oxygen saturations on home visits and decide when it is appropriate to try reducing the oxygen.

### How much oxygen will they need?

Before you leave hospital your baby would have had a 24 hour saturation study. This assesses whether your baby is maintaining adequate saturations for a specified amount of time. The saturations are recorded on a more sensitive monitor than the one they have previously been on in the unit. So if your baby is having 0.1L/m of low-flow oxygen and they 'pass' their saturation study, they will be prescribed 0.1L/m low-flow oxygen to go home with. Some babies require more than 0.1L/m and may need to have a saturations study repeated with an increased amount of oxygen, for example 0.2L/m or 0.3L/m. In hospital we can give oxygen in different increments, such as 0.05L/m, so if your baby still needs that little bit of oxygen we will increase it to 0.1L/m to perform a saturation study. This is because in a community setting (at home) the smaller increments of oxygen cannot be given.

### Can we go out with the baby on oxygen?

Of course you can! Your baby being on oxygen is no reason to not go out. In the first few days you will be getting used to your life at home with your baby, but once you feel

comfortable and more confident than there is no need to stay inside. You will be issued with some portable oxygen cylinders which are a lot smaller than the one you will have at home. You should also be given a rucksack type bag to carry a portable cylinder in. The cylinders are small enough to fit next to the carseat, in the footwell of the car and/or the carry space underneath a buggy/pram. Just remember to check that you have turned the portable oxygen cylinder on and the large home cylinder off before you go out.

Remember that people may look or stare at your baby, as seeing a baby on oxygen may not seem 'normal' to them (they may even make insensitive comments to you). But you are the expert for your baby! They do not know anything about what has happened in your baby's life. If you wish to, you can explain it to them if they ask, but if you don't want to then you don't have to.

### What about moving around the house with oxygen?

Most families will get two large static cylinders for use inside their home; one for the main living space and the other for the bedroom. It is fine to disconnect from one cylinder and walk to connect to the other within a few minutes. Some babies are even able to have the oxygen tubing removed while they are bathed and then have the oxygen tubing reapplied, as long as this is for a short period of time. Check with your doctor or nurse whether this will be suitable for you do with your baby. The higher the amount of oxygen that your baby requires, the shorter the amount of time they can go without oxygen.

## **Night time**

### What if the prongs come out of their nose while I'm asleep?

Do not worry too much; as soon as you notice that they are not in the baby's nose, just put them back. If the prongs are out of the baby's nose for a long time it is likely that your baby will wake or begin to become unsettled to indicate that they are lacking their oxygen. You don't need to call a doctor or have them seen, just pop the prongs back into their nose and they should recover quickly. Sometimes putting mittens on your baby's hands can reduce the risk of him/her grabbing at the prongs and pulling them away from their nose.

### Will we get any monitoring for our baby while sleeping?

Only in very exceptional circumstances is any monitoring equipment given to parents to monitor their baby. This is because machines such as an apnoea monitor can cause false alarms and panic parents when their baby is actually perfectly alright.

### What position is best for my baby to sleep?

**Always position your baby to sleep on their back.** For more information please go to: <https://www.lullabytrust.org.uk/safer-sleep-advice/sleeping-position/>

## Smoking

There are many things to consider if there is a smoker living within the household.

- **Safety:** Oxygen is one of the three elements needed for a fire to burn, along with fuel and a heat source, so having oxygen cylinders in your house is a fire hazard. When completing oxygen training with the nursing staff you will already have discussed fire safety, for example not placing the oxygen near any open fires, flames or other heat sources. Remember that while you're caring for your baby in a highly oxygenated environment your clothes and hair can become oxygen enriched. This can ignite and burn vigorously if exposed to a heat source, for example a lit cigarette or naked flame.
- **Smoking in the same room as your baby:** We would strongly advise that your baby is not in a room where anyone is smoking. This is the same whether your baby is on oxygen or not, or premature or not. A baby on oxygen has extremely fragile lungs, therefore ask if any smokers can smoke outside of the property.
- **Smoking increases the risk of cot death:** For more information on this go to: <https://www.nhs.uk/conditions/pregnancy-and-baby/reducing-risk-cot-death/>

## Illness

It is normal for your baby to become poorly from time to time, however in the winter months your premature baby on oxygen can be more susceptible to respiratory illnesses such as coughs and colds. To reduce the risk of infections being spread; make sure that you wash your hands with warm soapy water and encourage other members of your household to do the same as well as any visitors before they touch your baby. Remember that viral respiratory illnesses are easily spread, so avoid other people coming into your household with respiratory infections. If your baby does become unwell with a respiratory illness see your GP as soon as you can, if you know that you need to be seen sooner than you get a GP appointment please use your "Open Door" letter and follow the instructions it gives you to be seen in the hospital.

## Feeding your baby

Feeding your baby when they are on oxygen is very normal and you will probably already be used to doing this while still on the special care unit. However, babies on oxygen can get tired a little quicker than babies not on oxygen and then feed more frequently. Again, remember that your baby is an individual and they may take a large amount and sleep for a long time, or they could take a smaller amount and only sleep for an hour or two before they require feeding again. Premature babies are also more inclined to vomit; therefore, making sure that they are winded well can help. They may also projectile vomit. If and when this happens, be sure to look at their oxygen prongs to make sure that they are not blocked with vomit. If they are blocked with vomit, change to a new set of prongs and dispose of the blocked ones.

## **Oxygen supplies**

### Who provides the oxygen?

The company that supplies the south east of England is Dolby Vivisol. While baby is still in hospital nursing staff will go through an oxygen pack with you. In this pack you will receive a small yellow slip that has some important numbers on it, including Dolby Vivisol. We will also ask for your consent to share sensitive information with them, information such as: your address, names, dates of birth, GP details. After your baby has passed a saturation study we will then fax or email a Home Oxygen Order Form (HOOF) to Dolby Vivisol, giving them your details and the requirements of oxygen for the baby. They will then make contact with you to deliver the oxygen to your property and also to run through how to change the low-flow meter from one cylinder to another. They will also deliver nasal cannulae and sticky face fixings to you on a regular basis.

### How do we order more?

Dolby Vivisol will have a rough idea of how frequently you will need the large and portable cylinders replacing and will make appointments with you to deliver full cylinders. However, if you are running low on oxygen in the cylinders Dolby Vivisol are open 24/7 and you can contact them and ask for a next day delivery.

### Can we go on holiday with oxygen?

If you are going on holiday within the UK it will be alright to do so with some planning. Speak to Dolby Vivisol - they may give you extra oxygen to take away with you or arrange for the oxygen supplier that covers that area to deliver an oxygen supply to your holiday venue. Just remember to arrange this with plenty of notice.

If you are going abroad it may be more challenging and it may be better to postpone until your baby is off oxygen. Some airlines don't permit transport of oxygen and may insist that the baby has a 'fitness to fly' assessment as oxygen requirements increase while flying. An oxygen supply abroad is also not funded by the NHS and you will have to pay privately for an oxygen supply at your holiday venue if it is able to be accommodated. Some insurers will also not cover pre-existing conditions so research into your baby being covered for any respiratory issues as these need to be highlighted and discussed at length with any insurers.

## **Coming off of oxygen**

### Weaning oxygen

There are a few ways in which this can be done. The CCN will visit your home in order to check your baby's oxygen saturation. They may ring ahead and ask you to take the oxygen off or reduce the flow for a specified time before they arrive. This time will increase as your baby becomes bigger, stronger and able to tolerate more time without oxygen. Eventually your baby may only have oxygen while they are asleep and then the next stage is to remove the oxygen completely and see how they manage. This process can take a few weeks to a few months, depending how high the oxygen requirement was. This period

can be quite stressful for parents who may feel that the process is going too quickly or too slowly or are finding it a daunting prospect being without oxygen. Your baby's consultant will discuss with you how you think your baby is managing and they will also discuss your baby with their CCN. Remember, the oxygen is not going to be taken away straight away. Sometimes babies manage well while others need to have the oxygen back again for a few more weeks.

For other topics such as weighing, dietary advice and development, please get in contact with your health visitor. Your CCN will be focussing solely on the oxygen element of your child's care. When the oxygen is no longer required your CCN will then be reallocated to another family.

### **Important telephone numbers:**

Dolby Vivisol:	0800 917 9840	
Community Children's Nurses:	0118 378 3932	(Mon-Fri 9.00-17.00)
Dolphin Children's Ward:	0118 322 8079	

### **In an emergency call 999!!!**

*Quick word from the author: I took my baby home on low-flow oxygen; it was a really scary prospect at first, but as the days went by we got really comfortable with it and it was our 'normal'. The even scarier bit was when we no longer needed the oxygen. For weeks I was convinced I had forgotten something really important. It wasn't until we got home and had relaxed a bit that we remembered that we didn't have the oxygen and had been worrying about nothing all day! It will be fine and you will cope. This will be your normal for a while, until another change happens and then life will be another new normal and everyone's normal is something different anyway, so whatever your normal is, is normal for you.*

**Claire W**

Information based on advice taken from Bliss <https://www.bliss.org.uk/>

More information is available on the Trust website [www.royalberkshire.nhs.uk](http://www.royalberkshire.nhs.uk)

**This document can be made available in other languages and formats upon request.**

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