

Home oxygen therapy for babies

Information for parents



the women's
the royal women's hospital

Why does my baby need home oxygen?

Sometimes babies need oxygen therapy to help make it easier for them to breathe.

Additional (supplemental) oxygen may be prescribed for conditions such as:

- Bronchopulmonary dysplasia (BPD) – a common condition in very premature babies
- Other lung conditions including pulmonary hypoplasia, pulmonary hypertension, etc.
- Congenital heart disease (from birth)
- Palliative care – for symptom relief.

Oxygen therapy can make a big difference to babies who need it. It reduces breathlessness and irritability which improves their sleep, making them less tired, more alert and engaged. It also improves their growth.

How much does it cost?

In most cases, supplemental oxygen therapy is provided to you at no cost. The hospital funds the oxygen your baby needs for the first month after their discharge home. After the first month, Victorian residents can apply to the Victorian State-wide Equipment Program (SWEP) to fund the oxygen supply. The Neonatal Intensive Care Unit (NICU) Care Managers will help you with your application.

What equipment do I need?

You will need an oxygen cylinder or an oxygen concentrator. We will give you nasal prongs and tapes to secure the tubing in place.

Oxygen concentrator

- Electrically powered machine that weighs about 21-26 kg and is about 70cm high. It is on wheels so you can move it around your house easily.
- It extracts oxygen from the air and delivers it to your baby at high concentrations, depending on the required flow rate and type of concentrator used.

- It does not run out of oxygen or need refilling. If there is a power failure, you will need to use a portable oxygen cylinder until the power is back on.

Oxygen cylinders

- Contain 100 percent compressed oxygen and are used:
 - for patients that don't need a constant supply of oxygen
 - as portable oxygen system for patients
 - as emergency backup supply for patients using an oxygen concentrator.
- You will also be supplied with:
 - a regulator
 - flow meter kit
 - carry bag and/or trolley.

Getting started

While in hospital

- Before your baby is discharged from the Royal Women's Hospital (RWH) their treating team will determine how much oxygen they require.
- You will have an appointment with the Respiratory Team from the Royal Children's Hospital (RCH) before discharge. This is so that they can introduce themselves, talk to you about the equipment your baby will need, and answer any questions you have about managing oxygen therapy at home.
- The RWH NICU will ask the oxygen supply company to contact you to arrange the delivery of the equipment to your home. You (or someone who can act on your behalf) will need to be at home when it is delivered. This is so that the oxygen supply company can set up the equipment and show you how to use it. They will also give you safety information and a list of who to call if you have any concerns with the oxygen equipment.

- When your baby is ready for discharge, you will be able to 'room in' with your baby in one of our parent rooms in the NICU. This is so you can gain confidence using your baby's oxygen therapy before going home.
- When it's time for your baby to be discharged from hospital, you will need to bring the portable oxygen cylinder supplied by the oxygen supply company for your baby to use for on the trip home.

At home

- In most cases your baby will be provided with one month's supply of oxygen. The oxygen supply company will deliver and exchange the equipment on a monthly basis.
- You can contact the oxygen supply company directly when you require a new order.
Note: they will need at least 24hrs notice before you place an order.
- Try to avoid deliveries on weekends or public holidays as this incurs an extra cost which is not covered by the hospital or SWEP.
- You will be given enough oxygen to last your baby for a month. If you notice your supplies are getting low before the next delivery is due, call the RCH Respiratory Nurse on (03) 9345 5795 as they may need to review your baby's order.
- Let your electricity and telephone providers know that your baby is on oxygen therapy at home and ask for a 'priority service listing'. This means your home will receive priority if there is a power or telephone failure/repairs.
- Prepare an emergency telephone number list to keep with each telephone, in your bag/purse and in your baby's travel bag (see example on page 4).

How to use oxygen safely at home

Oxygen is safe to use as long as it is used correctly. Oxygen will not explode, but it does support combustion (burning), which means that any material already burning will burn much faster and hotter in an oxygen-enriched atmosphere.

It is **very important** to follow all safety precautions explained to you by your oxygen supply company so that you and your family are safe when your baby is on oxygen therapy at home.

When your baby is using oxygen

DO:

- Position the prongs on your baby's face and secure with adhesive tape.
- Check the tubing to ensure it is not blocked, kinked, or twisted; clear and/or change the prongs if necessary.
- Check your baby's nostrils to make sure they are not blocked by mucous and clear them if needed.

DO NOT:

- Smoke or allow others to smoke near the oxygen equipment.
- Cook over an open flame with your baby in your arms.
- Let your baby go near fires, fireplaces, heaters, or open flames, including birthday candles or sparklers.
- Use aerosol sprays in the same room as the oxygen equipment.
- Use hair dryers in the room where oxygen is in use.
- Let your baby sleep on a bed with an electric blanket.
- Place cloth or fabric on top of cylinders or concentrators.
- Use vapour rub or petroleum jelly on your baby. Most babies have no problems with nasal prongs. If your baby has discomfort or drying of the lining of their nose, ask your local pharmacist for a lip/nose care product that is safe to use with oxygen.

Caring for equipment

Clean equipment operates more effectively and helps prevent infections.

Make sure you:

- always wash your hands before cleaning or handling your baby's equipment
- wash the nasal prongs weekly (or more often if needed) in warm, soapy water, rinse well and allow to air dry
- do not repair broken equipment yourself. If you have any problems with the equipment, contact your oxygen supply company
- that when in the car, the safest way to transport a cylinder (or concentrator if you have one) is to keep it upright either on the floor of your car, or on the backseat restrained by a seatbelt.

Note: Concentrators must be always kept upright. Lying it flat in the boot of a car can damage the machine.

The oxygen supply company will give you more information about your baby's equipment.

How to safely store equipment

- Keep the equipment out of reach of children and pets.
- Do not store oxygen cylinders in the car boot or hot places.
- Make sure all valves are turned off when the oxygen is not in use.
- Always have a functioning smoke detector and fire extinguisher in your home.

Will my baby be on a saturation monitor at home?

Babies going home on oxygen do not routinely have an oxygen saturation monitor but sometimes it may be recommended. If your baby needs a saturation monitor the RCH Respiratory team will discuss this with you.

How do I know if my baby is getting enough oxygen?

Babies that are responding well to oxygen therapy should:

- show a good activity level
- be happy and alert
- have a good appetite, with expected weight gains
- breathe calmly
- sleep well.

Sometimes babies need extra oxygen after periods of activity, when they have a cold/respiratory infection, or when they travel to high altitudes.

If you are concerned that your baby is experiencing any respiratory difficulty, check for these symptoms:

- Breathing faster than usual
- Widening of the nostrils while breathing (nasal flaring)
- They are making a grunting noise
- Retractions (chest pulling in)
- Clammy or sweaty skin

- Stopping to rest more frequently while feeding or pulling away from breast/bottle
- Irritability and inability to sleep
- Sleepiness or limpness
- Duskiness, pale or greyish skin colour, or blueish around the lips, gums, or eyes.

Babies with BPD are more prone to respiratory infections. If possible, avoid confined areas, close contact with people who have a cold or who are smoking. If your baby does develop a respiratory infection, it is possible they will need additional oxygen and hospital treatment.

If you are worried your baby is not getting enough oxygen, is having difficulty breathing or is seriously ill, dial '000' for further assistance.

Our bodies are unable to store oxygen therefore, oxygen therapy only works when it is being delivered correctly. If the oxygen prongs are removed or the oxygen is turned off, the blood oxygen levels within your baby's body may drop to below normal limits.

What do I do if my baby is having problems?

To check the equipment is working properly, ask yourself the following questions:

- Is the cylinder/concentrator turned on?
- Do the gauges indicate there is enough oxygen in the cylinder?
- Is the flow rate correct?
- Is the tubing connected?
- Is the tubing kinked?
- Are the nasal prongs clogged with mucus?
 - If you are not sure, hold the tubing up to your face or hand to feel for the oxygen flowing from the end of the tubing.
 - If you are still not sure, place the end of the tubing into a bowl of water and look for bubbles; if there are bubbles the oxygen is flowing.
 - If the nasal tubing is clogged, change the tubing, or clean it with a damp cloth/cotton bud stick (do not use baby wipes as these are often alcohol-based).

If the oxygen is flowing correctly through the prongs, slowly increase the flow of oxygen to the level recommended by your baby's doctor.

If you are still concerned seek medical assistance by calling your doctor or take your baby to your local emergency department.

Can our family still have holidays?

In most cases oxygen can be arranged for domestic and international travel, however there may be additional oxygen costs. It's important to plan well in advance when booking your holiday. Contact the RCH Respiratory Nurse or your Respiratory Doctor as soon as possible before you intend to travel (ideally a month in advance) for advice on how to arrange and manage oxygen therapy while on holiday.

When can my baby stop using oxygen therapy?

- Your baby's progress will be monitored every 4 to 6 weeks at the RCH Respiratory Clinic. If you need to book or change your appointment time, contact the RCH Specialist Clinics on telephone (03) 9345 6180 or email clinics@rch.org.au
- Before your baby's appointment with the Respiratory Doctor your baby will have an air/oxygen test. This is a simple test where an oxygen saturation probe is attached to your baby's foot or hand to measure their oxygen levels while their oxygen supply is carefully lowered. The results are then given to your baby's Respiratory Doctor to help them decide if/when your baby can reduce or stop oxygen therapy.
- It is important not to take your baby off oxygen therapy unless their Respiratory Doctor decides your baby is ready.

Who can I contact for help and support?

Financial and medical assistance is available for families with babies on oxygen therapy:

Financial assistance

- **Electricity concession**
The Life Support Concession is a state government concession that is applied on each electricity bill. Speak to your electricity provider and hospital social worker for more information.
- **Centrelink**
You may be eligible for a *Carer Allowance*. This is not income or asset tested. Your baby may also be eligible for an *Essential Medical Equipment Payment* from Centrelink as well as any state and territory government scheme. If you have any questions about these payments talk to either the hospital Social Worker or NICU Care Manager before discharge.

Medical assistance

Emergency telephone number list

1. In an emergency telephone '000'
2. Your local hospital

3. Your baby's doctor

4. Home oxygen supply company and your baby's account number

5. Hospital in the Home Team (HITH) at the Women's

6. Royal Children's Hospital Respiratory Nurse (call between 9am-5pm Monday to Friday)
 - Direct telephone: (03) 9345 5795
 - RCH switchboard telephone: (03) 9345 5522 (ask to page the Respiratory Nurse)
 - If a non-emergency medical problem develops out-of-hours, please telephone RCH switchboard on (03) 9345 5522 and ask to speak to the Respiratory Doctor on call.