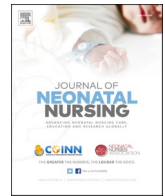




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## Guidance for home oxygen weaning in the community (PPLOG)

## ARTICLE INFO

## Keywords

Ambulatory oxygen therapy  
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## ABSTRACT

The aim of this home oxygen weaning guidance is to bring evidence-based knowledge and the experiences of Respiratory Clinical Nurse Specialists, Community Children's Nurses and Community Neonatal Nurses together, to address the unwarranted variation across community children & young people (CYP) services in relation to Long Term Oxygen Therapy (LTOT). This guidance has been created with an aim to ensure the management of CYP on home oxygen therapy is safe, effective, timely and standardised within London and other England regions especially when the oxygen process begins.

## 1. Background

In 2018, the Paediatric Pan London Oxygen Group (PPLOG) based in London launched the Home Oxygen Discharge Bundle. Based on feedback from numerous study days over the last three years, delegates highlighted the need for paediatric home oxygen weaning guidance. Consequently, PPLOG formed a sub-group to review current literature around weaning Children and Young People (CYP) on home oxygen therapy. Additionally, a survey was conducted to uncover how paediatric community teams across London wean CYPs off home oxygen therapy. The results of our survey are comparable to [Garde et al. \(2020\)](#), whereby a huge variation in practice and a significant number of Hospital Trusts did not have standardised weaning guidance for clinical staff and the CYP's carers to follow.

## 1.1. Literature synthesis and purpose for developing the guidance

Numerous CYP home oxygen therapy articles have been published which indicate the unwarranted variation in practice guidance when weaning off home oxygen therapy which is challenging. This variation is either due to services or organisations having no clear guidance or a lack of structured pathways ([Maclean et al., 2006](#); [Procaskey et al., 2018](#); [Everitt et al., 2020](#); [Garde et al., 2020](#), [Broderick, 2018](#) and [Nzirawa, 2018](#)).

The lack of agreement about the indications for home oxygen prescribing among specialist health professionals is another contending issue faced by many CYP community services ([Maclean et al., 2006](#); [Garde et al., 2020](#); [Everitt, 2020](#)). Our survey findings identified some teams started the CYP weaning based on the named consultant direction after the CYP had been reviewed at their first outpatient appointment.

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Whereas in some geographical areas across London, home oxygen weaning was independently started by the named community nurse within the home dependent on various assessments. This method of home oxygen weaning was identified by [Rhein et al. \(2020\)](#) and [Broderick \(2018\)](#).

[Rhein et al. \(2020\)](#) randomised controlled trial was divided into two groups. One group was seen in clinic monthly whereas the second group complied all the recordings and sent the data for review and feedback within 48 hours from the home setting. Both of Rhein et al. groups were reviewed by a senior medical doctor. Whereas, [Broderick \(2018\)](#) study was performed within a home setting downloaded by the community nurses. [Broderick's \(2018\)](#) data was a shared ownership between the community nurse and the senior medical doctor.

Therefore, the main considerations for clinicians caring for CYP's in the community is:

- When is the right time to start the home oxygen weaning program?
- What is the best evidence-based process to wean the CYP off oxygen therapy?
- What are the criteria to follow and who is clinically responsible for this process?

[Hayes et al. \(2018\)](#) highlights the lack of uniform guidance with only 8 % of specialist paediatric pulmonologist have a standardised weaning guidance for infants and where weaning guidance exist, it can take an interminable amount of time to completely wean the CYP off oxygen.

Whereas, [Yeh et al. \(2016\)](#) implied that on average, it took 10 months to completely weaned off oxygen and at least 32 % of CYPs had non-medical supervision during the weaning process. The consequences of unsupervised safe oxygen weaning can lead to concomitant diagnosis

of pulmonary hypertension in bronchopulmonary dysplasia infants. And this safety concern has some associations with high mortality rates in children that range between 14 and 38 %.

Where specialist input and supervision is incorporated in the home oxygen weaning process, CYP can successfully wean off oxygen within 7–9 weeks (Rhein et al., 2020; Broderick, 2018) with Rhein et al. (2020) stating that when CYP had monthly clinic visits, it took an average 74 days to wean off home oxygen. When a home oximeter was used, the average duration on home oxygen dropped to 53 days. Broderick (2018) findings indicated that prior to the implementation of a trust guidance it took an average of 21.75 weeks to wean off home oxygen compared to an average of 8.75 weeks once the home oxygen weaning guidance was implemented using recorded home oximetry and the team downloading and reviewing the results (Broderick, 2018). In comparison to Rhein et al. (2020) and Broderick (2018), PPLOG home oxygen weaning guidance takes an average of 33 days for the CYP to be completely off home oxygen therapy, accounting to around 28 days less.

In the final analyses, the literature review found that the use of oxygen therapy improves respiratory control, reduce apnoeas and episodes of desaturations and decreases the amount of time spent in periodic breathing. In addition, the use of home oxygen therapy has been found to be beneficial in CYP's, especially infants with chronic lung disease (Mayell et al., 2006; Batey et al., 2018; Everitt, 2020). The oxygen therapy enables the infant to have reduced work of breathing, therefore enabling some level of growth that is similar to healthy term infants (Mayell et al., 2006; Batey et al., 2018; Everitt, 2020). Significantly, the oxygen therapy has also been identified to improve neurodevelopmental outcomes, resolve pulmonary hypertension and reduce risk of sudden infant death (Mayell et al., 2006; Rhein et al. (2020); Batey et al., 2018; Everitt, 2020).

The aim of PPLOG weaning guidance is to bring evidence-based knowledge and the experiences of Respiratory Clinical Nurse Specialists, Community Children's Nurses and Community Neonatal Nurses collectively to develop a home oxygen weaning guidance for CYP on Long Term Oxygen Therapy (LTOT). This guidance ensure the management of CYP on home oxygen therapy is safe, effective, timely and standardised within London and other England regions.

### 1.2. Home oxygen weaning calendar

A home oxygen weaning calendar was created which starts the weaning programme from a flow rate of 0.1L/min to air. Although micro-flow meters exist (0.001–0.01 L/min), in theory the flow rate can be reduced further before weaning to air and there is limited evidence to support this practice. The size of the decrements used to wean oxygen flow rate, will result in infants being treated with LTOT for longer than expected (Garde et al., 2020). Balfour-Lynn et al. (2005) supports this and reasons that some carers may become confused with the decimal points by simplifying the process will ensure simpler and safer start to weaning oxygen from 0.1L/min.

In conclusion, PPLOG's emulates its ethos based around the World Health Organisation's (WHO, 2018) mission statement whereby every CYP has coordinated, continuity and integration of care that is equitable and within an appropriate specialist care pathway and delivered through a systematic approach.

### 1.3. Objectives

1. To develop standard guidance for weaning home oxygen therapy within children's services (tertiary and community settings).
2. To streamline the home oxygen weaning process for CYP on home oxygen therapy.
3. To deliver an educational programme for staff involved in facilitating home oxygen weaning process.

4. To deliver an educational programme for community staff delivering nursing care to children on home oxygen therapy and supporting the oxygen weaning programme within the community setting.
5. To support families with evidence-based information (leaflets, posters and etc.) on how to wean their child on home oxygen therapy.
6. To establish a platform of sharing the most current PPLOG home oxygen weaning guidance through the PPLOG study days, Facebook, Twitter and Newsletters.
7. PPLOG to review the guidance appropriately through different feedback mechanisms including surveys
8. To ensure that all PPLOG guidance's and pathways are reviewed every three years or earlier based on any new policies or evidence-based practices.

### 1.4. PPLOG home oxygen weaning contents

This home oxygen weaning document consists of:

- A guidance to wean from 0.2L/min or more following evidence-based research
- A weekly calendar to wean from 0.1L/min to air

This ensures a safe and timely weaning period off home oxygen. The diary is designed to be flexible depending on the community team's availability for home visits. This allows some teams to continue weaning over the weekend if resources allow. This diary focuses on safe weaning between Mondays to Fridays.

PPLOG is committed to improving guidance's and pathways in order to standardise care across hospital and community settings. This guidance for home oxygen weaning in the community is for use by clinical teams. The bundle elements should not be changed but the format and presentation of the documents can be amended for local use.

1. Guidance for weaning from 0.2L or more in the community
2. Guidance for weaning from 0.1L in the community
3. Week one calendar-weaning from 0.1L to air in the community
4. Week two calendar-weaning from 0.1L to air in the community
5. Week three calendar-weaning from 0.1L to air in the community
6. Week four calendar-weaning from 0.1L to air in the community
7. Week five calendar-weaning from 0.1L to air in the community

### 1.5. Step by step guidance

#### 1.5.1. If infant is receiving (0.2L)/min or more

It is not necessary to perform a baseline Overnight oximetry study (also referred as Sleep study) in the amount of oxygen the infant was discharged home in as this would have been performed in hospital prior to discharge. Inform the parents and clinician when the infant is ready to commence the oxygen weaning process. Wean oxygen by (0.1L/min) intervals, at each decrease do an overnight sleep saturation study. The infant's oxygen level should **NOT** be further reduced within the next 7 days (Millard et al, 2016; Mayell et al, 2006; Balfour-Lynn et al, 2005, 2009).

#### 1.5.2. If infant is receiving (0.1L)/min or less

Before oxygen weaning into air, the infant should be clinical stable, maintaining oxygen saturation  $\geq 93\%$  with all activities e.g. playing, feeding and awake. This will be assessed by the community nurse during the home visits over a period (days/weeks). The community nurse will then inform the parents and clinician when the infant is ready to commence the oxygen weaning process (**important to link with local guidance as some areas this is nurse lead by specialist community/respiratory nurses**). During the weaning process **oxygen saturations must be  $\geq 93\%$  in air** to safely continue. Time in air should only be when awake, unless you have previously monitored saturation levels

during a daytime sleep and is satisfied that saturation levels were maintained greater than or equal to 93 % (Mayell et al, 2006; Palm et al, 2011).

Before moving to the next stage, ensure weaning is being tolerated & consider the following:

1. Infant is thriving and weight has not plateaued. Growth is an important factor for oxygen weaning.
2. Infant's work of breathing has not increased.
3. Infant's level of activity, feeding or alertness have not deteriorated (Palm et al, 2011; Mayell et al, 2006)

It has been shown that most infants reach lowest saturations within 40mins of starting a room air challenge. Hence, the necessity for the first hour of weaning that the Community Children's Nurse be present in the home for the duration of time to assess and predict readiness for weaning (Mayell S.J., Harrison G.; Shaw N.J. 2006; Mayell et al, 2006; Balfour-Lynn et al, 2005; Primhak, 2007). On each occasion when infant's time in air is due to be stretched, a Community Children's Nurse should arrange their visit to coordinate with the additional time in air. This will be to assess work of breathing and continuously monitor their saturations for the duration of their visit. A single saturation check at the end of the time in air is NOT satisfactory (Balfour-Lynn et al, 2005). Monitor infant during a daytime oral feed at least once. If saturation levels are safe ( $\geq 93\%$ ), then oxygen can be stopped during daytime feeds. Feeding and activity times are the most likely times to stress respiratory reserve (Mayell et al, 2006; Balfour-Lynn et al, 2005; Balfour-Lynn et al, 2009). **NB: This is not applicable for babies who are tube fed.**

#### 1.6. Performing overnight oximetry study (also referred as sleep study)

Continue night-time oxygen until Overnight oximetry study (also referred as Sleep study) result is analysed, reported and reviewed by referring Consultant or Respiratory Clinical Nurse Specialist/Community Children or Neonatal Nurse within the local service that has been trained to review sleep studies. The Overnight oximetry study (also referred as Sleep study) is performed at home with a saturation monitor left with the parents/carers overnight. Parents/carers should be shown how to silence the pulse volume and reduce the alarm volume. The heart rate and saturation setting may also need to be altered following local guidance, so it does not cause unnecessary alarming. The monitor is collected the next day (to download the recording).

**(Do not forget to clear the previous data recorded in the saturation monitor).** It is important to highlight some community services have advanced oximetry monitors that have software linked digitally to the named community name computer, for speedy analysis. Parents/carers should be advised to record activity of the night (appendix 1), during the Overnight oximetry study (also referred as Sleep study) i.e. if the infant wakes up for feeding or crying, if the sensor is changed and when Overnight oximetry study (also referred as Sleep study) has completed. This is to enable correct interpretation (Everitt et al., 2020).

#### 1.7. Analysis of study

Overnight oximetry study (also referred as Sleep study) should be free of unexplained significant desaturations – however it is important to take note of any episodes of artefact and explained desaturations as part of the overall analysis e.g. episodes of distress, probe coming off, feeding etc. **(Please record these episodes on the OVERNIGHT OXIMETRY STUDY (ALSO REFERRED AS SLEEP STUDY) ACTIVITY SHEET).**

Time spent below 90 % should be no more than 5 % of the study. Mean saturation  $\geq 93\%$  (Starship Paediatric Respiratory Services, 2010, Littlewood et al, 2014, Rahimi, 2019; Balfour-Lynn et al, 2005; Everitt et al, 2020).

Parameter	Target
Mean SpO <sub>2</sub>	$\geq 93$
% time spent below 90 %	<5 % of artefact free recording

Peripheral capillary oxygen saturation of less than 90 % is associated with an increased risk of apparent life-threatening events, whereas a SpO<sub>2</sub> of 93 % or higher is not (Rahimi, 2019; Balfour-Lynn et al, 2009). Overnight oxygen should only be discontinued following Consultant's approval or Respiratory Clinical Nurse Specialist within the local service that has been trained to review sleep studies. Until then, the infant continues to stay on overnight oxygen. CCN to visit one week after oxygen is discontinued to assess infant's wellbeing as some infants may fatigue (Procaskey et al, 2018). For infants who have failed their overnight oximetry study (also referred as Sleep study) and did not meet the above parameters, it is recommended to repeat the study in 2–3 weeks duration until a satisfactory result is obtained. During this time, the infant can remain in nighttime oxygen only unless becomes unwell. **NB:** if the infant is unwell with respiratory symptoms, advise parents to stop the weaning process and place infant in 0.1L/min of oxygen 24 hours a day until assessed by a Community Children's Nurse. Restart weaning as before when fully recovered.

#### 1.8. Parents/carers involvement in the home oxygen weaning programme

The provision of home oxygen for infants with chronic neonatal lung disease meets the recommendations of the National Service Framework (NSF) for Children which states that children with complex health needs should receive coordinated high quality child and family centered services which are based on assessed needs, promote social inclusion where possible, enable them and their families to live ordinary daily lives. Parents/carers should be partners in the care delivery of their child throughout the transition from hospital to home and home oxygen therapy to weaning. Clear advice and written information should be given at every stage of the home oxygen weaning programme. At each stage, the parents/carers should be given opportunity to ask questions and the response from the health care professionals should be based on the most current evidence highlighted in this guidance or other recognised platforms. Evidently, having an infant on home oxygen therapy can be very overwhelming and place a huge emotional strain on the family. Therefore, referring or signposting parents/carers to other parent/carer support groups, buddies support or psychological therapy can minimise parental anxiety and stress. Most importantly, having a named health professional or team member delivering a coordinated home oxygen weaning care plan improves communication between parents/carers, and reduces their anxiety (Nzirawa et al., 2017); Bliss Going from the Neonatal Unit – a guide, (2020); NICE Scope published (2019) PH40 Social and emotional well-being: early years; WHO (2018)·Walston et al. (2011).

#### 1.9. Protecting the children

Parents/carers are advised about infection control, e.g. hand washing or using hand sanitisers before handling baby and minimising visitors especially those with coughs or colds (*neonates on home oxygen are more at risk of getting infection, due to their prematurity and impaired lung tissue*). During the winter season between October to the month of February, it is highly recommended that all infants under the age of two years on home oxygen therapy and/or with other co-morbidities have an immunisation called Palivizumab every 28 days. This helps to protect them from Respiratory Syncytial Virus (RSV) related infections and reduces the risk of being re-admitted to hospital (Nzirawa T: Infant immunisation cited by Green et al., 2019; Green book, 2015). ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/458469/Green\\_Book\\_Chapter\\_27a\\_v2\\_0W.PDF](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/458469/Green_Book_Chapter_27a_v2_0W.PDF)).

It is recommended that influenza immunisation should be given to children with chronic respiratory disease requiring home oxygen from 6 months as per green book guidance. Please note the vaccine is not licensed for those aged under 6 months. It is worthwhile immunising other household contacts and other caregivers to give protection to the child (Balfour-Lynn et al., 2005). [https://www.nhs.uk/conditions/vaccinations/child-flu-vaccine/https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/931139/Green\\_book\\_chapter\\_19\\_influenza\\_V7\\_OCT\\_2020.pdf](https://www.nhs.uk/conditions/vaccinations/child-flu-vaccine/https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/931139/Green_book_chapter_19_influenza_V7_OCT_2020.pdf).

## 2. Home oxygen equipment removal

Oxygen equipment can be left in the home for up to 2 weeks from the day home oxygen is weaned off. Some authors suggest leaving it in the home for up to 3–6 months during the winter period. However, there is no evidence that this is of any benefit and commissioners continue being charged for usage if it's in the home. Furthermore, there is temptation for parents/carers to re-start oxygen therapy when a re-assessment is required. Therefore, it's easier and cost effective to request for home oxygen equipment removal once the health professionals are happy with the infant/child progress off oxygen therapy. If any concerns arise, the recommendation would be to reassess the infant/child to ensure there is no further medical complications. If home oxygen therapy is needed again an emergency supply can be in place within 4 hours of a request being approved. The infant should not be discharged from the caseload until home oxygen have been removed from the home. Removal can be requested by the named nurse – CCNT or Respiratory Clinical Nurse Specialist via the oxygen company portal or in writing via an email to the provider. Parents/Carers will need to be advised to inform the HMRC that they no longer need the benefits e.g. disability living allowance as the child is no longer on home oxygen therapy.

### 2.1. Transition

Failure to reduce home oxygen supplementation after 1 year should lead to a referral to respiratory specialist to rule out concomitant conditions. If the infant has failed the oxygen weaning programme by their first birthday, the Community Neonatal Team should transfer the care to local Children's Home Care Team or Specialist Respiratory Team. If a child is about to become a young adult and has failed the oxygen weaning programme by their 16–17th birthday, a transition care plan would need to be started to ensure by their 18th birthday the CYP health care management should be fully transferred to local Home Oxygen Service Assessment and Review (HOS-AR) team. (Please see the PPLOG Transition CYP to Adult guidance [www.pplog.co.uk](http://www.pplog.co.uk)).

### 2.2. Recommendations

**Documentation:** It is important that all events are documented in the child's health record following the local Trust's record keeping guidance and NMC record keeping.

## 3. Summary

Although, the oxygen weaning guidance discusses the pathway for all children and young people, this has been done in particular to ensure that the guidance is adaptable to any age group especially the infants being followed up by the Community Neonatal Teams or Children's home Care Teams. Elements of this guidance have been used for over 15 years in community neonatal settings within North and North East London with successful outcomes based on the expert experience of health professionals delivering care to this specific group of children (Nzirawa, 2015, 2018; Wilson et al., 2019).

## Declaration of competing interest

This is to declare no conflict of interest and no funding received to produce this guidance.

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