



Northumbria Healthcare
NHS Foundation Trust

Weaning your child from oxygen

A guide for parents/carers

Issued by the Children's Community Nursing Service



Introduction

This leaflet has been written to provide parents and carers of children who go home on oxygen with some guidance with the process of weaning their child from oxygen. This leaflet will explore briefly why your child needs oxygen. The leaflet highlights the professional support that will be available to you while your child is receiving oxygen and throughout the weaning process. It is important to understand that this leaflet is only a guide.

Every child is different and therefore the process of weaning is a very individual experience and there is no set time-scale for this to happen. It is important that when weaning your child from oxygen, that it does not affect your child's growth and development. The length of time that your child remains on oxygen will depend on his/her individual progress and needs, and also the time of year that weaning is taking place. If your child is discharged home in the autumn and winter months the process of weaning may take longer. This is because of an increased chance of your child being vulnerable to winter viral chest infections, such as Respiratory Syncytial Virus (RSV) Bronchiolitis which can affect lung function and result in your child needing more oxygen for a longer period of time.

Why Does Your Child Need Oxygen?

Your child needs home oxygen because of chronic lung disease. This is a descriptive term for pre-term infants who have had an oxygen requirement for more than 28 days. It is essential to your child that he/she receives the appropriate level of oxygen to aid breathing, which will help to promote weight gain, growth and development. If your baby is putting too much effort into breathing this could affect their general growth and development.

Who Are the Professionals Who Will Work in Partnership with You during This Process?

The Paediatrician prescribes the level of oxygen that your child will require to go home in. The paediatrician will see your child in the outpatient clinic and will monitor your child's growth and development.

The Children's Community Nurse (CCN) will monitor your child's oxygen saturation levels in the home. The frequency of monitoring will be determined by, your child's condition and how confident you feel. The CCN will liaise closely with other involved health professionals as and when your child's condition dictates.

The General Practitioner (GP) and the **Health Visitor (HV)** will provide additional support with your child's growth and development and overall health and well-being. Other health care professionals such as the physiotherapist or the dietician may be involved as necessary.

When to Wean from Oxygen

The decision to begin the weaning process will be made between you, your child's paediatrician and the CCN. It will be dependent on the stability of your child's condition over a period of time. Before weaning begins your child must show clear signs that he/she is gaining weight and developing as would be expected. Your Health Visitor and GP will monitor your child's progress. A detailed record will be kept in your parent held record book.

The CCN will have been closely monitoring your child's oxygen saturations since discharge from hospital, and a record will be kept in your parent held record book. Your CCN will ask you to keep a diary of events during the weaning process, and a plan of care will be drawn up to follow. Your child's growth, development and saturations will continue to be monitored throughout the weaning process. Your paediatrician will be kept informed.

Cautions

It is important for you to be aware that your child's condition could change during the weaning process. It is important that you are observant to any changes in your child's condition and feel confident in how to approach them.

Changes such as; increased effort in breathing, a change in colour around the mouth, fingers and toes from pink to pale to dusky, irritability and difficulty in feeding are all indicators that your baby may not be getting enough oxygen.

If you detect this in your child you must turn the oxygen up or recommence it, and then call the CCN to come out and monitor your child's saturations. Your child may need medical attention.

Serious concerns call an ambulance.

It is important that you alert a health professional to any changes that you have made to your child's oxygen. Reducing or increasing the oxygen over a long period of time without professional advice may be harmful to your child's health.

Never hesitate to seek professional advice if you are concerned about your child's breathing or condition. You will have to be taught by staff on the Special Care Baby Unit (SCBU) or children's ward how to resuscitate your child should you need to in an emergency.

It is appreciated that caring for, and weaning an oxygen dependent child can be hard work and stressful. It is hoped that this leaflet will give you some indication of what to expect over the coming months. It is understood that this leaflet may have raised more questions for you, please do not hesitate to ask your CCN, HV, GP or Paediatrician for answers. The contact numbers are on the back of the leaflet.

Please try not to worry. Weaning your child from oxygen may seem like a daunting process as you read this leaflet for the first time, but it is a partnership process. You will not be expected to do this on your own. You will be well supported by health professionals throughout.

Weaning from Oxygen

- 1) Your child's oxygen saturations must remain stable at 94% and above in the same amount of oxygen during rest and activity periods, such as feeding, playing and crying.
- 2) When this is achieved the oxygen will be reduced slowly over a period of time. Your child will dictate how long this will take.
- 3) Once your child is maintaining his/her oxygen saturations at 94% and above in minimal oxygen ie, 0.1 litres/minute during rest and activity he/she will be monitored for a short period of 30 minutes in air.
- 4) If oxygen saturations do not fall below 94% in air, you can disconnect your child from oxygen for up to an hour in the morning or afternoon each day while he/she is awake.
- 5) As your child's condition and oxygen saturations remain stable and maintained above 94% the period off oxygen will gradually increase usually by 1hr per week until they are off oxygen all day, ie 8 hours, but no more than 12hrs.
- 6) Once your child can maintain oxygen saturations at 94% and above in air whilst awake and asleep the oxygen can be discontinued during the day. However, as a precaution you are advised to always have your portable oxygen cylinder with you during this time.

- 7) Before we can safely discontinue your child's oxygen at night you will be given an oxygen saturation monitor to use over a weekend to monitor overnight oxygen saturations in air.
- 8) If the oxygen saturations remain at 94% and above the CCN will pass on the results of the monitoring to your child's paediatrician and they will make the decision as to whether your child is ready to discontinue overnight oxygen therapy.
- 9) Once your child has been weaned from day time and night time oxygen we will arrange for the majority of the oxygen equipment to be removed from your house, leaving you with one portable cylinder. This needs to remain in your house for 2 months after your child has been successfully weaned from oxygen.
- 10) The Health Visitor will continue to monitor your child's growth and development alongside the paediatrician and the GP. However, the CCN will be only too happy to give advice or visit should you request it.

Where can you find us?

Northumberland Child Health Centre
Woodhorn Lane
Ashington
Northumberland
NE63 9JJ

Telephone: 01670 564070

Mobile telephone number: 07702690059

When do we work?

Monday to Friday from 8am until 6pm

Saturday, Sunday, Bank Holidays: 9am until 5pm

www.bliss.org.uk

Alternative Formats

If you would like a copy of this information in large print, another language, audio tape or other format please call the Contact Centre on **03 44 811 8118**

Other sources of information

NHS 111

NHS Choices

www.nhs.uk/pages/homepage.aspx

NICE (National Institute for Health and Clinical Excellence)

www.nice.org.uk

Patient Advice and Liaison Service (PALS)

Freephone: **0800 032 0202**

Text: 07815 500015

Email: northoftynepals@nhct.nhs.uk

Northumbria Healthcare NHS Foundation Trust

General Enquiries **03 44 811 8111**

www.northumbria.nhs.uk

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