



Chronic Neonatal Lung Disease (CNLD)

A guide for parents

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What is CNLD?

Chronic Neonatal Lung Disease (CNLD) is a term used for persistent breathing difficulties in babies. Babies 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).

It can get a little confusing. But they all refer to the same condition.

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 baby's lungs. 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**. This medication is given directly into your baby's lungs to reduce lung stiffness.
- **A breathing machine**, or ventilator, may also help. The ventilator uses pressure to open up your baby's lungs and delivers oxygen.

CNLD and its effects on your baby

As your baby was born premature, their lungs are very immature. They may need the support of a breathing machine (ventilator) for a period of time. The pressures used by the ventilator to keep your baby's lungs open may cause inflammation in their lungs. This will make your baby less able to breathe in oxygen.

Their lungs will eventually grow and your baby will no longer need the support of the ventilator. However, they may still need some extra oxygen to help them compensate for their lung injury. This extra oxygen is given to them via other less invasive methods, such as:

- Continuous Positive Airway Pressure (CPAP); or
- high or low flow oxygen through nasal prongs or a mask.

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

Oxygen will be used 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 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 that the oxygen

is only a support to allow your baby to develop and grow.

Before leaving hospital your baby will undergo an Air Challenge and a Car Seat Challenge. These tests will make sure your baby remains safe.

- During the **Air Challenge** test, the oxygen supply is disconnected for a maximum of 30 minutes. During this time we will test your baby's response to the lack of oxygen. We need to know this for the rare times that cylinders run out or get disconnected. The nursing team will check your baby throughout the test, to make sure baby's oxygen levels do not drop to unsafe levels.

Failure to pass the Air Challenge does not delay or stop your baby's discharge from hospital. However, further advice about safety will be given by your nursing team.

- All infants on home oxygen should undergo a **Car Seat Challenge** before leaving hospital.

What will happen next?

Discharge planning meeting

Before leaving hospital, you will be part of a discharge planning meeting. This meeting could include:

- Relevant professionals from the multi-disciplinary team (MDT)
- Parents / carers and / or family members
- The nurse looking after your baby
- A senior medical team member (registrar / consultant)
- A Community Children's Nurse (CCN)
- Your health visitor (if available)
- Your GP (if applicable)
- A social worker (if applicable).

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

A member of the Community Children's Nursing team will visit your home. This will be at an agreed time, which is usually within a week of you and your baby leaving hospital, preferably within the first 48 hours. After this visit, arrangements should be made for review / saturation checks with community teams. Any visits will be arranged and agreed with parents.

Further visits by community nurses will be arranged to check-up on your baby. Use these visits to ask any questions you may have. These visits are usually weekly, but the nurses can visit more regularly if clinically needed.

Usually, babies with CNLD will stay on home oxygen for the first 3 months. This is until they see the consultant in the specialist Home Oxygen Clinic. The consultant will assess whether the amount of oxygen therapy should remain the same or be reduced.

Baby is weaned off home oxygen depending on the following conditions

- Is your baby clinically well? Baby is in no significant respiratory distress. There has been no recurrent wheeze or infections.
- Has baby grown enough? Is baby getting enough nutrition? For example, is your baby following their centile charts and meeting their targeted weight.
- Are your baby's vital signs stable? These include heart rate, respiratory rate, work of breathing, and stable oxygen saturation.
- Has your baby been admitted to hospital? If so, how many times? Preferably none within the last month.

If home oxygen supplementation has not been reduced after 1 year, your baby should be referred to a respiratory / ENT specialist in London. This is so any related conditions can be ruled out. In some cases, a local paediatrician with respiratory interest can be contacted. They can give further advice and management.

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 be given?

Practical tips

- **Nasal cannula:** this will allow a low flow of oxygen to reach your baby's lungs.
 - Change the nasal cannula weekly (or if clogged-up).
 - Clean the cannula daily with a warm soapy cloth or disinfectant wipe. Do not fully cover the nasal cannula in water.
 - The nasal cannula may irritate your child's nose and skin. You will be shown a water-based moisturiser gel that can help with this.
- **Home oxygen cylinders**
 - You will be given two home oxygen cylinders (one is a reserve).
 - If you notice a fault in a cylinder, switch to your back-up supply. Contact your oxygen supplier immediately.
 - Try to keep the cylinders upright. 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 bag protects the cylinder and keeps it clean.
 - Carry the bag on your back or place it in the shopping compartment of your buggy. 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 can still play whilst on oxygen. However, there are a few safety measures to be aware of when your baby is playing.
 - Secure the oxygen cylinder you are using, to stop it falling over.
 - Make sure the nasal cannula tubing is long enough to allow your child to play freely. The tubing 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 equipment for your baby
- do necessary safety checks, and
- explain how to use the equipment.

You will need to remember to check the oxygen levels. When you are close to running out of oxygen, call Dolby Vivisol.

Contact Dolby Vivisol on 0800 917 9840 if at any point:

- there is a problem with the equipment
- you are not sure how to use it, or
- you need more oxygen.

- **How can I check if my oxygen cylinder is working correctly?**

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 oxygen is coming through. If there are no bubbles there may be a fault and the oxygen is not flowing as it should.

If you are still uncertain, contact Dolby Vivisol on 0800 917 9840 and they can advise you further.

- **Returning home oxygen equipment**

Once your clinical team is happy that your baby no longer needs oxygen therapy, the equipment can be removed from your home. Your doctor and community nurses will support you with this. A time will need to be arranged with Dolby Vivisol to have the equipment removed, as soon as it is no longer needed.

- **Infection control**

As parents / carers, you should follow infection control measures. For example:

- Wash your hands or use hand sanitizers before handling your baby.
- Limit the number of visitors your baby has, especially visitors with coughs or colds.

Babies on home oxygen are more at risk of getting an infection, due to their prematurity and impaired lung tissue.

- **Respiratory Syncytial Virus (RSV) prevention**

During the winter season (between October and February), all infants under the age of 2 years on home oxygen therapy and / or with other problems, should have an immunisation called Palivizumab every 28 days. Palivizumab helps to protect your child from Respiratory Syncytial Virus (RSV) related infections. This reduces your baby's chance of being re-admitted to hospital.

The community nurses will check whether your child is eligible to have this vaccination before you leave hospital. They will also organise the injections, usually when your baby is ready to go home.

- **Influenza (flu) vaccine**

The influenza vaccine should be given to all children with chronic respiratory disease, who need home oxygen from 6 months after birth.

Please note the vaccine is not licensed for children aged under 6 months. Other household contacts and caregivers can also have the vaccine, to protect your child.

Everyone in your baby's immediate family can have the annual influenza vaccine as well. Please talk to your GP to arrange this.

What do I do if my baby is 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 Children's Nursing 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.

Depending on where you live, you will have open access to:

- Padua Ward, **William Harvey Hospital**, Ashford
Telephone: 01233 616296
- Rainbow Ward, **Queen Elizabeth the Queen Mother (QEQM) Hospital**, Margate
Telephone: 01843 234578

If your baby is unwell, you must call one of the above wards and tell them you are coming to hospital. You can then go straight to the ward rather than going through the Emergency Department.

Local Emergency Departments with paediatric (child) facilities

- William Harvey Hospital
Kennington Road
Willesborough, Ashford
TN24 0LZ
- Queen Elizabeth the Queen Mother (QEQM) Hospital
St Peter's Road
Margate
CT9 4AN

Important numbers and links for more information

- **In an emergency: call 999**
 - Community Children's Nursing team 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** (<https://www.vivisol.co.uk/>)
 - Freephone support: 0800 917 9840
- **Bliss** (<https://www.bliss.org.uk/>)
Bliss is a charity dedicated to supporting premature babies and their families.
 - 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)

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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