

Guidance for Home Oxygen Weaning in the Community (PPLOG)

Version 3.0 February 2021

Review: February 2024



This document has been endorsed by:





Name	Organisation
Rebecca Smith	The Royal London Hospital- Bart's Health NHS Trust
Tendai Nzirawa (Chair)	NHS England & NHS Improvement
Sook Lin Yap	The Whittington Health NHS Trust (now Scotland)
Alison Camden	Oxleas NHS Foundation Trust

Contributors: Sook Lin Yap - Neonatal Outreach Sister

Alison Camden - Senior Community Children's Nurse

Ceara Turner - Community Children's Nurse

Tendai Nzirawa - Quality Improvement Manager & Chair to PPLOG

Caroline Lock- Respiratory Nurse Advisor Rebecca Smith- Respiratory Nurse Specialist Abigail Beddow - Paediatric Capacity Manager

PPLOG members

Tamsyn Hernandez

St Thomas Hospital, London

Tyree Rawsthorne

Meadway Health Centre, Manchester

Ceara Turner

Bromley Healthcare, London

Billie Coverly

Kings College Hospital, London

Miri Osinibi

Kings College Hospital

22009

Paediatric Pan London Oxygen Group (PPLOG)

Background

In 2018, the PPLOG Home Oxygen Discharge Bundle was launched. Significantly, based on the numerous study days that PPLOG hosted over the last three years, most of the delegates feedback highlighted the need for paediatric home oxygen weaning guidance. Therefore, early 2020 PPLOG decided to create a sub-group that only focused on reviewing current literature around weaning Children and young people (CYP) from home oxygen therapy.

In addition, a survey was conducted to investigate how the community teams across London are weaning CYP off home oxygen therapy. No doubt, as also highlighted by Garde et al (2020) huge variation was identified across London and indicated that a significant number of Trusts did not even have a standard weaning guidance for carers and staff to follow.

Literature review

Accordingly, there are numerous published articles in relation to home oxygen therapy in CYP, however the most challenging element is the unwarranted variation in practice guidance when it comes to weaning off home oxygen therapy. This variation in health care settings is either based on the services or organisations having no clear guidance or a lack of structured pathways for the weaning of home oxygen therapy for CYP (Maclean el al, 2006; Procaskey et al, 2018; Everitt et al, 2020; Garde et al, 2020, Broderick, 2018 and Nzirawa, 2018)

The lack of agreement about indications for home oxygen prescribing among specialist health professionals is another huge challenge faced by many CYP community services (Maclean et al, 2006; Garden et al, 2020 and Everitt, 2020). Based on our survey results it was identified that across London some teams started the CYP weaning programme based on the named consultant direction after the CYP had been reviewed at their first outpatient appointment. However, in some geographical areas home oxygen weaning was independently started by the named community nurse within the home setting according to the readiness of the CYP based on various assessments. This way of home oxygen weaning was also mentioned by Rhein et al (2020) and Broderick (2018). Rhein et al (2020) conducted a randomised controlled trial, one group was seen in clinic monthly and the other group did all the recording from home and then sent the data for review with feedback within 48 hours. Both groups in Rhein et al (2020) were reviewed by a senior medical doctor. Whereas, Broderick (2018) study was all done within a home setting and included data recording that was downloaded by the community nurses. Furthermore, in Broderick (2018) study the review of the data was a shared ownership between the community nurse and the senior medical doctor.

Therefore, the main issue that tends to arise within many community settings once the CYP is at home is when would be the right time to start the home oxygen weaning program and 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?

Evidently, Hayes et al (2018) highlights that there are no uniform guidelines for weaning home oxygen therapy for infants and there are only

Paediatric Pan London Oxygen Group

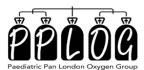
8% specialist paediatric pulmonologist that have a standardised weaning guideline. In cases, where there is weaning guidance developed it can take a long period of time to completely wean the CYP off oxygen. Based on a study by Yeh et al (2016) it took an average of 10 months to wean a child off home oxygen therapy. Furthermore, the study found that at least 32% of the children identified had non-medical supervision during the weaning process (Yeh et al, 2016). Consequently, unsupervised oxygen weaning if not done safely could lead to concomitant diagnosis of pulmonary hypertension in bronchopulmonary dysplasia infants (Yeh et al, 2016). Yeh et al (2016) points out that this is a safety concern that has some associations with high mortality rates in children that can rate between 14-38% (Yeh et al, 2016).

In cases that specialist input and supervision is part of the home oxygen weaning process, CYP can successful wean off oxygen within 7-9 weeks. This was highlighted in the studies by Rhein et al (2020) and Broderick (2018). Rhein et al (2020) found that when CYP had monthly clinic visits it took an average of 74 days to wean off home oxygen. However, when it was recorded using a home oximeter it took an average of 53 days. Whereas, Broderick (2018) found that before implementing 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 the final analyses, the literature review found that the use of oxygen therapy improves respiratory control, reduce apnoes 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 the CYP especially infants with chronic lung disease (Mayell et al, 2006; Batey et al, 2018 and 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 and 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 and Everitt, 2020).

Therefore, the aim of the PPLOG is to bring evidence-based knowledge and the experiences of Respiratory Clinical Nurse Specialists, Community Children's Nurses and Community Neonatal Nurses together, and develop a home oxygen weaning guideline for CYP on 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.

Hence a home oxygen weaning calendar was created. The calendar starts the weaning programme from a flow rate of 0.1L/min to air. Although very low flow meters exist, in theory the flow rate can be reduced further before weaning to air however there is limited evidence to support this practice. Garde et al (2020) points out that the size of the decrements used to wean oxygen flow rate, will result in infants being treated with LTOT for longer than expected. Furthermore, (Balfour-Lynn et al, 2005) argues that there is a concern that some carers may become confused with the decimal points therefore simpler and safer to start weaning off oxygen from 0.1L/min (Balfour-Lynn et al, 2005). Compared 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 conclusion, PPLOG's main ambitions are based on the WHO (2018) that 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.



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 guidelines and pathways are reviewed every three years or earlier based on any new policies or evidence-based practices.



PPLOG Home Oxygen Weaning Documents Contents:

This home oxygen weaning document consists of a guideline to wean from 0.2L/min or more following evidence-based research and a weekly calendar to wean from 0.1L/min to air. This ensures a safe and timely weaning off home oxygen. The diary is flexible depending on the community team's availability for home visits. Some teams can continue weaning over the weekend if they have the capacity. This diary is mainly focused on safe weaning between Monday to Friday. As PPLOG, we are committed to improving guidelines and pathways in order to standardize care across hospital and community settings. This guideline 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.

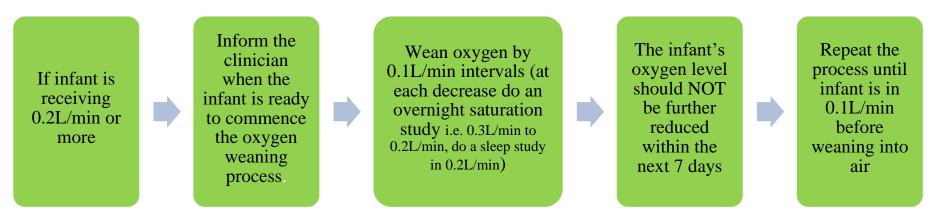
Please acknowledge PPLOG as the source.

1.	Guideline for weaning from 0.2L or more in the community	Page 8
2.	Guideline for weaning from 0.1L in the community	Page 9
3.	Week one calendar- weaning from 0.1L to air in the community	Page 9
4.	Week two calendar- weaning from 0.1L to air in the community	Page 10-11
5.	Week three calendar- weaning from 0.1L to air in the community	Page 12
6.	Week four calendar- weaning from 0.1L to air in the community	Page 13
7.	Week five calendar- weaning from 0.1L to air in the community	Page 14-15





Part A:



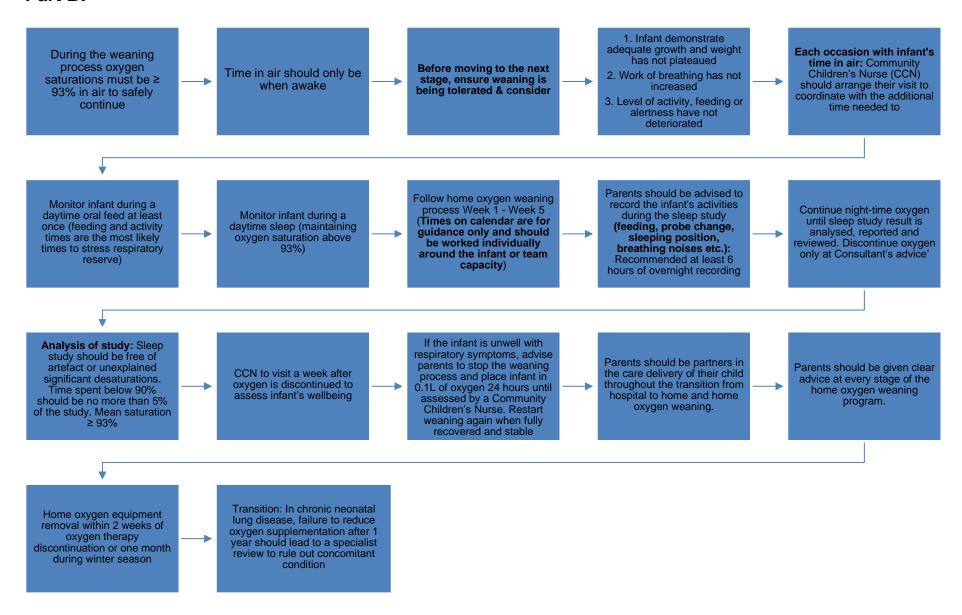
It is not necessary to perform a baseline study in the amount of oxygen the infant was discharged home in as this would have been done in the referring hospital. Obtaining a copy of the study would be useful as a comparison when you start weaning.

Evidence suggests an infant is ready to start weaning when they have demonstrated:

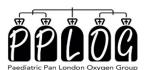
- Clinically well no significant respiratory distress, no recurrent wheeze or infections
- Adequate growth and nutrition i.e. Following along their centile charts and meeting targeted weight
- Stable vital signs heart rate, respiratory rate, work of breathing and stable oxygen saturation
- Number of hospitalisations preferably none within the last month
- Parental agreement

Process if infant is receiving (0.1L)/min or less Part B:





Home Oxygen Weaning in the Community



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

- It is not necessary to perform a baseline 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. (Appendix 2: Weaning from 0.2L/min to 0.1L/min)

(Millard et al, 2016; Mayell et al, 2006; Batey et al, 2019; Balfour-Lynn et al, 2005, 2009)

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

- Before oxygen weaning into air, the infant should be clinical stable, maintaining oxygen saturation ≥ 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 ≥ 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)
- 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 (≥ 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.

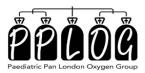


.

Home Oxygen Weaning Calendar: If infant is receiving (0.1L)/min or less



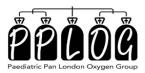
NAME:				DOB:						
NHS No:	NHS No:									
WEEK ONE	DAY ONE	DAY TWO	DAY THREE	DAY FOUR	DAY FIVE	DAY SIX	DAY SEVEN			
Times on calendar are for guidance only and should be worked individually around the infant	One hour off oxygen e.g. 10am – 11am CCN visit 10:00am for at least 45 mins to assess if patient is suitable to start weaning. Nurse to observe for any signs of respiratory distress. O2 saturation to be ≥ 93% in air. If morning visit successful parent may take infant off oxygen for another hour in the afternoon e.g. 3pm – 4pm	One hour off twice a day No CCN visit unless parent concerned about breathing	One hour off twice a day No CCN visit Phone family to enquire about infant	One hour off twice a day No CCN visit	Plan: 2 hours off oxygen if infant is making good progress and tolerated 1 hour off twice a day CCN visit at 1hr 30mins off oxygen to assess if infant can stretch to 2 hours i.e. 10-11am off, visit at 11.30am Two hours off oxygen e.g. 8-10am + 2-4pm Recommend parents to allow at least a 2-hour gap between periods of time in air.	2 hours off twice a day No CCN visit	2 hours off twice a day No CCN visit			



	DAY EIGHT	DAY NINE	DAY TEN	DAY ELEVEN	DAY TWELVE	DAY THIRTEEN	DAY FOURTEEN
	2 hours off twice a day	Plan: 4 hours off oxygen if infant is making good progress and	4 hours off a day	4 hours off a day	4 hours off a day	4 hours off a day	4 hours off a day
WEEK TWO	Phone family to enquire about infant	tolerated 2 hours off twice a day CCN visit for respiratory assessment at	No CCN visit unless parent concerned	Phone family to enquire about	No CCN visit	No CCN visit	No CCN visit
	No CCN visit unless parent concerned	3hr 30mins off oxygen to assess if infant can stretch to 4 hours i.e. 8-10am off, visit at 11.30am		infant (you are looking for any change in activity ie. Lethargy / taking extra naps / slow to feed)			
		Four hours off oxygen e.g. 7- 11am		,			
		Try working around infant's activity					



	DAY FIFTEEN	DAY SIXTEEN	DAY SEVENTEEN	DAY EIGHTEEN	DAY NINETEEN	DAY TWENTY	DAY TWENTY ONE
	Plan: 6 hours off oxygen if infant is making good progress and tolerated 4 hours off a day	6 hours off No CCN visit	6 hours off No CCN visit	6 hours off No CCN visit	Plan: 8 hours off oxygen if infant is making good progress and tolerated 6 hours off	8 hours off No CCN visit	8 hours off No CCN visit
WEEK THREE	CCN visit for respiratory assessment at 5hr 30mins off oxygen i.e. 7-11am, visit 12.30pm		Phone family to enquire about infant		CCN visit for respiratory assessment at 7hr 30mins off oxygen i.e. 08:00-14:00pm, visit 15.30pm		
	6 hours off oxygen e.g. 08:00-14:00pm				8 hours off oxygen e.g. 08:00- 16:00pm		



	DAY TWENTY TWO	DAY TWENTY THREE	DAY TWENTY FOUR	DAY TWENTY FIVE	DAY TWENTY SIX	DAY TWENTY SEVEN	DAY TWENTY EIGHT
	8 hours off	8 hours off	Plan: Day time off oxygen if infant is making	Day time off oxygen	Day time off oxygen	Day time off oxygen	Day time off oxygen
WEEK FOLID	No CCN visit unless parent concern	No CCN visit	good progress and tolerated 8 hours off oxygen	Continue in night time oxygen	Continue in night time oxygen	Continue in night time oxygen	Continue in night time oxygen
WEEK FOUR				No CCN visit	No CCN visit	No CCN visit	No CCN visit
	Phone family to enquire about infant		CCN visit for respiratory assessment at the end of the 8th hour or 9th hour off oxygen i.e. 08:00-16:00pm, visit 17:00pm		Phone family to enquire about infant		
			Remove nasal cannula when infant is awake in the morning				
			Continue in night time oxygen when infant goes to bed				



	DAY TWENTY NINE	DAY THIRTY	DAY THIRTY ONE	DAY THIRTY TWO	DAY THIRTY THREE	DAY THIRTY FOUR	DAY THRITY FIVE
WEEK FIVE	Day time off oxygen	Day time off oxygen	Plan: Undertake sleep study in air tonight	CCN visit to collect saturation monitor	Remain in night time oxygen until sleep study is reviewed by Consultant and a		
WEEKFIVE	Continue in nighttime oxygen	Continue in nighttime oxygen		Download, analyze and report sleep	decision made		
	No CCN visit	No CCN visit	CCN visit to arrange for	study			
			sleep study with parent/carer - take saturation monitor + activity record sheet	Email report to referring hospital / Consultant			

Performing Sleep study

- Continue night-time oxygen until 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 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.

Paddiatric Pan London Oxygen Group

 Parents/carers should be advised to record activity of the night (appendix 1), during the sleep study i.e. if the infant wakes up for feeding or crying, if the sensor is changed and when sleep study has completed. This is to enable correct interpretation (Everitt et al, 2020)

Analysis of study:

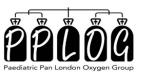
- Sleep study should be free of unexplained significant desaturations however it is important to take note of any episodes of artefact and explained desaturations as part of the overall analysis e.g. episodes of distress, probe coming off, feeding etc.(please record these episodes on Appendix 1: SLEEP STUDY ACTIVITY SHEET).
- Time spent below 90% should be no more than 5% of the study
 Mean saturation ≥ 93%

Parameter	Target
Mean SpO2	≥ 93
% time spent below 90%	< 5% of artefact free recording

(Starship Paediatric Respiratory Service, 2010, Littlewood et al, 2014, Rahimi, 2019; Balfour-Lynn et al, 2005; Everitt et al, 2020)

- Peripheral capillary oxygen saturation of less than 90% is associated with an increased risk of apparent life-threatening events, whereas a SpO2 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 <u>one week</u> after oxygen is discontinued to assess infant's wellbeing as some infants may fatigue (Procaskey et al, 2018)
- For infants who have failed their sleep study and did not meet the above parameters, it is recommended to repeat the study in 2 to 3 weeks duration until a satisfactory result is obtained. During this time, the infant can remain in nighttime oxygen only unless becomes unwell.

<u>NB</u>: 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.



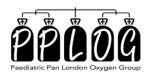
Parents/Carers involvement in the Home oxygen weaning programme:

- 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) Primary care givers of infants on home oxygen therapy; Bliss Going from the Neonatal Unit a guide, (2020); NICE Scope published (2019) PH40 Social and emotional well-being: early years; WHO (2018)

Protecting the children:

- Parents/carers are advised about infection control, e.g. hand washing or using hand sanitizers before handling baby and minimizing 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.
 - (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/458469/Green_Book_Chapter_27 a v2 0W.PDF . Nzirawa T: Infant immunisation cited by Green et al (2019) Health Promotion
- 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 immunizing other household contacts and other caregivers to give protection to the child (Balfour-





https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/931139/Green_book_chapter_19_influenza_V7_OCT_2020.pdf

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 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. 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 as the child is no longer on home oxygen therapy.

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)

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.



References:

Abbvie (2017) Synagis (palivizumab): A guide for parents. P. 3-8.

Balfour-Lynn IM, Field DJ, Gringras P, hicks B, Jardine E, Jones RC, Mage AG, Primhak RA, Samuels MP, Shaw NJ, Stevens S, Sullivan C, Taylor JA, Wallis C (2009) BTS Guidelines for Home Oxygen in Children, Thorax, Vol. 64(Suppl II), ii1-ii26.

Balfour-Lynn IM, Primhak RA, Shaw BNJ (2005) Home oxygen for children: who, how and when? Thorax, Vol. 60, p. 76-81.

Batey N, Batra D, Dorling J, Bhatt JM (2018) Impact of a protocol-driven unified service for neonates with bronchopulmonary dysplasia, ERJ Open Research, Vol. 5, 00183-2018.

Broderick J (2018) Implementing an oxygen weaning guideline for babies with chronic neonatal lung disease; Devon Integrated Children's service. NICE Shared learning

Connie A, Hillman NH (2019) Bronchopulmonary Dysplasia: When the Very Preterm Baby Comes Home, Missouri Medicine, Mar-Apr, Vol. 116(2), p. 117.122.

DeMauro SB, Jensen EA, Bnn CM, Bell EF, Hibbs AM, Hintz SR, Lorch SA (2019) Home Oxygen and 2-Year Outcomes of Preterm Infants with Bronchopulmonary Dysplasia, Pediatrics, May, Vol. 143(5), e20182955; DOI: https://doi.org/10.1542/peds.2018-2956.

Everitt LH, Awoseyila A, Bhatt JM, Johnson MJ, Vollmer B, Evans HJ (2020) Weaning Oxygen in Infants with Bronchopulmonary Dysplasia, Paediatric Respiratory Reviews, doi: https://doi.org/10.1016/j.prrv.2020.10.005.

Garde A. J, Bhatt J. M, Rjabova T and Evan H. J (2020) Home Oxygen in Neonatal Chronic Lung Disease. Poster presented Paediatric Respiratory -National survey: Long term oxygen therapy (LTOT) in neonates with chronic lung disease of prematurity

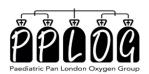
Green book (2015) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/458469/Green_Book_Chapter_27a_v2_0W.PDF

Hayes D, Cardamone S and Tobias J.D (2018) Duration of Home Oxygen Therapy in Young Children Enrolled in an Accountable Care Organisation. Annals ATS, 15(&), pp. 891-893

Krivchenia K, Hawkins SM, Iyer NP, Hayes Jr. D, Deterding RR, Ruminjo J, Thomson CC (2019) Clinical Practice Guideline Summary for Clinicians: Home Oxygen Therapy for Children, Annals ATS, Vol 16 (7), p. 781-785.

Littlewood S, Dharmaraj S (2014) Weaning Home Oxygen Therapy in Infants with Chronic Lung Disease of Prematurity, Archives of Disease in Childhood, Vo. 99, Issue Suppl 1

MacLean J. E and Fitzgerald D. A (2006) A rational approach to home oxygen use infants and children. Paediatric Respiratory Reviews, 7, pp. 215-222



Mayell SJ, Harrison G, Shaw BJ (2006) Management of infants on home oxygen, Infant, Vol 2(4), p. 147-151.

Millard K, Hurley M, Prayle A, Spencer S, Batra D, Bhatt JM (2016) Weight-based oxygen flow rate is predictive of successful weaning of long-term oxygen therapy in babies with bronchopulmonary dysplasia, European Respiratory Journal, Vol. 48 Issue supple 60, PA 1298

Nzirawa T, Haque A and Mas A (2017) Primary care givers of infants on home oxygen therapy. Journal of Neonatal Nursing, 23, pp 185-187

Nzirawa T (2015) Caring for children with complex need. Nursing Management, 22 (5), pp. 32 – 38

Nzirawa T (2018) Management of chronic lung disease infants in the community. Journal of Neonatal Nursing, 24, pp. 11-115

Nzirawa T: Infant immunisation case study- cited by Green et al (2019) Health Promotion: Planning and Strategies 4th Edition

Palm K, Simoneau T, Sawicki G, Rhein L (2011) Assessment of Current Strategies for Weaning Premature Infants From Supplemental Oxygen in the Outpatient Setting, Advance Neonatal Care, October 11(5), p. 349-356.

Procaskey A, White H, Simoneau T, Traeger n, Lahiri T, Au Jawdeh EG, Kremer T, Sheils C, Meyer K, Rosenkrantz T, Krishnan S, Hartman T, Feldman H, Rhein L (2018) The Optimization of Home Oxygen Weaning in Premature Infants Trial: Design, Rationale, Methods, and Lessons Learned, Contemporary Clinical Trials, Vol 75. P 72-77.

Primhak R (2007) Home oxygen therapy in children. Paediatrics and Child health, 17 (50), pp. 202 – 205

Rahimi S (2019) New guidelines for home oxygen therapy in children, The Lancet, Vol. 7(4), p. 301-301

Lawrence Rhein, MD, MPH1,2; Heather White, BS1; Tregony Simoneau, MD3; Nadav Traeger, MD4; Thomas Lahiri, MD5; Ted Kremer, MD2; Catherine Sheils, MD6; Kathleen Meyer, MD7; Ted Rosenkrantz, MD8; Krishnan Sankaran, MD3; Tyler Hartman, MD9; Henry A. Feldman10; Elie Abu Jawdeh, MD (2020) Monitoring Oxygen Levels of Premature Babies at Home and in the Clinic—The RHO Trial. Patient-Centered Outcomes Research Institute (PCORI). https://doi.org/10.25302/08.2020.CER.140210292

Walston F, Dixon V, May J, Harris S, Metayer L and Curley A (2011) Bridging the gap: A survey of neonatal community care provision in England. Journal of Neonatal Nursing, 17, pp. 69-78

Wilson E, Nzirawa T and Mannan K (2019) Quality of life of parents with premature babies on home oxygen therapy. Journal of Neonatal Nursing, 26 (1), pp. 49-52 http://doi.org/10.1016/j.jnn.2019.07.005

Yeh J, McGrath-Morrow SA, Collaco JM (2016) Oxygen Weaning After Hospital Discharge in Children with Bronchopulmonary Dysplasia, Pediatric Pulmonary, November 51(11), p. 1206-121





CCNT - Tick if sleep study performed in air Include the activities reported by parents	
Air Oxygen amount	
	SLEEP STUDY ACTIVITY SHEET

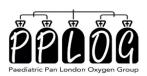
Name: DOB: NHS No: Consultant:

Please use this sheet to record any activity / concerns observed during the sleep study. This will help us to identify the artefacts when downloading the study. It is important to write on the activity sheet of the child / baby.

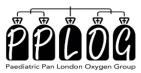
Examples: 1. Snoring 2. Asleep 3. Unsettled/Crying 4. Nappy change 5. Breathing noise 6. Sleeping position

DATE & TIME	ACTIVITY





Name:							
NHS Number:			DOB:				
	DAY ONE	DAY TWO	DAY THREE	DAY FOUR	DAY FIVE	DAY SIX	DAY SEVEN
WEEK 1	Home visit to assess infant in 0.1L/min of nasal cannula oxygen with the intention of weaning from 0.2L/min to 0.1L/min	4 hours 0.1L/min over 24 hours	4 hours 0.1L/min in 24 hours	4 hours 0.1L/min in 24 hours	4 hours 0.1L/min in 24 hours	4 hours 0.1L/min in 24 hours	4 hours 0.1L/min in 24 hours
Times on calendar are for guidance only and should be worked individually around the infant	Reduce home oxygen to 0.1L/min when you visit. Assessment should include: -infant's ability to manage in 0.1L/min while in activity i.e. feeding/ playing - assessment should also include one day-time nap if possible This should not be a spot check saturation but at least 30mins observations (aiming for SaO2 above 93%) Plan for 4 hours in 0.1L/min a day of nasal cannula oxygen						
	DAY EIGHT	DAY NINE	DAY TEN	DAY ELEVEN	DAY TWELVE	DAY THIRTEEN	DAY FOURTE EN
WEEK TWO	Home visit to increase time in 0.1L/min of nasal cannula oxygen Visit after infant have spent 4 hours in 0.1L/min i.e. 10-14pm – visit after 14pm (15/16/17pm according to team's ability) Infant is still managing well in 0.1L/min - observations are stable - no increased work of breathing - no change in daily activity - continue to gain weight Plan for 8 hours in 0.1L/min	8 hours in 0.1L/min over 24 hours	8 hours in 0.1L/min over 24 hours	8 hours in 0.1L/min over 24 hours	8 hours in 0.1L/min over 24 hours	8 hours in 0.1L/min over 24 hours	8 hours in 0.1L/min over 24 hours



	DAY FIFTEEN	DAY SIXTEEN	DAY SEVENTE EN	DAY EIGHTEEN	DAY NINETEEN	DAY TWENTY	DAY TWENTY ONE
WEEK THREE	Home visit to increase time in 0.1L/min Visit infant at the end of 8 hours in 0.1L/min if possible Your assessment should include - stable observations -no change in daily activity -continue to gain weight Plan for daytime in 0.1L/min of nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen	Day time in 0.1L/min nasal cannula oxygen
	DAY TWENTY-TWO	DAY TWENTY THREE	DAY TWENTY FOUR	DAY TWENTY FIVE	DAY TWENTY SIX	DAY TWENTY SEVEN	DAY TWENTY EIGHT
WEEK FOUR	Plan for sleep study in 0.1L/min nasal cannula oxygen	Home visit to collect saturation monitor to be downloaded and analyzed Infant remains in 0.2L/min of nasal cannula oxygen in the night until a satisfactory sleep study is obtained	Infant spends 7 days in 0.1L/min of nasal cannula oxygen before weaning into air begins				