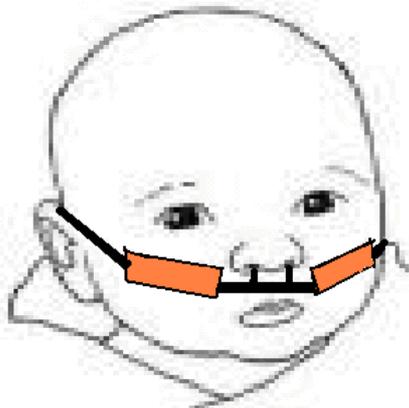


INFANTS ON HOME OXYGEN

Babies mature before birth, but their organs develop at different rates. The lungs are one of the last organs to develop, so are the commonest area to be under-developed when babies are born prematurely. Some infants will be dependant on oxygen for some months while growing and developing. These infants are otherwise well, and no longer require hospital care and may be cared for at home while receiving oxygen therapy.



fact sheet

How is oxygen given at home?

Oxygen is usually given to the infant via soft plastic nasal prongs that are placed in the infants nose and secured to the infant's cheeks. These prongs are connected to oxygen tubing, which is attached to an oxygen cylinder. You will be instructed in positioning and taping of this tubing prior to discharge from hospital.

What equipment is required?

Oxygen tubing and nasal prongs

An extra long length of green oxygen tubing will be provided by the oxygen supply company. This tubing will allow you to move your baby freely about your home, without having to move the large cylinder. Nasal prongs to fit your infant will be supplied by Neonatal and Parents Support Service (NAPSS) and the oxygen supply company.

Oxygen cylinders (delivered by oxygen supply company)

- One large E cylinder, trolley, and dual gauge regulator with low flow unit.
- Two smaller C cylinders. You will need these to enable you to travel home from hospital and to allow you to take your baby out and about. One cylinder is kept as a spare. The cylinder in use needs a dual gauge regulator and a low flow unit. A carry bag will be supplied
- Oxygen Compressor – this may be needed if your infant is on 0.5 Litre or more of oxygen per minute at the time of discharge.

Oxygen cylinders

Size of Cylinder	Flow rate in Litres per minute (L/min)				
	1/2 (0.5)	1/4 (0.25)	1/8 (0.125)	1/16 (0.06)	1/32 (0.03)
"E" Cylinder (3,800 L)	126.5 hours	253 hours	506 hours	1012 hours	2024 hours
	5.2 days	10.5 days	21 days	42 days	84 days
"C" cylinder (440 L)	14.5 hours	29 hours	58 hours	116 hours	232 hours
	-	-	2.2 days	4.5 days	9 days

Note – this is an approximate guide only

Who supplies the equipment?

NAPSS will arrange for the oxygen to be supplied at home. It takes about 48 hours for the oxygen order and supply to be arranged. We will also supply you with duoderm (soft skin adhesive tape) and tape to keep the prongs on and several pairs of oxygen prongs to take home. The oxygen supplier is dependent on where you live (ACT or NSW) and we will give you written information about supply in your oxygen information kit.

Once your baby is home and you need to order further supplies you need to ring your oxygen supply company yourself.

- If a cylinder is less than 1/4 full then it should be refilled.
- Please give 24 hours notice when ordering more cylinders.
- These companies deliver in the ACT/Queanbeyan region Monday to Friday; alternatively you may collect the cylinders yourself.
- Please ensure you have oxygen for the weekends and public holidays.

How much will it cost?

Costs also vary depending on where you live (ACT or NSW) – this is also explained fully in a leaflet in your oxygen information kit.

Before your baby is discharged you should apply for the Carers Allowance from the Department of Social Services (DSS). The social worker or NAPSS staff can help you fill in the form, which is available from the social worker. If you live in NSW you will complete a Home Oxygen Program (HOP) form. The cost of home oxygen is means tested. The information that you give on the HOP form will be used to offset the cost of home oxygen.

Travelling with oxygen

Oxygen cylinders may be used on commercial flights, we recommend checking with your airline when booking. A letter from your baby's doctor will be needed, stating that the baby is stable to travel.

Home oxygen supply companies can arrange for home oxygen to be delivered to an interstate address for temporary use.

Setting up oxygen therapy at home

- Your oxygen supply company should show you how to change the regulators on the oxygen cylinders and how to read the gauges.
- Gauge one measures the amount of oxygen delivered to your baby in litres. Gauge two measures the amount of oxygen in the cylinder.
- The oxygen tubing is attached to the 'E' cylinder and the nasal prongs are attached to the oxygen tubing using a plastic connector.
- Ensure that the tubing is not kinked or blocked.
- Turn the cylinder on and then turn the oxygen on to the appropriate rate.
- Check the oxygen flow.

What happens when my baby comes home?

In the ACT and Queanbeyan, the NAPSS team visits babies on home oxygen therapy regularly. On the spot saturation monitoring is attended during these visits to assess if your baby is saturating well and does not need any changes to be made in his/her oxygen therapy. An overnight download is attended approximately 2-4 weekly – this entails leaving a monitor with you overnight to assess the baby's saturation over six to eight hours while he/she is asleep. This information will be discussed with your baby's paediatrician and any necessary changes to your baby's oxygen therapy will be made. In rural NSW your paediatrician will arrange for appropriate monitoring to be attended, if possible at your local hospital.

You can also apply for a Disabled Parking Permit, which you will find useful when taking the baby and oxygen out in the car.

Changing the Oxygen Prongs

Prongs need to be replaced weekly or at times when there is a build up of secretions around the opening of the prongs.

If the prongs are not due to be changed but the tapes have become loose, re-apply the duoderm and leucoplast as required. It is often easier to have two people present when changing the prongs or retaping.

Equipment

Duoderm, leucoplast, no sting barrier wipe, oxygen prongs, scissors

- Wash your hands
- Wrap your baby and place them on a firm surface. One person should ensure that your baby does not get their arms out while the prongs are being changed
- Cut the duoderm to fit along each cheek (about 6 cm long and 2.5 cm wide)
- Cut leucoplast tape slightly smaller than the duoderm. In each of the leucoplast tape, make a small cut into each end in the middle of the tape
- With the no sting barrier wipe remove the old tape and duoderm
- Once the old tape is removed, take out the old prongs and position the new prongs onto your baby's face
- Remember to connect the new prongs quickly to the oxygen supply
- Apply the duoderm to your baby's cheeks
- Position the prongs over the duoderm and apply the leucoplast tape
- Cuddle and comfort your baby once finished

What to look for at home

- Check the equipment each day to ensure that it is functioning well and that there is adequate oxygen. Check that the flow rate is correct.
- Watch your baby's breathing. Become familiar with how fast he/she breathes and the amount of effort used for breathing.
- Monitor your baby's colour, recognise if/when baby becomes dusky and for how long.

Flaring of nostrils, increased recession or unusual breathing noises means that your baby is making more effort than normal to breath. If your baby is doing any of these please phone your baby's paediatrician or NAPSS, or Emergency Department Canberra Hospital or 000.

- Nasal discharge (especially green) indicates a respiratory infection and you will need to consult your General Practitioner (GP).

What to do if you are worried

- If it is dark, turn on the lights and check your baby's breathing and colour.
- Check that there is oxygen in the cylinder and that the flow rate is correct. Check the prongs for blockages and the tubing for kinks.
- In an emergency, if your baby is finding it difficult to breathe or not responding to stimulation then call an ambulance. The emergency number is 000.

Safety Issues

- No smoking or lighting matches in the room.
- No open fires, oily rags, mechanical toys, electrical appliances with exposed wires (including heaters).
- E' cylinder is usually best located centrally in your home. It needs to be in a secure area, out of the way of toddlers and young children.No compressors to be operated within a radius of 3 metres of where the oxygen is running.
- Cylinder(s) need to be secured in the car.
- Signs for the front door indicating that oxygen is being used in the house. (The oxygen supply company usually supplies these).

Telephone and Electricity Company Notification

You should complete a Telstra Priority Assistance form, which is available from your telstra office. This ensures that if there is a fault with the telephone, that you will receive priority service.

If your baby requires 0.5L/min or more of home oxygen, then you may require an oxygen compressor which will be organised through the home oxygen company. The compressor requires electricity supply in order to work. If you are required to use a compressor it is advisable to contact your electricity supplier eg AGL, to complete the required forms to ensure that if a power failure occurs you would receive priority service and or be provided with an alternate power source

From one "HOT Family" to Another

These are some practical suggestions that have been provided by families to help support families that are about to take their baby home on Home Oxygen Therapy (HOT).

Clothing

- Front fastening grow suits.
- T-shirts, which button along the shoulder, so they can be put on from the bottom up.

- When your baby starts to roll and move around, thread the tubing down inside the clothing and out the legs.

Going Out

- Restrict outings to limit exposure to infections.
- Be organised, take spare tapes and tubing just in case.
- Try to have the oxygen cylinder on the left hand side of the car so that when you parallel park, you can put the baby and the cylinder straight in the pram.
- Carry the baby in a pouch and the oxygen bottle over the shoulder.
- A backpack for the smaller bottle makes movement easier.
- On cold days put a clear plastic cover right over the pram so that the baby is not taking in big breaths of cold air.
- When curious people ask about tapes and tubing, and you don't want to get into detailed explanation, just tell them the baby has asthma. People seem to accept this more easily.

Prams

- I used a pram with a metal carry basket underneath.
- I bought a pram that had a detachable carry basket.
- My baby slept in his big pram for the first few months; it was easier to take him around the house with the small oxygen bottle stored in the tray underneath.

Handling Home Oxygen and Cylinders

- Find a place to put the cylinder so that you are accessible to as much of the house that you can by having 10 metres of tubing.
- If you have a two-storey house keep the large cylinder upstairs besides the cot for night sleeping and use the smaller bottle during the day.
- Establish a regular checking system and check the tubing and gauges last thing at night and first thing in the morning.

Looking After Yourself

- While it is important to keep the environment safe for your baby, you need to be looked after too. Make sure you get a break, locking yourself away for months may not be in your best interest.
- The love and support of my family and friends was my biggest asset. They did the shopping and housework and were just there.

Children

- Parents have initial fears about other children playing with tubing etc.
- Children are like sponges, keep them informed and explain what is happening. Siblings can be very useful, advising visitors of the 'rules', keeping tubing out of the way and untangling tubing.
- Explain to the children in your family down and explain how children 'carry' germs, where germs come from and how school, kindy etc is a great place for a germ to meet them! Discuss hygiene and the importance of washing hands.
- Sit the children in your extended family down and explain why it will be some time before they can visit and play with the baby.
- If you are uncomfortable having other children (non-siblings) around your baby, organise them to see the baby through the window and then offer them a reward (like a sticker) for their patience and understanding.

Support Services

If you have any concerns or problems with oxygen delivery contact your oxygen supply company. Their phone number will be given to you at your baby's discharge from hospital

- NAPSS will visit you at home if you live in the Canberra and Queanbeyan region. They will monitor your baby's oxygen saturations and arrange for a 'download' of sats to be done on a regular basis. They will discuss feeding and weigh your baby.
- If your baby requires long-term oxygen therapy at home then NAPSS will organise for your local Maternal and Child Health Nurse/Early Childhood Nurse to visit you at home as well.

Tapes and Tubing

- Changing tapes and tubing was easier after we had bathed our baby, he seemed calmer and therefore it was easier to manage.
- I stuck kids 'glow in the dark' stickers at different points of the oxygen tubing so I could see it at night as she slept in my room. It also made the tubing on the floor more visible in the day.
- To prevent yanking my child's head off when the tubing became caught on something as I was walking or if someone trips on the tubing, I wrapped some tape around the tubing behind my baby's head at about shoulder level leaving a piece sticking out like a 'tab' and I safety pinned the tape to his clothing.
- Take good care of baby's skin where the tubing and adhesive tapes are applied to avoid possible scarring. If one tape seems to cause a reaction to the skin try a different type.
- Changing tapes and tubing is easier if there are two of you. One can distract and amuse the baby and assist with passing the bits 'n' pieces while the other does the job.

Travelling

- A friend made a bracket, which bolted to the floor of the car to hold the cylinder.
- We used seat belt webbing to strap the bottle under the front seat of the car.
- We travelled by plane while the baby was on oxygen. It caused a few problems with the airline. But with medical statements from the paediatrician it was survivable.

Visitors

- Restrict visitors to ensure a safe environment.
- Many visitors don't understand how vulnerable these babies are.
- We put oxygen in use signs at the front door so that they were clearly visible to warn any smokers.
- Tell visitors not to come if they are at all unwell, runny noses etc. Most people are great when you explain in advance why you are so concerned.