





Paediatric Respiratory Medicine

Guidelines for Home Oxygen

The guideline aims to facilitate all professionals involved in the discharge and continuing care of children and families who require home oxygen therapy. We aim to work in partnership with families and professionals and achieve a safe, smooth transition from hospital to home. It has been developed by the paediatric respiratory team with reference to facilities and support available locally as well as national guidelines.^{1,2}

If you have a patient who you think needs home oxygen, please refer them to the paediatric respiratory service, either directly to the consultant on service or via the registrar. Your patient will be integrated into the weekly paediatric respiratory MDT meetings and their follow up managed using established home oxygen protocols. Please also contact the specialist paediatric respiratory nurses on 42116 as soon as possible as it is helpful if they are also involved early in the process.

CHILDREN WHO MAY NEED OXYGEN AT HOME

- Children who are otherwise medically fit for discharge, in whom oxygen is the most appropriate
 form of respiratory support, and in whom stable or predictable oxygen requirements have been
 established before discharge.
- Children who are unwell and potentially unstable, where oxygen therapy may be part of a palliative approach to symptom management.

HOME ENVIRONMENT

- Carers must be able and willing to manage oxygen at home.
- The discharge environment must be suitable and risk managed.

The paediatric respiratory team will assess children referred for home oxygen, establish that the patient is suitable for home oxygen and assess their requirements. The team will organise discharge planning for patients going home with oxygen, and coordinate appropriate education and training, delivery of oxygen into the home and early follow-up.

ASSESSMENT FOR HOME OXYGEN

The needs of the oxygen-dependent child and family are complex and the burden on the child and family is significant. The assessment of a child's suitability for home oxygen should be performed by the paediatric respiratory team, and may involve:

- Clarification of the diagnosis causing persistent hypoxaemia.
- Establishing that oxygen is the most appropriate form of respiratory support.
- Defining target oxygen saturations.
- Performing pulse oximetry. This should be performed overnight and potentially during other
 activities such as resting awake, during feeding and during exercise. Overnight traces should
 capture a minimum of 6 hours. The agreed lower limit saturations should be met at least 95% of
 recorded time (with a good trace).
- It may be necessary to assess CO₂ levels, for example in patients with chronic hypoxia, chronic lung disease, neurological disease or central breathing disorders. Oxygen therapy may modulate breathing patterns in these patients, and can cause apnoea.
- Cardiac referral may be necessary for assessment of pulmonary hypertension.
- Home and family risk assessment.

TARGET OXYGEN SATURATIONS

A patient's optimal oxygen saturations may vary depending on underlying disease, co-existent cardiac disease, and if there is any pulmonary hypertension. In some situations the difficulties of using home oxygen outweigh the potential benefits of achieving optimal saturations.

As a general rule, the following thresholds are used:

Patient characteristics	Target saturations
Patient with no pulmonary hypertension	≥92%
Patient with pulmonary hypertension	≥95%
Co-existent respiratory and congenital cyanotic cardiac disease	Oxygen is not usually used to treat low oxygen saturations seen in congenital heart disease, but may be used if there is coexistent pulmonary disease.

DIFFERENT TYPES OF HOME OXYGEN AND OXYGEN DELIVERY

- Home oxygen refers to any additional oxygen required outside of a hospital setting. Heated Humidified Hiflow Oxygen (*HHHF, MyAirvo HiFlo therapy*) is not considered here, and patients requiring this therapy at home should be referred to the South Wales Home ventilation service at the Children's Hospital for Wales.
- Long term oxygen therapy (LTOT) can be continuous (24 hour), sleep related (including naps) or nocturnal.
- Nasal cannulae can be used for flows up to 2L/min
- Oxygen flows >2I/min via nasal cannula are not well tolerated. Facemask oxygen cannot be given at <5I/min.
- Oxygen via a tracheostomy is usually administered via Swedish nose up to 3l/minute.
- Portable oxygen should be available to all children receiving home oxygen therapy during the daytime
- Intermittent or episodic oxygen therapy is used less commonly for conditions where recurrent hypoxaemia may occur without the need for hospitalisation. This is an unusual situation and suggests patient vulnerability as their condition is variable this requires careful planning and consideration of potential risk.

HOME AND FAMILY RISK ASSESSMENT

- Family structure single/supported/siblings
- Patterns of daily living occupation, social activities, smokers/non-smokers
- Home circumstances Type of accommodation & suitability
- Proximity to Health Service transport available, closest hospital for emergency
- Family dynamics main carer, level of involvement of other carer, siblings, extended family
- Responsiveness to child's needs performance of simple and complex care activities

DISCHARGE PLANNING

• Children who need home oxygen should have a written discharge plan at the bedside so that parents, nursing and medical staff can refer to it and work through it.

RESPIRATORY NURSE SPECIALIST ROLE

1) PLANI	NING
0	Assessment of existing level of knowledge and learning needs Introduce the concept of home oxygen with the family, named nurse and respiratory nurse Facilitate parental involvement in all aspects of care and special needs Identify and resolve specific social problems (for example, no telephone)
2) INTER	Discuss need for home oxygen with family Provide 'Taking your child home on oxygen' booklet Facilitate oxygen saturation recording (with or without CO2 monitoring) Complete HOOF and send to Baywater (Oxygen provider) once level of oxygen requirement is established. Copies of HOOF should be sent to the GP and local health board Oxygen Lead Perform home and family risk assessment Complete the Discharge Teaching Checklist prior to discharge (see appendix 1) Attend a Multi-Disciplinary discharge planning meeting involving both hospital and community staff. Ensure roles of health professionals are clearly identified and help parents understand different roles. Ensure parents know who to contact with questions following discharge, the out of hours open access policy (if appropriate) and where they should seek more urgent assistance. Patients who are given 'open access' should be shown around the local Children's Assessment Unit. Ensure Baywater have installed the oxygen equipment in all appropriate environments to cater for the child's needs e.g. home and school. Ensure Baywater have taught parents/carers/teachers the principles of oxygen therapy, use of equipment and safety aspects. Check parents/carers/teachers have understood the training provided by Baywater, and clarify any queries they may have. Ensure parents understand the follow-up plan after discharge Arrange for a discharge summary to be completed and sent to the G.P., Community Paediatrician, Health visitor, Respiratory Nurses file, C.A.U. open door policy file, social services, parents and child's notes. This should be completed by the Lead consultant for the patient.
3) HOME	For local patients home visit should be performed within 24 hours of discharge by the paediatric respiratory nurse specialist or assigned community paediatric nurse. Repeat oximetry should be performed as planned prior to discharge. The frequency of oximetry studies will depend on individual circumstances and will be decided by the patient's consultant.
4) FOLIC	First visit within 24 hours of discharge Ongoing assessment of safety and equipment Ensure oximetry studies are performed as per the patient's care plan. Evaluate and reassess the planned programme of care for the child and family Maintain communication between the child and family with the multi professional team Work with the family to address concerns or anxieties, and build confidence with home oxygen Facilitate access to support, for example respite care or financial help Review oximetry studies once downloaded. Take advice on a trace showing saturations <93% in air or <95% in oxygen, or desaturations lasting longer than 40 seconds accompanied by increased heart rate. Present oximetry to local respiratory lead clinician and generate outcome report.

ORDERING EMERGENCY OXYGEN OUT OF HOURS

It is usually best to wait and allow home oxygen therapy to be organised by the specialist paediatric respiratory nurses during working hours. The nurses will be able to establish home non-ambulatory oxygen on the same day if need be.

There are however exceptional circumstances where oxygen may need to be established at home immediately during out of hours. This is usually for palliative symptom management.

This will need to be managed by the discharging team who can hand over responsibility to the paediatric respiratory team on the next working day.

Details of how to organise emergency home oxygen are given below:

Go to www.uhwchildren.com/respiratory and find the home oxygen section

Download

- Consent form
- HOOF A form
- IHORM form
- Obtain patient / parent consent for home oxygen before prescribing.
- Complete an emergency HOOF A (Non-Specialist or Temporary Order)
 The form available on-line has been partially completed for palliative oxygen
- Compete the **IHORM** form and document on the HOOF-A from that you have done so
- The HOOF A form needs to be filled in electronically and emailed to BHLTD.ehoof@NHS.net
- You should receive a confirmation of receipt for this email
- Email a copy to the specialist respiratory nurses (<u>Claire.briggs@wales.nhs.uk</u>) or contact them directly on the next working day (telephone 02920742116 or extension 42116) to discuss and share relevant clinical information. The respiratory nurses will contact the GP and follow up the patient.
- HOOF A forms are only applicable to emergency out of hours oxygen provision. For non-urgent home oxygen provision contact the paediatric respiratory specialist nurses in working hours.

FITNESS TO FLY

Children discharged on home oxygen should be advised to contact the paediatric respiratory team prior to booking flights to discuss the need for assessment and likely additional oxygen during the flight. Guidance on fitness to fly protocols can be found at **www.uhwchildren.com/respiratory**

HOME OXYGEN CHECKLIST	
Diagnosis causing hypoxaemia	
Other significant diagnosis	
Pulmonary hypertension	Yes / no
Pulmonary hypertension on treatment	Yes / no
Target saturations	
Oxygen requirements following oximetry	
Parental agreement for oxygen at home	
Parental understanding for need for oxygen	
Home environment risks	
Family structure	

¹ British Thoracic Society guidelines for home oxygen in children (2009)

²Home oxygen for children: who, how and when? Balfour-Lynn IM, Primhak RA, Shaw BN.Thorax. 2005 Jan;60(1):76-81.