

Chronic Neonatal Lung Disease

A Guide for Parents





Thank you to all the parents who gave permission for their babies to be featured in this leaflet



Tiny Toes is a charity which supports the work of the Neonatal Intensive Care Unit and Special Care Baby Unit at East Kent Hospitals University NHS Foundation Trust

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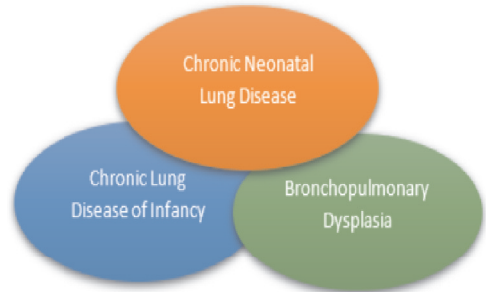
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What is CNLD?

Chronic Neonatal Lung Disease is a term used to define persistent breathing difficulties in babies. Babies are said to have CNLD when they still need extra oxygen at 36 weeks gestational age (one month before their due date).

CNLD is sometimes called Bronchopulmonary Dysplasia (BPD) or Chronic Lung Disease of Infancy (CLDI) - so it can get a little confusing! But they all refer to the same condition.



What causes CNLD?

Chronic Neonatal Lung Disease most commonly occurs in premature babies, whose lungs are under-developed and fragile and usually struggle to open up properly after birth. This leads to an inadequate supply of oxygen reaching the baby's lungs and they may need extra help and support with breathing.

Two important strategies that can help in the early days

- Your baby may be prescribed a special medication called **surfactant**, which is given directly into their lungs to reduce lung stiffness.
- A breathing machine, or **ventilator**, may also help. The ventilator uses appropriate pressure to open up the lungs and makes sure oxygen is delivered.

Your baby and CNLD

As your baby's lungs are very immature they may need the support of the breathing machine (ventilator) for a period of time. The pressures used by the ventilator to keep their lungs open may cause inflammation and some damage in the lungs, making them temporarily less efficient at getting oxygen.



The lungs will eventually grow and your baby will not need the support of the ventilator any more. However, they may still continue to need some extra oxygen to help them compensate for their lung injury. This oxygen is then delivered via other methods such as Continuous Positive Airway Pressure (CPAP), high flow or low flow oxygen through nasal prongs or mask.



Babies with CNLD use a lot of energy breathing and may need more high calorie feeds. Although breastfeeding is best for your baby sometimes if there is growth or feeding concerns, babies may go home with a feeding tube (a nasogastric tube, or NGT) that goes through their nose in to their stomach. Specialist nurses will support you if this happens.

Oxygen will continue to be given to support your baby until their lungs have matured enough to breathe on their own all the time. Most babies will be able to come off oxygen completely by their first birthday.

Home Oxygen

Once your baby is healthy enough, you and your doctor may decide if it is safe for your baby to go home 'on oxygen'. Specialist nurses and doctors will support you with this. It is important to remember, the oxygen is only a support to allow your baby to develop and grow - your child will not suddenly collapse if the oxygen is taken away.

What will happen next?

The healthcare professionals in charge of your baby will prescribe the oxygen levels your child needs. For safety reasons, this may be a slightly higher amount of oxygen than your baby needed in hospital. As parents, you will be trained on how to use home oxygen before going home and hospital staff will help you with this training and organise fitting of necessary equipment at your home.



A healthcare professional will visit your home at an agreed time soon after you and your baby have gone home. Further visits by community nurses will be arranged (usually weekly but they can attend more regularly if clinically needed) to check up on your baby and answer any questions you may have.

Usually, babies with CNLD will stay on home oxygen for the first three months until they see the consultant in the specialist Home Oxygen Clinic. The consultant will assess whether or not the amount of oxygen therapy should remain the same or can be reduced. To learn more about the decision-making surrounding your child's oxygen please refer to the **timeline** section of this leaflet.

What equipment will I receive?

Nasal Cannula



Oxygen Cylinder



Oxygen Concentrator



Oxygen Cylinder Bag



Practical Tips

- **Nasal cannula:** this will allow a low flow of oxygen to reach your baby's lungs. You should change the nasal cannula weekly (or if clogged up) and clean it daily with a warm soapy cloth or disinfectant wipe but avoid fully covering it in water. The nasal cannula may irritate your child's nose and skin and you will be shown a water-based moisturiser gel that can relieve this.

- **Home oxygen cylinders:** you will receive two home oxygen cylinders (one is a reserve). If you notice a fault in a cylinder, switch to your back-up supply and immediately contact your oxygen suppliers. Try to keep these cylinders upright and avoid them getting damaged.
- **Going out with my baby on oxygen.** Feel free to take your baby outside, even though they are on oxygen. The safest way to do this is with the **oxygen cylinder carrier bag**. This makes sure the cylinder is protected and stays clean. You can carry the bag on your back or place it in the shopping compartment of your buggy. Please do not balance the cylinder on top of your baby's buggy or place it next to your child. Make sure that you have enough oxygen in the cylinder before leaving your house - most oxygen cylinders last for four hours, but you can check with the oxygen company if needed.
- **Play and social interaction.** Your baby should still be allowed to play whilst on oxygen. However, there are a few safety measures to be aware of when your baby is playing. The oxygen cylinder in use should be secured to stop it falling over and the nasal cannula tubing should be long enough to allow your child to play freely, but it should not become kinked, blocked, or cause a trip hazard.

Having a child less than two years old with bulky medical equipment means you qualify for a **blue badge** from your local authority - contact them to arrange this.

Do not allow smoking or naked flames in the same room where your baby is receiving oxygen, or where the oxygen cylinder is stored.

Frequently asked questions

How is home oxygen fitted at home?

In Kent, home oxygen therapy is provided through the company Dolby Vivisol.

They will:

- deliver and install the suitable equipment for your baby
- undertake necessary safety checks; and
- explain how to use the equipment.



You will need to:

- remember to check the oxygen levels; and
- when you are close to running out of oxygen, call Dolby Vivisol.

If at any point there is a fault with the equipment, uncertainty on how to use it, or you need more oxygen contact them on **0800 917 9840**.

How to recognise if your oxygen cylinder is not working

If you suspect that your oxygen cylinder is not working, place the end of the oxygen tubing into a glass of clean water. If a stream of bubbles appears then the oxygen is coming through. If there are no bubbles then it is possible that there is a fault and the oxygen is not flowing as it should.

If you are still uncertain then you should contact Dolby Vivisol and they can advise you further.

Respiratory Syncytial Virus prevention

Babies with CNLD are at a slightly higher risk of getting a common chest infection called bronchiolitis in winter months, especially one caused by a virus called RSV (Respiratory Syncytial Virus). There is a medicine (called **Palivizumab**) that helps reduce the risk of your baby getting this infection.

Palivizumab is an injection given monthly in winter, which gives your baby extra infection-fighting antibodies. The community nurses in charge of your baby's care will check whether your baby is eligible for this medicine and organise (usually when your baby is ready to go home).

Everyone in your baby's immediate family is entitled to the annual flu/influenza vaccine as well - talk to your GP to arrange this.

What to do if your baby is unwell

If your baby seems unwell, firstly make sure all tubes are connected and nothing is blocked. Then check the oxygen supply in the cylinder.

Signs to look for, when your baby is unwell

- **Increase in breathing rate**
- **Increase in heart rate**
- **Colour changes:** blue around the mouth, lips, or fingernails, looking pale/grey
- **Grunting**
- **Nasal flaring**
- **Use of other muscles to breathe (recession).** Chest sucks in below neck or rib-cage
- **Changes in alertness**

Call 999 immediately if you feel your baby is seriously ill or getting worse quickly

In a non-emergency situation, call your community nurse team

- Weekdays 8am to 8pm: **0300 790 0294**
- Weekend/out of hours: **01227 766877** and ask to page the community children's nursing team. They will be able to advise you on what to do next.

You will have open access to Padua Ward at the William Harvey Hospital. If your baby is unwell you must call Padua Ward on **01233 616296** and tell them that you are coming in, and you can go straight to the ward rather than going through Accident and Emergency (A&E).

Local emergency departments with paediatric facilities

William Harvey Hospital
Kennington Road,
Willesborough,
TN24 0LZ



Queen Elizabeth
The Queen Mother Hospital
St Peter's Road,
Margate, CT9 4AN



Your baby is born!

CONGRATULATIONS

You have a beautiful baby! But the doctor has told you that your baby has some difficulty breathing, and requires oxygen.

Baby goes to NICU

He/she will likely go to the NICU (Neonatal Intensive Care Unit). Here the staff are specially trained to care for babies that need extra support. Your baby may stay here for days, weeks, or even months until they are ready to go home.

Meet the community nurses

Parent competencies



Before your baby is discharged, the community nurses may come to the ward to meet you. These nurses will be caring for you and your baby when you go home

Looks like your baby is nearly ready to go home!

The team must ensure you can do the necessary tasks to meet your baby's extra needs. This includes training you on how to use oxygen at home and resuscitation



GOING HOME



Your baby is ready to come home!

Don't worry, the oxygen company will install all the equipment the day before you go home, and the community nurses will visit you within 24 hours to make sure everything is ok

Home

Nurse Visits

The specialist community nurses visit weekly - but if needed they can come more often. They will assess your baby to make sure he/she is healthy.



Home oxygen clinic

Your baby will stay on oxygen for at least 3 months. He/she will be assessed in the home oxygen clinic by a specialist doctor, who will decide if your baby should stay on the same amount of oxygen, or start to be weaned off it. All babies are different, but most are weaned off oxygen by 1 year gestational age.



Your baby will also have neurodevelopmental follow up clinics until 2 years of age.

Weaning

The weaning will be done slowly, guided by your community nurse - who will continue to monitor your baby regularly. Your baby will be tried off oxygen for greater and greater amounts of time, starting with half an hour a day, moving up until he/she is off oxygen all day, and eventually the night as well. The nurses are experts and will guide you all the way.



Whichever stage of this process you are at, you should be proud of yourself. It is not easy being a parent to a baby with CNLD, but the doctors, nurses, healthcare assistants, and many others are here to support you, and you are doing a great job to get this far!

Important numbers and links for more information

In an emergency: 999

- Community nurses 8am to 8pm: **0300 790 0294**
- Out of hours/weekend: **01227 766877** and ask to page the community children's nursing team
- Padua Ward: **01233 616296**

Dolby Vivisol

- Website: www.dolbyvivisol.com
- Freephone support: **0800 917 9840**

Bliss

Bliss is a charity dedicated to supporting premature babies and their families.

- Website: www.bliss.org.uk
- Free phone helpline: **0500 618140**
- Email support service: hello@bliss.org.uk

One You Kent Smoke Free Service

For free and friendly help with quitting smoking.

- Phone: **0300 123 1220**
- Text: **QUIT to 87023**
- Email support: oneyou.kent@nhs.net

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This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 or 01227 864314, or email ekh-tr.pals@nhs.net

Further patient leaflets are available via the East Kent Hospitals website www.ekhufft.nhs.uk/patientinformation