

A woman with long brown hair, wearing a dark blue jacket and a grey knit beanie with a pink flower, is smiling at the camera. She is sitting on a swing. A baby is sitting next to her on the same swing. The baby is wearing a light blue onesie with dark blue stars, a dark blue and yellow striped beanie, and brown boots. The baby is also smiling and has a clear oxygen tube connected to their face. The background is a grassy area with trees and a building in the distance.

Going home on oxygen

Bliss

for babies born too soon,
too small, too sick

Going home on oxygen?

Who is the booklet for?

- Parents
- Families
- Friends
- Carers

of babies coming out of hospital on oxygen

What is it for?

To help you and your family prepare to take your baby home

Who can help?

- Your health visitor
- Your baby's dietitian
- Speech and language therapist
- The Bliss freephone Helpline

“Taking Anna home after being in hospital for so long was both a happy and an anxious time for us. But once we had a routine and had shown all our friends and family how to care for Anna, we realised that we knew the best place for Anna was at home with us. She is now off oxygen and is learning new things everyday.”

Josie, mum to Anna, born 26 weeks

Important notes to readers

The information contained in this booklet should be used in consultation with the health care team caring for your baby.

All babies are different and should be treated as individuals.

The oxygen company will supply you with the most suitable equipment to the prescription or Home Oxygen Order Form (HOOF) received.

Home Oxygen Order Form

A member of staff will order your baby's oxygen on a Home Oxygen Order Form (HOOF). They will also fill out a prescription of HOOF for the amount of oxygen your baby will need. This will be forwarded directly to the home oxygen provider covering your area and they will contact you to arrange for delivery and installation of the oxygen supply to your home. You will be asked for your consent for the company to get in touch with you.

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What to do in an emergency

You will be advised before you leave about who to contact if you have concerns about your baby when they have been discharged from the hospital.

If you are worried your baby or child is not getting enough oxygen, has difficulty breathing or is seriously ill, dial 999. An ambulance will take you straight to the emergency department at your local hospital. Take all the medicines and inhalers etc. with you. The ambulance will call ahead and tell them why you are coming in.

You should also make sure that your closest emergency department has paediatric facilities.

A few simple things you can try yourself:

- Check that the prongs or tubes are not blocked and are properly connected.
- Check the oxygen supply in the cylinder.

Questions about going home on oxygen

The nurses and doctors in the unit will have already discussed with you why your baby is now ready to go home. Usually it means that he or she is generally in good health, gaining weight and growing and feeding in a way that can be continued at home.

Occasionally a baby may need extra feeding with a tube through their nose or mouth (nasogastric feeding) or into his or her stomach (gastrostomy).

Your baby still needs oxygen, however, to help with breathing and growing.

You should not be expected to do anything at home that has not been explained and demonstrated to you by a health professional. Unit staff will arrange a meeting with you before your baby is discharged so you can discuss the future and ask any questions. If there is a community outreach worker or family care worker attached to the unit (someone who will visit you once your baby is at home), it is likely they will co-ordinate the discharge. This will include talking to you about the practical side of caring for your baby at home and what it means for the family. If you do not have a community outreach worker, then someone from Special Care Baby Unit (SCBU) will arrange the discharge instead.

What is oxygen?

Oxygen is a gas that is necessary for all cells in the body to generate energy and function properly. The air we breathe normally has 21 per cent oxygen but a maximum of 100 per cent oxygen can be given. Your baby is prescribed oxygen and therefore it is important to follow the guidelines given to you by your baby's doctor or nurse for administration.

Why does my baby need home oxygen?

Your baby's lungs are not working well enough for them to get enough oxygen from the air. The most common reason for this is because of inflammation resulting from premature birth and immaturity of the lungs, but your baby may be needing oxygen for other reasons. If you are in any doubt, ask the doctors or nurses who are looking after your baby.





How will we know what level of oxygen to use?

Your paediatrician will have explained the amount of oxygen required. Reducing or increasing oxygen over a long time without your health professional's advice may be dangerous. But, as the closest contact with your baby, you are well placed to notice if you think the level needs changing, however you must discuss this with a relevant health

professional. Do expect the levels to vary as your baby's needs change.

How long will my baby be on oxygen?

Of course parents want their baby to look like other babies – without the tubes. This will come. Your paediatrician may give you an idea of how long your baby is likely to need oxygen for and will monitor progress so he or she isn't on oxygen for longer than necessary.

This will depend on your baby's individual progress and needs. Take comfort that this is not going to be forever.

"At first it was so daunting to have James at home and on oxygen. But the outreach team were really supportive and after 3 months at home he came off oxygen. He has been poorly a few times, but he is a happy robust little boy"

Helen, Mum to James,
born at 27 weeks

Your oxygen supplier will have a call centre open 24-hours a day 365 days a year for urgent enquiries regarding the equipment. Please see page 26 for contact details of your local supplier.

How will I know if my baby needs more oxygen for a short time?

Discuss with your paediatrician what signals your baby might give if he or she needs more oxygen. This will depend on their activity and it will not always be necessary to give more. As you would expect, some babies need more energy when feeding, playing, crying or bathing; this is when they need to be watched more closely to see if they need extra oxygen. After the activity, the oxygen needs to be turned down to the rate advised by your health professional. It should not need to be increased for much longer than an hour. Not all babies will need this so talk to your community nurse and perhaps they can watch you and your baby at these times and advise you.

You will be familiar with oxygen saturation monitors which are used in hospital to measure your baby's oxygen levels. This will be used at home when the nurse visits to check the levels and help decide when it may be appropriate to start reducing your baby's oxygen flow rate. Overnight saturation monitors help to provide information for you to do this. It is not usually necessary to have a monitor at home all the time as the oxygen requirements should be stabilised before discharge.

If you find your baby is irritable and cross or there is extra difficulty when feeding him or her, you should seek advice from your community nurse as soon as possible. In some cases, this can be an indicator that he or she is not getting enough oxygen.

Medication

The paediatrician will review any medication at the follow-up appointments and may change the medicines your baby is on and the dosage required.

It is important to give your family doctor advance warning of any new medicines needed for your baby. For example, if you are in a remote area, you will need to plan ordering the prescriptions so your supplier can provide them on time and regularly.

Fixing the tubes

Make sure you are comfortable with securing the tubes before being discharged. Do it over and over again.



If you decide to tape the tubes in place, you should use plenty of skin protector under the tubes as this will help prevent the skin from becoming inflamed. Only use KY jelly or RoEezit for safe use with oxygen. Oxygen can make your baby's nose, lips and mouth dry. If this is a problem, use a water-soluble lubricating jelly such as KY jelly or RoEezit on their lips and nose. Care should be taken when using any lubricating gels to ensure they do not contaminate the mask or cannula. Do not use oil based lubricants as they can become a fire hazard.

Will I have an apnoea monitor?

An apnoea monitor is used to detect pauses in breathing (apnoea) or breathing problems in young babies. The alarm sounds when breathing movements in a baby have been undetected for more than 20 seconds. False alarms are common as the baby moves or there may be poor connections to the monitor.

It may not be necessary, but some parents prefer to have one if their

baby has had a difficult time with breathing. If you are worried about apnoeas, discuss this with the SCBU staff and they will advise you as to whether you need a monitor.

Can I leave the house with my baby?

Yes! It is important that you and your baby get used to being out and about with the oxygen.

You will need to have a supply of portable oxygen to do this. Portable oxygen is prescribed along with the oxygen supply requested for use inside your home. Discuss your baby's oxygen requirements outside the home before you leave the SCBU. Remember to check the oxygen flow and contents of your portable oxygen supply before leaving the house.

People may stare, because they are not used to seeing a baby on oxygen, and you may have to deal with comments you find insensitive. If this happens, remember you are now the expert here and they may have no experience of this.



If you are using public transport or taxis, check it's ok to take oxygen on board as some companies may refuse.

Portable cylinders will come with a carry bag for ease of use when out and about. When using a portable cylinder, check that the oxygen supply is enough for the time you will be out.



Moving around

Moving around the house and going upstairs may seem like an ordeal, but it isn't. The best and safest way is to take the baby to the room you want to go to, and then come back for the low flow meter and tubing. Do discuss your need to move around with your baby with the technician installing the oxygen in your home or ask the neonatal staff before you take your baby home.

Before going home your baby will be monitored without oxygen for a short period to assess their reaction. This will help reassure you that it is alright to quickly move from room to room when needed. If this monitoring has not happened ask your healthcare professional or community nurse for advice. Some babies do not react well to being disconnected so it is important to be clear what to do before you go home.

Try to arrange for another family member or a friend to be present when your oxygen is being installed to benefit from the training given by the technician.

Ask if it is alright to take your baby off oxygen for very short periods of time for moving around the house. However, some babies do not react well to being disconnected. It is important to clear this with the medical staff before you do so.



How well wrapped should I keep my baby?

When indoors:

After discharge from a neonatal unit, babies on oxygen do not need significantly more bedding or clothing than other newborn babies.

Feel your baby's tummy or back of the neck – this should feel warm, not hot, and certainly not sweaty. If your baby is sweating then remove one or more of the layers. If their tummy does not feel warm, add extra bedding or clothing. Do not rely on feeling the baby's hands or feet as these are often cool in young babies.

When indoors, babies should not wear a hat as this can make them too hot. The room temperature should, in general, be in the range 16 to 20 degrees Celsius (60 to 70 Fahrenheit). Purchase a good thermometer to make sure the room temperature is correct.

You may find it helpful to talk to another parent through Bliss' Buddy Scheme. This service provides parents with one-to-one telephone support from a parent volunteer who is likely to have had a baby in similar circumstances. It can be very useful to those who cannot attend a local Family Group. Call the Bliss Freephone Helpline on **0500 618140** for more information.

When outdoors:

Babies are more vulnerable to cold weather than adults, particularly if there is a wind. They can lose a lot of heat from the head so a hat is especially important although this needs to be taken off once the baby is back inside.

What can I expect at night?

Your baby may wake up and become agitated if he or she isn't receiving enough oxygen, but not all babies do. If you are using an apnoea monitor and your baby is in a deep sleep it may not pick up breathing movements resulting in frequent false alarms.

Try and get someone to sit with your baby during the day while you take a nap. Take any offers of help. It is hard work having a baby on oxygen, but remember that this is only a temporary arrangement.



What if the oxygen tubes or prongs come out when my baby is asleep?

You should replace the tubes or prongs as soon as you notice they have come out. Some babies will be fine if the oxygen comes off for a few minutes. Others, particularly those who are receiving large amounts of oxygen may be more sensitive to the effects of stopping the oxygen and may start to cry or whimper if they are short of oxygen. As your baby gets better, this will become less and less of a problem.

Putting mitts on your baby at night might help to reduce the risk of the prongs being pulled out.

What is the best sleeping position for my baby?

As for all babies, sleeping on their back is best. The Foundation for the Study of Infant Deaths (FSID) produces free leaflets (available through the Bliss Family Support Service) on sleeping positions.

If you have not been given this information, it is strongly advised that you ask the SCBU staff or your health visitor. You will be advised if any other position is appropriate.

Can my baby sleep with me?

The safest place for your baby to sleep is in a cot in your room for the first six months. You should not share a bed with your baby if:

- Your baby was born premature
- You or your partner are smokers (no matter where or when you smoke)
- You have been drinking alcohol
- You take medication or drugs that make you drowsy
- You feel overly tired

Do not fall asleep with your baby on you if you are sitting in an armchair or sofa.

If your baby weighs less than 2.5kg the risk of cot death is significantly increased in these cases.

Can anyone babysit?

Life with a new baby, whether they are healthy or not, can be extremely tiring and taking a regular rest from looking after your baby can help you recharge.

Whoever looks after your baby when you do this will need to be trained and confident about what to do if there are any problems.

Respite care may be available in some parts of the country. This is care provided by health professionals to give parents a break. However, this is not always available and it may be useful if family or friends receive training to use home oxygen to enable them to babysit.



What about infections?

Premature babies are more vulnerable to infections than other babies so regular handwashing is essential. Babies on oxygen are particularly prone to chest infections and commonsense measures should be taken to avoid exposing them to other people's coughs and colds. This is not always possible if you have other children. Bear in mind that babies catch infections easily, so the less crowded a place is the lower the risk of infection. For more information please contact the Bliss Freephone Helpline for a copy of the booklet *Common Winter Illnesses*.

Reducing the risk of infection

- Washing hands frequently is vitally important in the fight against infections.
- Wash with warm soapy water and dry your hands well before handling your baby.
- Encourage others to do the same.

Respiratory illnesses

All respiratory viruses spread easily, so you should try, where possible, to avoid being with other babies, children and adults with respiratory infections. The Joint Committee on Vaccinations and Immunisations recommends that all babies with Chronic Lung Disease over six months old receive the flu vaccination.

If you know your child has been in contact with someone with a respiratory illness or, if he or she has an unusual cough or wheeze, see your family doctor as soon as you can.

Smoking

If there are smokers in your home, then it is important to know about certain aspects of caring for your baby on oxygen.

A baby on oxygen has fragile lungs and can become ill very rapidly. The biggest effect on your baby is being in a room in which people smoke, even if the baby is not there when someone is smoking.

When people who smoke come to visit, ask them to smoke outside the house. Most people will understand your reasons for this.

Will smoking increase the risk of cot death?

Smoking does increase the risk of cot death and the risk increase depends on the average daily exposure. For



every hour of the day that a baby is in a room where people routinely smoke, the risk of cot death increases by 100 per cent. For example, if the baby is exposed for two hours a day, the risk of cot death is doubled. If they are exposed for eight hours a day, the risk increases by eight times.

Can my baby sleep with me if I have been smoking?

The risk of cot death is significantly increased for babies who share a bed with a parent who smokes.

If you smoke, you are putting your baby at a greater risk of cot death if they sleep in your bed

Dangers of smoking

Smoking on or near to oxygen is extremely dangerous and the following points should be adhered to strictly: Your clothing and materials could become enriched with oxygen, whilst you are caring for your baby, this will burn vigorously if ignited. Your clothing may still be enriched with oxygen even after the oxygen supply has been turned off. Make sure you ventilate your clothing in the open air for at least 15 minutes before smoking or going near an open flame or source of ignition.

How do I bath my baby?

The unit staff will have shown you how to bath your baby. However, you can always ask your community nurse for advice. Remember, you may need to increase the oxygen a little to allow for the extra energy your baby will be using. You may find it easiest to use a baby bath with a slip mat. As you already know, your baby cannot regulate their temperature very easily and so it is best if the room is kept at a warm, stable temperature.

Try and have someone else with you if possible. Keep calm and don't panic if, to make life easier, you have to disconnect the oxygen temporarily during this time. As mentioned earlier, some babies are not comfortable with being disconnected.



Feeding

Feeding babies on oxygen is a common worry; this is not unusual. Oxygen dependent babies may have difficulties and it is important to know you are not alone.

It is common for premature babies to vomit. They may projectile vomit and throw their sick a long way. It is always helpful to use a large wipe clean floor mat when you are feeding them. This avoids having to wash any carpets or rugs.

Your baby may have feeding difficulties and he or she may feed little and often. They may only take an ounce or two per feed as often as every two hours and this is usual.

This can be upsetting and it is important to know that generally it will get better. If these problems continue and you are worried, ask for your baby to be seen by a dietician and/or speech and language therapist. They can help with feeding problems and can offer advice. Your baby's weight will be checked regularly. You will not be expected to assess his or her progress on your own.

However, you are the person who has most contact with your baby and it is

Throughout all of this, remember you have the right to ask the doctors and nurses about anything that's worrying you or anything that would make your life easier.

important to talk to your family doctor and health visitor to tell them how you are feeling about your baby's feeding and weight gain as they can arrange any additional support for you. Bliss also has a free booklet called *Weaning your premature baby* that you may find helpful. Call the Freephone Helpline for a copy.

Respite care

Some hospitals have information about training and local respite care services in your area, and you could ask about any local organisations or charities that may provide appropriate and suitably qualified babysitting services.

Follow-up appointments

Once your baby has left the unit, you will be asked to attend follow-up clinics for many aspects of your child's health and development. Before you go to any appointments, it is a good idea to write down any questions you have. This will help you to be in control once you get to the clinic and makes sure you ask everything you want to know.



Oxygen supplies and safety

Oxygen comes in three forms:

- Gas oxygen cylinders
- Liquid oxygen cylinders portable units
- Oxygen concentrators (oxygen concentrators will be installed for babies needing higher oxygen flow rates)

The oxygen company will supply you with the most suitable equipment to the prescription or *Home Oxygen Order Form* (HOOF) received. The technician fitting the equipment will give you comprehensive safety precautions and instruction on how to use the equipment supplied.



However, the Fire Service advises the following precautions for cylinders:

- Cylinders must be kept away from any heat source for example fires, radiators, hobs, ovens.
- If the cylinder is exposed to heat, the gas expands and this is a hazard.
- Cylinders should be stored in a cool place where possible. When in use, the cylinders should be kept in the shade.
- If there is a leak, turn off the cylinder and take it outside.
- Keep oil and grease away from connections as they may cause an explosion. If a connection is stuck, do not lubricate it. The cylinder should be returned and another used.

Your local Fire and Rescue Service offer a free home fire risk check. This is where a Fire Service team will come to your home to identify and help rescue potential fire risks and help you plan an escape route in case a fire breaks out; they may also install a free smoke alarm. You may find the phone number for your local fire and rescue service in your phone book or to find out more information on how to protect you and your home from fire go to www.direct.gov.uk/firekills

Oxygen suppliers

There is an oxygen provider for every region in the UK providing a one-stop-shop for oxygen cylinders, concentrators, portable oxygen equipment, low flow regulators and nasal cannulae (prongs). They will provide you with information packs, some training and support line telephone numbers. Hospital staff will advise you on your local supplier. Please see page 26 for contact details.

Oxygen prescriptions or HOOF prescriptions are needed for oxygen supplies and parts. Suppliers deliver Monday to Friday so there is no need to stock up on oxygen.

A designated health professional, who will most likely be your hospital consultant, will fill this in to reflect your baby's requirements and pass this on to your local supplier. The oxygen supplier will recommend the most suitable equipment for your baby and family life. This might vary across the country. Training for the use of the equipment will be given to you by the supplier. Parents can then order repeat supplies directly from the supplier.



Any changes in flow rate will require a new prescription.

Oxygen cylinder

Gas oxygen cylinders are made from extruded steel or aluminium and are usually black and white. Colours may vary by supplier but they will have a flat bottom for standing upright. Please check with individual Oxygen Company the maximum number of cylinders allowed for storage.

Discuss where you would like these to be situated with the technician installing the equipment for ease of use and to reduce the number of times these have to be moved about.

Portable oxygen cylinders

Portable oxygen cylinders are readily available but they must be ordered by your healthcare professional. Life can be quite isolating if your baby is on home oxygen. Having the portable oxygen will mean that you can leave the house and lead a more active life.

The time these cylinders last for depends on the amount of oxygen your baby needs. It is important to check the level of oxygen before you leave the house to ensure that you have enough for your outing. You will be advised by the oxygen supplier roughly how long the cylinder will last depending on the flow rate being given.

The oxygen is delivered through oxygen tubes linking the cylinder to the baby.

A flow meter attached to the head of the cylinder tells you the rate at which the oxygen is being delivered.

Oxygen concentrator

A concentrator can be installed in your home. The oxygen company will do this and they should talk with you about the best place to install it. This is usually a well-ventilated area to ensure a good circulation of fresh air. The oxygen tubing will then be piped,

inconspicuously, around the room with outlets in another room for ease. Lengths of tubing can then be attached to any of these points to allow movement in the house.

An oxygen concentrator



takes in air, removes the nitrogen and provides a high concentration of oxygen. This is then delivered through the oxygen tube to a flow meter and then through the oxygen tubes/nasal cannulae to your baby. The rest of the air is returned to the room.

Concentrators are generally less trouble to use than cylinders although they do make some noise. If you have a concentrator, you will also need a cylinder as a back-up in case of mechanical failure. All electricity used to power concentrators is reimbursed. All concentrators have a meter which is read every six months but a three monthly reimbursement can be arranged.

Liquid Oxygen (LOX)

Liquid oxygen comes supplied in a base unit containing on average 30 litres of liquid oxygen. Each litre of liquid, when turned into its gaseous form is equal to 860 litres of gaseous oxygen. Each base unit when full is the same as having 53 gas cylinders in your home at any time but all in a small space.

Liquid oxygen portable containers are lighter than most portable cylinders, and depending upon your baby's flow rate could last you all day.

The base unit can be used as the baby's main source of oxygen as flow can be regulated in the same increments as those on a cylinder, however it is recommended that 0.125 l/min is the lowest flow rate that should be used when using liquid oxygen. Unlike a concentrator, the base unit does not use electricity and is completely silent. The base unit does require refilling, but much like cylinders arrangements will be made by you and the oxygen supplier for the refills to be made

Cleaning the equipment

The oxygen company will advise you about the safest way to store and clean the oxygen equipment. The nurses will have shown you how to clean the oxygen tubes/nasal cannulae and you need to check these regularly throughout the day to ensure that there is a free flow of oxygen to your baby. If the nasal cannulae become blocked, you will need to replace them.

Your community nurse and oxygen supply company will ensure you have sufficient supply of these and other equipment needed. Remember to get spare parts.



Oxygen in the home and car

Do we need to adapt our house for the oxygen?

The Fire Service advises that there are no special alterations or adaptations that need to be made to enable your baby to come home on oxygen. There are no concerns about whether you have gas or electricity at home although it is essential to follow the safety precautions. Your supplier notifies the Fire Service and updates them monthly with the details of patients on oxygen

Your local SCBU recommend you inform your local fire station that you have oxygen at home. And also inform them when it's removed.

Who to notify that you are storing oxygen in the house

Gas and electricity suppliers

The electricity companies will be informed by your supplier that you are storing oxygen in the house so they can prioritise you when there is a power cut.

Car and household insurance

Your household and car insurers need to be told in writing that you are carrying and storing oxygen in the house and car as it may affect your claim if you do not tell the company. It is useful to have something in writing from them stating that they have noted on the policy that you have oxygen in the house or car. Most companies should not charge extra. If your company does, you may want to consider looking elsewhere.

If you are living in rented accommodation or Local Authority housing, advise the Housing Association, council or property owner that you will be having oxygen in the house. If you have any concerns about this, ask social services for assistance.

How will I carry the oxygen?

Oxygen companies usually provide carrier cases for portable equipment. When you are transporting the oxygen, it is essential that it is secured safely. This prevents tubes and fittings being dislodged during the journey. Your supplier will give you an information card for you to display when you are transporting oxygen by car. In the event of an accident hand this card to the emergency services.

Carrying concentrators in cars

Concentrators may be taken on short journeys if you are travelling within your suppliers region. Please ensure that this is kept upright and that the oxygen supply company is aware of you doing this. If it is outside your supplier's area you will need your clinician to prescribe a second prescription/ HOF stating dates to and from the address you are travelling to. You should allow two weeks' notice.



Prams and pushchairs

It may be a good idea to do some research about what kind of pram or pushchair would be good for you. You can ask your community nurse or the Bliss Family Support service for advice.

- Your pram will need to be sturdy with a tray or basket underneath.
- You cannot hang portable oxygen cylinders over the handles, as the weight of the portable cylinder will pull it over.
- As an alternative, you can carry the portable oxygen in your carrier case.
- You may need to wrap the cylinder securely in a towel to prevent damage to any of the connections.

Don't put anything else on the pram, like shopping or another child. It won't be able to carry the weight. Some parents advise using a double buggy of the kind where one baby seems to sit on top of another child. This gives a sturdy place for the oxygen to sit.



Going away

If you are travelling in the UK

Discuss with a clinician in advance to arrange a holiday HOOOF, inform them where you will be staying with the dates to and from. Before booking contact the holiday venue to check they allow oxygen on the premises.

It is a good idea to find out in advance where the local hospitals are, in case you need to go there. It may also be useful to take a letter from your family doctor or a copy of your medical discharge notes, explaining your baby's condition. Take all the telephone numbers of the health professionals who usually see your baby.

Take all the medication and prescriptions you need for the time that you are away and bear in mind that not all chemists will stock all medication.

If you are travelling abroad

Think carefully about this, because it can be very stressful and it may be better to delay the trip until your baby is off oxygen.

You must be aware that oxygen requirements will go up in an aeroplane and that you will need to contact your clinician as a fitness test may be necessary. You must ensure that you have enough time before the flight to arrange this. It is also important to note that many babies who have come off of oxygen in the last six months may also require a fitness to fly assessment. Please discuss all your needs with your clinician well in advance.

Your supplier can advise of the best way to arrange oxygen therapy whilst abroad by giving contact numbers and advising on the processes of getting oxygen abroad. However it is your responsibility to organise this, it is not covered by the NHS and you will have to pay privately. If your travel is within the European Union you may be able to claim a refund from the Department for Work and Pensions.



More information can be found on the NHS Choices website.

It can be difficult to arrange travel insurance. Advise the insurer or broker that your child is on oxygen so they can find you an appropriate policy. Some may exclude pre-existing health conditions, but not all insurance companies do, so it is worth checking more than one.

It's advisable to keep the oxygen plumbed in at home until your baby has been off for at least six months, however in winter you may want to wait until the flu and cold period is over. It is better to have it ready to hand but unused than worry about being able to get it quickly if needed.

Coming off oxygen

Babies are usually weaned off oxygen gradually, some advise to begin weaning in the daytime and then at night. The flow rate might be reduced first, prior to weaning onto air. Your baby's healthcare professionals will decide the best way to approach this.

Not surprisingly, this can be quite a difficult period as it can be very daunting to be away from oxygen at first and it is wise to be prepared for setbacks even at this stage. As parents, however, you are in a good position to judge how well your baby is doing off oxygen.

If you are concerned your baby is not coping well or the treatment is not appropriate, speak to a health professional and get a referral to your neonatal consultant.

Although this stage is something you will almost certainly have been longing for, it is quite natural to feel a little anxious about such a big change. By the time your baby is well enough to cope without oxygen, you will have become much more comfortable dealing with it. Remember, too, that oxygen is not likely to be withdrawn suddenly and you will have an opportunity to ask questions of your baby's doctor when the decision is made.





Available benefits

Please see the Bliss booklet *Financial advice for families* for more information.

A hospital social worker should talk to you about benefits that you may be entitled to. For example, as your baby is on oxygen, you may be able to claim Disability Living Allowance (DLA) once they have been discharged from hospital. Also, if you are looking after your baby for more than 35 hours a week and receiving DLA, you can apply for Carer's Allowance.

Telephone

It is essential to have a telephone at home. If you do not have a telephone which can be used in an emergency you should discuss this with the neonatal team before going home.

If you need to have the line repaired, your telephone company should be told it is a priority.

Blue Badge parking scheme

Recent changes to the Blue Badge scheme (disabled persons' parking) now mean that anyone with a child under the age of two needing to travel with bulky medical equipment can apply for a badge. Blue Badges can be obtained through your local authorities.

Remember you are still a family and it is important to share things and do things together.

- Arrange activities that all the family can take part in
- Don't keep problems to yourself, talk to each other or call the Bliss Helpline and talk to an advisor
- Be kind to yourself and your partner. it's important to eat healthy, regular meals and to get enough sleep.



Linnea's story, by her mum, Maria

Linnea was born at 24 weeks. It was such a shock and the whole experience was so alien to me.

She weighed 593 grams and they told us she had a 50 per cent chance to live. I didn't even know babies that young could survive.

She is two years old now and really just a normal child. We've seen her go through so much but she is a little fighter and she never complains. I take my inspiration from her.

She's had trouble with her vision (we're trying to persuade her to wear glasses right now) and an operation on her heart. But the main problem has been her lungs.

At birth she went on a ventilator and she needed that for eight weeks. Then she was able to go onto Continuous Positive Airway Pressure (CPAP). Three months after she was born, she came off the CPAP and just had oxygen. She was finally out of her incubator.

Linnea came home on oxygen and kept on it until ten months after she was born. We were pretty confident about using it, because the nurses had taught us everything while she was still on the unit. They were brilliant and always made sure we were involved in her care while she was in hospital. Because we were prepared, it didn't seem like such a bad thing. You just get on with it.

We always had three oxygen cylinders at home; one that she was using, one to change over to when the old one was finished, and a spare just in case. At first, I worried that Linnea would stop breathing if she pulled the tubes off, but it was fine. The amount of oxygen she needed went down quite quickly. It was tricky when she started eating solids because food kept getting in the tubes.

Worries like this would come up but we always had help and advice from the hospital nurses. They came to see us every week, until we had Linnea weaned off the oxygen altogether. It's comforting to have someone to talk to and important to get that support from the hospital and be able to ask questions – it was a lifeline for me and my husband Adrian.

One of the biggest difficulties was the way people would stare at Linnea when we went out. People can ask quite rude questions. Most people are nice, though. When you get to talking, you realise that a surprising number of people know a child who's been on oxygen – maybe even their own child. It's more common than you think. If this happens to you, my advice is to just go on about your business like you normally would. You shouldn't let it stop you going on holiday or whatever, as long as it's safe. That's how we coped with the whole experience.

Glossary

Apnoea monitor

A small monitor used to check the regularity of the baby's breathing with an alarm warning signal.

Chronic Lung Disease (CLD)

CLD is a common condition in very premature babies caused by inflammation of the lungs.

Cyanosis

Blue colouration of the lips, tongue, gums and also fingers and toes, particularly the nails.

Family care worker or community outreach worker

A person who supports the family when they are discharged from hospital.

Gastrostomy

A tube into the stomach that can be used for feeding.

Home Oxygen Order Form (HOOF)

Form used by health professionals to order oxygen and equipment.

Nasogastric tube (NG tube)

A tube passed down the nose into the stomach; it can be used for feeding.

Nasal cannulae (or nasal prongs)

Two fine hollow tubes about 1cm long for the introduction of oxygen to the baby through the nose. The oxygen runs from the oxygen cylinder or concentrator via oxygen tubes to cannulae in the baby's nose.

Oxygen cylinder

A cylinder used for storing oxygen.

Oxygen concentrator

A device that removes nitrogen from the air to provide a high concentration of oxygen.

Oxygen saturation levels

A measurement of the amount of oxygen being carried in the blood. It is usually shown as a percentage figure on an oxygen saturation monitor.

Oxygen saturation monitor

A monitor indicating the oxygen saturation levels in the blood.

Respiratory syncytial virus (RSV)

Also known as Bronchiolitis, this is a viral infection of the lungs that spreads very easily. Commonly causes breathing difficulties in young children over the winter months.

Special Care Baby Unit (SCBU)

Low dependency area of neonatal care.

More information and support

Useful organisations and groups

Regional oxygen suppliers

Air Liquide (Homecare) Ltd

North East England

† 0808 202 0999

www.uk.airliquide.com

South West England

† 0808 143 9999

www.uk.airliquide.com

South London, South East Coast,

South Central

† 0500 823773

www.uk.airliquide.com

Air Products

Yorkshire, East Midlands, West Midlands,
Wales.

† 0800 373580 (8-5pm)

www.airproducts.com/medical/uk

BOC Medical/Vitalair

Information about where to get oxygen
supplies when travelling abroad

† 0800 136603

www.vitalair.co.uk

References:

<http://www.nhs.uk/Conditions/home-oxygen/Pages/Introduction.aspx>

<http://www.nice.org.uk/guidance/index.jsp?action=download&o=38919>

[http://www.airproducts.co.uk/homecare/patients_
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[http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/
oxygen-therapy-administration-in-a-non-emergency-situation/](http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/oxygen-therapy-administration-in-a-non-emergency-situation/)

http://www.airproducts.co.uk/homecare/pdf/HOOF-2012_guidance.pdf

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or visit our parent messageboard
www.blissmessageboard.org.uk

To volunteer your time or to join our local
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**for babies born too soon,
too small, too sick**