

Clinical Guideline: Home Oxygen

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For use in: EoE Neonatal Units
Guidance specific to the care of neonatal patients.

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Approved by:

Neonatal Clinical Oversight Group	
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Introduction and selection of appropriate babies

Currently about 70% of infants born at 25 weeks or below remain oxygen dependent at 36 weeks corrected (EPICure 2 study)¹. A minority of other infants may show a persistent oxygen requirement at this age due to factors such as pulmonary hypoplasia. As the infant nears term and is otherwise stable, options for ongoing care should be discussed with the family.

For stable but oxygen dependent term infants, it is generally accepted that care at home is the best option in most cases. Even parents who are initially unsure about the idea of home oxygen may be more enthusiastic about it with education and support, or if the duration of an alternative hospital stay increases².

It is now relatively rare for a baby with chronic lung disease (CLD) to remain as an inpatient past term unless there are coexisting medical or social concerns. However each family should be supported on an individual basis. It may be appropriate to revisit the idea of home oxygen over a period of time, depending on the baby's progress and family wishes/concerns.

Physiological benefits of long-term oxygen treatment^{3,4}

1. Hypoxaemia causes pulmonary hypertension but the severity and duration required to do this is unclear. Average saturation levels of > 94-95% reduce pulmonary hypertension in babies with CLD.
2. Risk of apparent life-threatening events in CLD babies increases if average saturation <90%, not if average saturation > 93%. The same thresholds apply to impaired sleep quality.
3. Growth of CLD babies is reduced with average saturation < 92%.
4. Significant hypoxia with saturation < 85% may have adverse effects on cognition and behaviour.

Once infants reach near term and have a fully vascularised retina, the risks of ROP become less significant in comparison to other factors above.

The median baseline saturation in healthy term infants during the first year of life is 97-98%, and in only 5% of healthy infants does the saturation fall below 90% for > 4% of the time.

Information to be given to families with initial discussions

BLISS 'Going Home on Oxygen' leaflet should be used in an appropriate form for the family (translations are available).⁵

Support for smoking cessation should be considered at an early stage, as this may be difficult for parents to achieve during stressful periods when the baby first goes home.

All parents need unit-based local information re CCN support and who to contact for emergency advice.

It is useful for parents to meet their allocated CCN or outreach nurse if possible while decisions about home oxygen are being made, and for this member of staff to help coordinate the discharge process.

Preparation of the infant for discharge (Appendix 1)

1. Choose stable oxygen flow rate that keeps saturations > 93% (see BTS guidelines³) including feeds and sleep periods.

This should be agreed with the nursing staff caring for the baby, so that adjustments of oxygen flow rate are avoided and the frequency of observations can be reduced as discharge approaches. The aim should be to get closer to the routine which the baby and family will be using at home.

The new target saturation may mean that the infant's oxygen requirement appears to have increased from previously – explain to parents that this is due to a planned change of clinical priorities and does not mean that the baby is deteriorating.

2. It is unusual for a baby still needing more than 0.5 l/min nasal cannula oxygen to be well enough to be discharged home (BTS guidelines³).
3. A baseline oxygen saturation study can be considered if available. This should include at least 6-8 hrs of recording and capture episodes of feeding and sleeping, as well as periods when the baby is awake and settled.
4. Some units may undertake a car seat challenge, although this is not imperative. Monitor the baby's saturation for one hour in their own car seat with straps secured, and document whether it is necessary to increase oxygen concentrations during the test.
5. Cardiac ECHO at approaching term is useful to exclude pulmonary hypertension.
6. Baseline CBG is useful for later comparison should the baby be readmitted with acute respiratory symptoms.
Capillary or arterial pCO₂ is an indirect index of the severity of the chronic lung disease, but it may not accurately predict the duration of the baby's oxygen requirement.
7. Most units will discharge the baby without a continuous saturation monitor in the home, but will measure saturations intermittently as part of the follow up process.
8. Discharge with an apnoea monitor is not routine, but may be considered in some units or individual cases. The family should be aware that apnoea alarms will not pick up all life threatening events eg obstructive apnoeas, and that careful observation of their baby (with access to advice if they are concerned) is more important than relying on monitoring equipment.

A 'rough' baseline guide to the individual baby's usual heart rate, respiratory rate and work of breathing should be agreed with the family for use in deciding when to seek medical review.

9. Families taking a baby home in oxygen should be offered basic life support training, and given the standard advice on safe sleeping and temperature control for their baby.
10. There should be a local arrangement in place for the prescription of palivizumab to babies who fulfil the current national criteria for RSV prophylaxis.

Usually first doses for the winter season are given in October. Babies discharged in the summer months may still require palivizumab for their first winter but this depends on their gestation and their postnatal age at the start of the RSV season – please consult current guidelines and agree eligibility at the time of discharge from the neonatal unit. Give the first dose of palivizumab prior to discharge for eligible babies who go home between October and March.

11. Babies still in home oxygen will be eligible for the influenza vaccine for their first and subsequent winters if they are over 6 months postnatal age. Initially this will need to be intramuscular rather than nasal. Also encourage parents and siblings to have influenza vaccine if possible.
12. Babies discharged in oxygen should be considered as extremely clinically vulnerable to covid 19, please see up to date public health information and ensure that the family are aware of standard advice re handwashing and social distancing.
13. Consult local dietician or CCN for arrangements re any NGT supplies or feed deliveries required.
14. Check follow up plans, and whether the baby needs separate respiratory and neonatal/developmental clinic visits? Does the baby need official referral to the general paediatric and/or respiratory team?

Preparation of parents for discharge (Appendix 2,3,4)

1. Competencies –supporting parents to prepare for discharge and ensure parents feel confident with the skills they have learnt during their stay-i.e; check that parents can assess signs of respiratory distress or general signs of illness in their baby, can feed baby safely by whichever is their chosen method (including NGT if needed – see network guideline), and are happy with safe fixation of cylinders, checking level of remaining oxygen, safe attachment of cannulae to baby's face.
2. Discuss fire safety – even though this will also be covered by the oxygen delivery company – and give a list of suitable emollient creams that can be used in combination with oxygen (see appendix 2)

3. Ensure parents have made contact with their GP and that the baby is registered as a patient. GP details need to be included on the oxygen prescription. Clarify which if any long-term prescriptions or follow up needs will be the GP's (rather than the hospital's) responsibility.
4. Arrange options for 24 hr emergency contact advice and check parents have all numbers and know who to ring first weekdays/ out of hours/at weekends.
5. Gain consent for information sharing with the home oxygen company (Home Oxygen Consent Form and Initial Home Oxygen Risk Mitigation Form need to be signed by parent – see appendix 3 and 4)
6. Parents need to update home insurance and car insurance accordingly.
7. Once oxygen is ordered, oxygen supply company will arrange a home visit and fitting directly with the parents, and will also cover safe use of oxygen and delivery arrangements.

Ordering home oxygen – completion of HOOF forms

Usually a named professional in each unit will be responsible for ordering home oxygen, and a HOOF form B ('after specialist assessment') can be completed. This gives more options re type of cylinder than the general part A form. If unsure, please discuss the form with the oxygen company as they will reject the order if they cannot process the request.

Many units in the East of England are currently covered by BOC Healthcare. They now request on line applications via their Home Oxygen Portal (www.bochop.co.uk).

Choose a suitable number of hours per day to be available from an ambulatory cylinder and allocate the remainder of 24 hours to be given from a static cylinder. All families should have an ambulatory cylinder prescribed, unless their baby only uses oxygen at night. Lightweight or standard ambulatory cylinders may be possible but this depends on the flow rate required. The flow needs to be prescribed as a stable rate rather than a range of values. Very low flow rates may need a special flow meter to be prescribed.

Occasionally the oxygen company may prefer to supply a concentrator rather than cylinders for an individual baby on higher flow rates, but this does not affect the baby's medical management and is rare. If a baby has a home oxygen concentrator then the electricity used for this can be reimbursed.

Ensure that a copy of the HOOF is in the baby's record.

Check with nursing staff that supplies such as Duoderm, fixation tape for oxygen cannulae, oxygen tubing etc are either provided by the oxygen company or requested as part of TTO. The oxygen cannulae supplied by the company may differ slightly from those typically used in hospital, so it may be helpful to check which suits the infant best.

Planning date of discharge

1. Consider discharge planning meeting, especially if baby has other complex medical needs or if the family are known to other services or may have difficulty accessing help
2. Consider encouraging family to room in with their baby using the same oxygen equipment that they will have at home, and off saturation monitoring if appropriate
3. Check that family know how to order new cylinders and equipment, and have oxygen company contact numbers. Parents should know approximately how long each cylinder lasts at their baby's individual flow rate, and how much notice the oxygen company usually needs to replenish supplies. Do not assume that all parents can access written information.
4. Discharge baby early in day if possible, not just before a weekend unless there is 24 hr CCN or nursing outreach support available
5. Inform the general paediatric ward/ team that baby would be readmitted to if necessary, and introduce the parents to staff there.
6. Plan an early home visit.

Monitoring of home oxygen

1. Each CCN visit document saturation, HR, RR, weight and any parental concerns
2. Check and document oxygen safety knowledge and practice at the first post discharge visit, and then at least annually (most babies will have weaned off their oxygen by this stage).
3. Overnight saturation study (sleep study) to be done at agreed intervals, for example monthly, and reviewed by allocated medical team.
4. Usual criteria for satisfactory sleep study:
 1. At least 8 hours of good quality saturation recording
 2. No more than 5% of the time with saturation < 93%
 3. Mean oxygen saturation should be > 93%
 4. Dip rate/ stability of the average saturation may also be taken into consideration - more than 4 dips/hr of > 4% would in older children suggest upper airway obstruction, but may be less applicable to neonates

Benefits

1. On current rules the baby will become eligible for Disability Living Allowance once the postnatal age of 3 months is reached. This should be explained to parents and is not means tested, but it is only applicable after the baby has been discharged from hospital. DLA helpline: 0800 121 4600 www.gov.uk/disability-living-allowance-children

2. Families can also apply for a Blue Badge for their vehicle in view of the need for the baby to be 'always accompanied by bulky medical equipment, or kept near a vehicle in case of needing emergency medical treatment' – medical letters of support may be needed, but on-line application is possible (www.gov.uk/apply-blue-badge).

3. Check that parents are aware of the potential arrangements for oxygen delivery to a second address eg for holidays or visits to family. A new HOOOF is not usually required, and arrangements can be made directly with the oxygen company.

Home Oxygen Safety

This advice will be reinforced by the oxygen company, but please see appendix for general guidelines on oxygen storage, fire risks, and care of cylinders.

Weaning of home oxygen

1. Do not start to wean oxygen until at least 2 weeks post discharge home
2. Pause/ do not start further weaning during periods of upper respiratory tract infection.
3. Weaning criteria:
 - feeding well
 - gaining weight
 - saturations stable
 - some units use a sleep study prior to a reduction, but an alternative is to wean on clinical grounds and with brief period of saturation monitoring, then check with sleep study on the new lower flow rate

Most infants reach their lowest saturations by 40 minutes and a level of 92% or above best predicts readiness for weaning^{7,8}.

4. Reduce flow rate initially by steps of 0.1 l/minute at a time until 0.1 l/min is reached.
5. Do not adjust daytime and night-time rates separately at this stage unless for individual clinical reasons⁴.
6. It is usual to check that the new flow rate is tolerated with either a CCN visit and saturation check (should still be > 93%), or a repeat sleep study or both – this may vary between units.
7. Review re further potential weaning in 2-4 weeks if stable.
8. Once stable on 0.1 l/min, and especially if the child is becoming more mobile and less tolerant of the oxygen cannulae, start to introduce brief daytime periods in air. One example of a weaning schedule is suggested in appendix 5.
9. Repeat sleep study when the baby is out of oxygen for most of their daytime hours.
10. As a final step, stop night time oxygen and repeat sleep study assessment.
11. Arrange for oxygen to be removed from the home address once stable out of oxygen for 1-2 months (depends on season, previous clinical progress and local service arrangements)

Follow up

By virtue of their gestation and the likely severity of their initial illness/RDS, babies with chronic lung disease are at high risk of neurodevelopmental complications. Developmental follow up should be undertaken in line with network and national guidance⁶. Respiratory follow up may be undertaken separately in some units.

Appendices

1. Check list prior to discharge
2. Oxygen safety advice for parents
3. Home Oxygen Consent Form
4. IHORM form (Initial Home Oxygen Risk Mitigation)
5. Suggested schedule for weaning into air

Appendix 1

DISCHARGE PLAN FOR HOME OXYGEN THERAPY

ID label

Date of planned discharge		
Consultant		
CCN name and phone number		
Name of parents/ carers		
Parents landline number		
Parents mobile number		
GP		
Health Visitor		
Other professionals		

Action	Sign and Date	Comments
Consultant discussion with parents		
BLISS Home Oxygen Guide given		
Referral made to CCN team		
HV and GP informed of plan for home oxygen		
Discharge MDT meeting planned		

Home visit by CCN or HV prior to ordering oxygen		
Parent to sign consent to information sharing by home oxygen service (HOOF)		
Parent to complete Home Oxygen fire safety questionnaire (IHORM form)		
HOOF form completed on BOC Home Oxygen Portal, copy filed in notes		
Copy of HOOF form sent to local Home Oxygen Service Lead		
Copy of HOOF sent to GP		
Parents to inform car and home insurance, and electrical supplier		
Hazard sign given to parents for car +/- front door		
Parents to request Disability Living Allowance form from DWP		
Offer parents overnight stay on unit		
Oxygen competency demonstrated by parents and documented – include use of cylinders, nasal cannulae and skin care		
Supply of nasal cannulae, dressings, adhesive removing wipes – if discharged with saturation monitor, also supply probes and posey wraps		
Immunisations up to date (Advise flu vaccine at start of winter once over 6 months old)		
Eligible for palivizumab? (Refer to latest NHS England Commissioning document)		
Follow up appointment with consultant booked (within 4-6 weeks)		

CCN visit arranged (within 24 hrs post discharge)		
Open access arranged to paediatric ward		
Escalation plan and hand held summary given, with 24 hr contact numbers		
Parents have been taught basic life support		

Appendix 2

Home Oxygen Safety

Parent teaching will be given by the oxygen company when installing the equipment, but should be emphasised by staff whenever possible. The Paediatric Pan London Oxygen Group suggest there should be an annual documented review of safety advice if the baby remains in oxygen for longer than this. Initial home visits should ensure that access to the property is clear and that this does not present a fire risk. The practicality of managing baby and buggy with an oxygen cylinder should also be checked, eg stairs and lifts.

Advice for parents:

1. Store cylinders away from direct heat or cold, in shade when in use
2. Store cylinders secured in an upright position, or laid flat (and safe from young children and pets). In the car ideally secure the cylinder in the boot, never in the front passenger seat. On a buggy/ pushchair the cylinder is steadier in the basket beneath than on the handle.
3. Do not store oxygen equipment near flammable liquids or near soft furnishings/ clothes/ bedding/ paper. Oxygen will pool on clothes or bedding so ensure good ventilation, do not leave cannulae on a bed or chair when oxygen switched on. Do not hang clothes on oxygen cylinders.
4. Wash hands before changing cylinder heads.
5. Make sure cylinder valves are closed when not in use – if there is a leak, take the cylinder outside then contact suppliers immediately
6. Open cylinder valves gently to avoid a rush of pressure
7. When the cylinder is empty, close the valve and re-fit the plastic cap to prevent moisture entering the cylinder

8. After closing the valve, any residual gas needs to be discharged from the cylinder head
9. All empty cylinders need to be removed by the oxygen company and swapped for new ones. Allow at least 48 hrs for delivery of new supplies (monitor level of oxygen via cylinder dial).
10. All oxygen tubing will be supplied with a 'firebreak' valve which is very important to protect the baby, and should never be removed or turned around.
11. DO NOT USE OXYGEN NEAR FIRE OR CANDLES. DO NOT SMOKE IN THE HOUSE.
12. Do not use aerosol sprays near oxygen cylinders.
13. DO NOT USE PARAFFIN-BASED CREAMS OR LIPSALVES (baby or parent). Vaseline or E45 should be avoided.
14. Beware of oxygen tubing as a trip hazard, and ensure it cannot be kinked or trapped on furniture.

Appendix 3

IHORM IG approved 298

Patient agreement to sharing information



Form issued by:			
Unit/Surgery		Address	
Contact name			
Tel no.			
Email		Postcode	

Patient			
Name		Address	
D.O.B.			
NHS number			
Tel/mobile no.		Postcode	
E-mail		(only include if the patient agrees to email contact)	

My doctor or a member of my care team has explained the arrangements for supplying Oxygen at my premises, that my personal information will be managed and shared in line with the Data Protection Act 1998, Human Rights Act 1998, and common law duty of confidentiality and I understand these arrangements, such that:

1. Information about my condition/condition of the patient named above* will be provided to the Home Oxygen Service (HOS) Supplier to enable them to deliver the Oxygen treatment as per the Home Oxygen Order Form (HOOF).
2. The HOS Supplier will be granted reasonable access to my premises, so that the Oxygen equipment can be installed, serviced, refilled and removed (as appropriate).
3. Information will be exchanged between my hospital care team, my doctor, the home care team and other teams (e.g. NHS administration) as necessary related to the provision, usage, and review, of my Oxygen treatment, and safety.
4. Information will also be shared with the local Fire Rescue Services team to allow them to offer safety advice at my premises and where appropriate install/deliver suitable equipment for safety.
5. Information will also be shared with my electricity supplier/distributor where electrical devices have been installed.
6. From time to time, I may be contacted to participate in a patient satisfaction survey/audit. (Should you wish not to participate please tick this box) ☐
7. I understand that I may withdraw my consent at any time (at which point my HOS equipment will be removed).

* Delete as applicable

Patient's signature		Date	
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(see note 4 where signed and witnessed on patient's behalf)

I confirm that I have responsibility for the above-named patient e.g. parental responsibility, lasting power of attorney.

Signature		Name	
Relationship to patient		Date	

I confirm that I am the healthcare professional responsible for the care of this patient and I have completed this form on his/her behalf as s/he is unable to provide/withhold consent. The patient has been given a copy of this form.

Clinician's signature		Date	
Name			

Appendix 4

IHORM IG approved 298

Initial Home Oxygen Risk Mitigation Form (IHORM) and Home Oxygen Consent Form (HOCF) for new patients only.

BOTH FORMS MUST BE COMPLETED AND SIGNED BEFORE OXYGEN CAN BE INSTALLED.

DO NOT SEND FORMS TO SUPPLIER FORMS WILL BE PLACED IN PATIENT NOTES

THERE ARE CONFIRMATION BOXES ON THE HOME OXYGEN ORDER FORMS.

Oxygen can pose a risk of harm to the user and others in the event of fires, falls and inability to use complex equipment. The initial identification and onward communication of these risks is the responsibility of the health care professional ordering the oxygen and remains so until that prescription ceases or is superseded. The table below reflects risk factors that are based on evidence of real life serious and untoward incidents, 90% of which are smoking and e-cigarette/charger related.

The Initial Home Oxygen Risk Mitigation (IHORM) is to be completed in conjunction with the Home Oxygen Consent Form (HOCF) prior to oxygen being ordered from the oxygen supplier via the Home Oxygen Order Form (HOOF). It is the responsibility of the registered health care professional who is gaining consent to complete and add the IHORM with the HOOF and HOCF to the patient's notes. If all documents are not confirmed as being completed in full the Home Oxygen Order cannot be fulfilled.

If the risks identified on the IHORM indicate significant levels of risk the patient should be discussed directly with the local Home Oxygen Service or Clinical Oxygen Lead for a full risk assessment prior to oxygen being ordered as recommended in the British Thoracic Home Oxygen Guidelines June 2015. Regardless of risk or diagnosis all adult patients should be referred the Home Oxygen Assessment and Review Service (HOS-AR) for the team to determine next steps if deemed relevant.

If any responses below fall within a shaded box, please refer to the Required Action column and supporting notes.

All actions should be explained to the patient and why they are being taken in line with service contracts. Ensure that both verbal and written information has been given to the patient or their representative.

Patient Name			DOB	
Address			Oxygen requested?	No- Risk too high
Recorded at	Hospital/Clinic		NHS No	
Risk Level	Risks		No	Yes
HIGH	Does the patient smoke cigarettes / e-cigarettes?		☒	☐
	Have they smoked in the last 6 months?		☒	☐
	Quit date: _____		☒	☐
	Does anyone else smoke at the patients premises?		☒	☐
	A recent history of drug or alcohol dependency?		☒	☐
	Patient reported they have had a fall in the last 3 months?		☒	☐
	Have they had previous burns or fires in the home?		☒	☐
MODERATE	Does the person have identified mental capacity issues?		☒	☐
	Can the patient leave their property un-aided?		☒	☐
	Is the patient or any dependents/ in the property vulnerable? E.G. disabilities/ children		☒	☐
	Do they live in a home that is joined to another?		☒	☐
	Patient reports they have working smoke alarms at home? (if unknown please state no)		☒	☐
Do they live in a multiple occupancy premises (Bedsit/flat)		☒	☐	
Mitigation actions taken e.g. contacted falls team Referred to Fire and Rescue 				
Declaration I confirm that I am the healthcare professional responsible for the care of this patient. I have discussed the risks listed on this form with the patient/carer/ guardian (delete as necessary) and from the responses given Oxygen can/cannot (delete as necessary) be requested at this time.				
Clinicians Signature			Profession	
Print Name			HOS team	No
Contact No.			Date	
Lead Consultant is (Hospital Discharge only)			Discharge Date	

Appendix 5

Possible schedule for weaning home oxygen

This assumes that the baby is well, thriving and saturations remain > 93% when briefly disconnected from oxygen for 10-15 minutes, and that baseline oxygen flow rate is 0.1 l/minute.

Exact timing and frequency of CCN visits will vary between units, and this may influence the details of monitoring. Saturation may be either checked by parents with a home monitor, or solely by CCN visits with checks during the time the baby is off oxygen. Evidence is lacking at present as to a single best practice method.

Week 1	Twice daily periods off oxygen	Build up from 30 mins bd to 3 hrs bd	If sat 93% or above continue weaning – if not replace oxygen and try this stage again in 1 week
Week 2	Sleep study, whilst continuing to build up twice daily periods in air	Review by named consultant	Do not increase above 6 hrs in air bd – only progress if sleep study satisfactory
Week 3	Continuous single period off oxygen	12 hrs once daily, increase to 18 hrs in air once daily (oxygen only at night)	If sat 93% or above continue weaning – if not replace oxygen and try again in 1 week
Week 4	Sleep study	Review by named consultant	Stop oxygen if sleep study satisfactory
1 st week continually in air	Consider sleep study		
After 1 month in air	Sleep study		Arrange for oxygen removal from home if satisfactory

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Exceptional Circumstances Form

Form to be completed in the **exceptional** circumstances that the Trust is not able to follow ODN approved guidelines.

Details of person completing the form:	
Title:	Organisation:
First name:	Email contact address:
Surname:	Telephone contact number:
Title of document to be excepted from:	
Rationale why Trust is unable to adhere to the document:	
Signature of speciality Clinical Lead:	Signature of Trust Nursing / Medical Director:
Date:	Date:
Hard Copy Received by ODN (date and sign):	Date acknowledgement receipt sent out:

Please email form to: Kelly.hart5@nhs.net requesting receipt.

Send hard signed copy to: Kelly Hart

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