Background

Infants with chronic lung disease can avoid prolonged hospitalisation with a well designed and well-supported home oxygen programme. Studies have also demonstrated that appropriate and selective use of home oxygen for this high-risk group may significantly reduce length of hospital stay and health care costs.

From 1999 to 2002, 14 preterm infants were discharged home from the RPA Centre for Newborn Care while still receiving oxygen. The mean gestation at birth for these infants was 26 weeks (range 24-29 weeks) and the median number days they remained on supplemental oxygen following discharge was 47 days (range 12-126 days).

Introduction

For many parents the thought of taking their infant home while still on oxygen is stressful. All management plans must therefore be made in partnership with the parents, NFST (newborn family support team) and the nursery clinicians. For some parents discharge of their infant while on oxygen may not be the best option such as those with a lack of transport options, heavy smokers or poor parenting skills. Other families may need time to adjust to the idea. The approach and management of families at this time needs to be supportive and individualised according to the needs of infant and family.

Difficulties experienced by parents caring for an infant on home oxygen include less time with family and friends, little energy or motivation to socialise, difficulty in finding a reliable care giver, impaired mobility due to associated equipment and the stress of regular visits / travel to hospital. In addition to these difficulties, anecdotal reports by parents from our programme include concerns about possible equipment failure, difficulties with the safe transport of oxygen cylinders on outings etc, reaction of friends / general public, ongoing concerns about the growth and development of their infant. Parental anxiety decreases as their infant improves and oxygen flow rates are lowered.

In addition McLean et al. reported that caring for a premature infant on home oxygen has an adverse impact on the quality of life for that period of time infants remain on oxygen, emphasising the importance of ongoing support and guidance. Recognition that discharge of premature infants while still on oxygen places substantial demands on the family unit further emphasises the need for effective discharge planning, parent teaching and domiciliary visits by skilled neonatal nurses.

Ongoing financial implications for the families with infants discharged on oxygen should be discussed. Liaise with social worker as appropriate.

Criteria for discharge on oxygen

Infants who remain oxygen dependent at time of discharge who are otherwise well and live within the Central Sydney Area Health Service may be eligible for discharge on the Home Oxygen Programme. This programme is coordinated by the NFST ext. 56435 / 56436.

As part of the discharge planning process, the NFST initiates early contact with the families of preterm and / or sick infants. On transfer of the infant from high dependency to special care, NFST in consultation with the neonatologist initiates discussion regarding possible discharge of the infant while on oxygen therapy.

Babies who are discharged on oxygen usually fit the following criteria:
• at least 36 weeks post conceptual age
• live in the area serviced by NFST or else responsibility transferred to another centre of care
• fully established on oral feeds 2–3, 6
• otherwise well with no other acute medical problem
• free of apnoea
• immunised 7
• consistently gaining weight 2, 3, 6
• without aggressive Retinopathy of Prematurity stabilised or in regression
• without continuous SpO₂ monitoring for at least one week prior to the expected date of discharge
• stable on O₂ flow rate £ 0.5L/minute 3 with satisfactory intermittent SpO₂ downloads 2–3 times / week see Nursing Management of O₂ Therapy in Infants with Chronic Lung Disease.

In addition to the infant being well, the parents should be given at least two weeks notice of the discharge date and feel confident about the care of their infant while on oxygen. With permission the family’s general practitioner will also be contacted and consulted regarding plans for the infants discharge.

**Preparation for Hospital Discharge**

Parent education is an important and effective method of preparing parents for discharge of their supplemental oxygen dependent infant 8–9. Discharge teaching of parents remains the responsibility of all team members see discharge planning policy. Encouraging parents to attend the nursery parental support and education groups is important. Specific learning needs are more appropriately explored with the NFST team (see below). This ensures consistency of information and effective assessment of the parents confidence and competence in the care of their infant - see form "Home Oxygen Therapy Check List".

**Key specific learning areas for NFST:**

• Educating the parents to recognise respiratory problems and how to decrease the risk of their occurrence. Hospital readmission in this group of infants is high, mainly due to the development of respiratory complications 10, 11, 12.

• Ensuring the parents are confident in the safe storage and use of oxygen. It is essential that both parents and other carers in the household be trained to use the equipment. Home help and any other community services should be investigated and utilised where appropriate to support the parents in the home.

• For ongoing assessment, a pulse oximeter will be periodically used for oxygen downloads pre and post hospital discharge. Monitor alarms are permanently silenced, and display dimmed. It is important for parents to understand that use of this monitor does not prevent S.I.D.S.13.

In addition the primary care givers must demonstrate

• change of the nasal catheter
• management of oxygen and change of cylinders
• correct titration of the low flow meter to deliver the prescribed amount of oxygen
• use of additional monitoring equipment if required
• signs of hypoxia and relevant action
• infant resuscitation techniques 14.

Information sheets for parents are available from the "Home Oxygen Programme Resource Folder" situated in the NFST office. This information includes:

• Oxygen in the home
• Detecting Illness or Infection in your baby
• Protecting your Baby from Infection
• Information for parents, Radicalä signal extraction pulse oximeter(Masimo Corporation)
• Infant Resuscitation Guidelines
Pre discharge visit

Early in the discharge process, the NFST should make a home visit. The main focus of this visit is to ensure the safety and logistics of caring for an infant on supplemental oxygen at home. Although no injuries to children or parents, associated with use of oxygen in the home were found in the literature, injuries to chronically oxygen dependent adults have been documented. These injuries mainly related to smoking and alternative ignition sources such as stoves or heaters. 15, 16.

In particular the nurse will focus on and discuss:

- the space needed to accommodate equipment - at least one E / two C oxygen cylinders
- that sleeping arrangements are consistent with S.I.D.S recommendations
- the type of heating used in the house - oxygen cylinders must be stored and used away from heating sources with the need for adequate ventilation as oxygen levels may build up 16
- the danger associated with smoking in the household (SIDS).17
- the importance of having an adult trained in the use of oxygen equipment caring for the infant at all times
- road accessibility
- type of fire service in the area
- distance to the nearest hospital
- the importance of maintaining a telephone connection
- avoiding infection
- immunisation

Documentation prior to discharge

In addition to routine discharge documentation - see Discharge Policy - completion of the following is required:

1. "Hospital Discharge Request O₂ Form"
2. "Programme of Appliances for Disabled People (PADP) O₂ Request Form" - application for funding
3. "Claim for Child Disability Allowance" from Centrelink / social worker

Correspondence to:

1. Telecom - Consumer Service & Revenue Department - to ensure services are not disconnected and priority coding is placed on their telephone
2. Local Fire Station - storage of flammable gas in a domestic dwelling needs to be documented by emergency services. In addition some stations may make home visit and review safety issues with parents.
3. Medical Gases Australia or Sunrise Medical Pty Ltd - for delivery and payment of medical gas and associated equipment

for sample letters see "Home Oxygen Programme Resource Folder" situated in the NFST office.

Liaise with:

1. Early Childhood Nurse
2. General Practitioner
3. Other community services as appropriate

Cost for Parents of infants on Home Oxygen Programme

- RPAH pays all costs for the 1st month following discharge
- If parents do not qualify for PADP allowance the NFST will pay for ongoing costs
- Most Health Funds will not pay benefits for home oxygen ask parents to contact their fund and discuss options
Home visits by NFST

- the first home visit by NFST is usually made the day following discharge
- visits may be made with other members of the team if appropriate for example physiotherapist / social worker
- discuss with parents their infants general progress, problems or anxieties
- assess families coping mechanisms and general wellbeing
- ensure links with community are established Early Childhood Centre and other resources as appropriate
- full physical examination (weekly)
- weight and head circumference (weekly)
- ensure satisfactory function of all equipment

1. Nutritional needs

Weinstein & Oh,\textsuperscript{18} demonstrated a 25% higher resting oxygen consumption in infants with bronchopulmonary dysplasia compared with controls and postulated this may be due to increased respiratory effort. Some authors report no difference in growth rates for low birth weight infants with chronic lung disease compared with similar preterm control groups \textsuperscript{13, 19}, while others \textsuperscript{20} reported growth failure and others \textsuperscript{21} a smaller mean head circumference but no difference in weight or length at 12 years of age. In support of this finding other studies \textsuperscript{22, 23} did not find a difference in growth at 8 and 10 years of age between infants less than 1500 with or without chronic lung disease. In addition it has been recognised by clinicians and others that infants with chronic lung disease may also go through a catch up growth phase as respiratory status improves \textsuperscript{12}.

Clinical experience however does suggest that an increase in calories may have to be considered for a slowing or plateau in growth. For infants who are bottle feeding this is usually achieved with the addition of Polyjoule a glucose polymer (one level teaspoon) to 50mls formula / EBM = 25kcal/30mls.

For breast feeding infants, further assessment of maternal supply and observation of a full feed may be required to evaluate if additional supplements or modification in feeding regimen is needed.

Episodes of oxygen desaturation during and after oral feeding have also been reported in infants with bronchopulmonary dysplasia \textsuperscript{24}. Individualised feeding strategies that incorporate parental education, change in feeding regimens or reduction in feed volume with a concomitant increase in calories may have to be considered.

2. Oxygen downloads and monitoring of O2 requirements

Infants are discharged home on oxygen when oxygen flow rate is £ 0.5L / minute \textsuperscript{3}. The ultra low flow meters used in the home have a lower limit of 20-30mls / minute and parents are instructed to leave the flow rate at the prescribed level.

Infants are not routinely referred to a respiratory physician but remain under the management of their primary neonatologist. The NFST will organise oxygen saturation downloads to assess the infants progress. This involves supplying an oximeter periodically for over night monitoring.

Parents are advised to increase flow rate and take the infant to hospital when breathing rate or effort is significantly increased, infants colour is mottled or pale or infant appears generally unwell.

In the event of cyanosis, apnoea or if the infant is unresponsive, parents have been instructed to commence first aid and dial "000" for urgent assistance.

Following discharge, the frequency of downloads is ordered by the neonatologist, in collaboration with the NFST, according to the general wellbeing and stability of the infant. The first oxygen saturation download (minimum 8 hrs) is generally performed within 48 hours of discharge as an assessment of needs. Subsequent downloads are then performed approximately 1-2 times per week and/or 24 hours following alteration to oxygen flow. In the absence of evidence to do otherwise, it is
usually more convenient for the parents to perform the download overnight, as the monitor is less intrusive. This epoch should include periods of sleep, feeding, and normal activity.

*For download procedures see "Home Oxygen Programme Resource Folder" situated in the NFST office.*

3. **Oxygen Saturation Target Range**

Due to a dearth of information in the literature, our programme has adopted a pragmatic and individualised approach to targeting these infants oxygen requirements. This regimen has been developed from our 10-year experience with home oxygen therapy and includes a tailored approach to each infants needs. Any alteration of oxygen is made with the infants weight gain and general well being in mind.

The target range for SpO\(_2\) (functional) levels is 90-95% \(^{25, 26}\).

<table>
<thead>
<tr>
<th>Condition</th>
<th>Action</th>
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<tbody>
<tr>
<td>If SpO(_2) samples are 90-95%&gt;50% of the time</td>
<td>do not alter oxygen flow.</td>
</tr>
<tr>
<td>If SpO(_2) samples are &gt; 95% more than 50% of</td>
<td>the time, then decrease flow.</td>
</tr>
<tr>
<td>time</td>
<td></td>
</tr>
<tr>
<td>If SpO(_2) samples are &lt; 90% more than 50% of</td>
<td>the time, then increase flow.</td>
</tr>
<tr>
<td>time</td>
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The download programme currently in use at RPA has been specifically developed for use with Masimo technology and is now available (click here to view). This programme demonstrates the distribution of valid SpO\(_2\) data over the download (12 - 24hr) epoch.

Ideally decisions to alter oxygen levels should be made as soon as possible following the download as it is likely that the parents will be anxious to know the results. Examination should also include assessment of the infants general well being as a labile SpO\(_2\) and other signs such as poor growth or a respiratory tract infection may result in change to oxygen titration guideline. It may be possible to examine the oxygen download using a laptop at the families home or via email thus facilitating immediate feedback.

The infants requirements may remain stable for long periods and as such the frequency of downloads may be variable. Too frequent downloads are intrusive for the parents and therefore should always be performed with consideration of the clinical needs of the infant thus avoiding unrealistic expectations when weaning off supplemental oxygen.

4. **Discharge from the Home Oxygen Programme**

Once weaned to air it is essential to perform at least one download. Parents are advised to keep oxygen in the house for up to a month following the first satisfactory download in air. This advice may vary depending on the time of year and the general well being of the infant. Review at the follow up clinic with the Neonatologist is routine for this group of infants, and will continue once supplemental oxygen has ceased. The NFST are likely to link the family into the Early Childhood Centre if not already established.

**References**


Last Reviewed: September 2003