Going home: Facilitating discharge of the preterm infant

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At the time of discharge home, parents of preterm infants in the neonatal intensive care unit often feel apprehensive and may question their ability to care for their baby. The well-planned, comprehensive discharge of a medically stable infant helps to ensure a positive transition to home and safe, effective care after discharge. This statement provides guidance in planning discharge of infants born before 34 weeks' gestational age from tertiary and community settings. Discharge readiness is usually determined by demonstration of functional maturation, including the physiological competencies of thermoregulation, control of breathing, respiratory stability, and feeding skills and weight gain. Supporting family involvement and providing education from the time of admission improve parental confidence and decrease anxiety. Assessing the physical and psychosocial discharge environment is an important part of the discharge process. The clinical team is responsible for ensuring that appropriate investigations and screening tests have been completed, that medical concerns have been resolved and that a follow-up plan is in place at the time of discharge home.

Key Words: *Apnea; Bradycardia; NICU; Screening; Thermoregulation*

Rentrer à la maison : faciliter le congé du nourrisson prématuré

Au moment du congé à domicile, les parents de nourrissons prématurés qui séjournent à l'unité de soins intensifs néonatals se sentent souvent pleins d'appréhension et peuvent remettre en question leur aptitude à s'occuper de leur bébé. La démarche de congé complète et bien planifiée d'un nourrisson stable sur le plan médical contribue à garantir une transition positive vers la maison et des soins efficaces et sécuritaires après le congé. Le présent document de principes permet d'orienter la planification du congé des nourrissons nés avant 34 semaines d'âge gestationnel dans un hôpital général ou de soins tertiaires. L'aptitude au congé est généralement déterminée par la démonstration d'une maturation fonctionnelle, y compris les compétences physiologiques de thermorégulation, de contrôle de la respiration, de stabilité respiratoire et de capacité à s'alimenter ainsi que de prise de poids. Si on soutient la participation de la famille et qu'on l'éduque dès le début de l'hospitalisation, les parents gagnent en confiance et se sentent moins anxieux. Pendant le processus de congé, il est important d'évaluer le milieu physique et psychosocial où vivra le nourrisson. L'équipe clinique est responsable de s'assurer que les examens et les tests de dépistage ont été effectués, que les préoccupations médicales sont résolues et qu'un plan de suivi est en place au moment du congé à domicile.

Preterm infants and their families experience an unfamiliar, highly technical and often overwhelming journey through the neonatal intensive care unit (NICU). As the time to go home approaches, parents may question their ability to care for their baby without the support of NICU staff and technology. The comprehensive, well-planned discharge of a medically stable infant helps ensure a positive transition to home and safe, effective care after discharge. Supporting and involving parents in the discharge process gives them confidence in caring for their preterm infant at home. This statement provides guidance to health professionals in planning the discharge to home of preterm infants born before 34 weeks' gestational age (GA) from the NICU or special care nursery of a tertiary or community centre. Discharge of late preterm infants (34 to 36 weeks' GA) is discussed in the Canadian Paediatric Society statement 'Safe discharge of the late preterm infant'.(1)

HOSPITAL STAY

For infants born at <34 weeks' GA, postmenstrual age (PMA) at discharge is usually between 37 and 40 weeks.(2,3) Variation among centres may result from differences in resources, geography and practices. Duration of hospitalization and PMA at discharge are inversely correlated with GA at birth.(4,5) Morbidities, including sepsis, necrotizing enterocolitis, retinopathy of prematurity (ROP) and bronchopulmonary dysplasia (BPD), further prolong hospital stay.(5) In Canada's regionalized system of neonatal-perinatal care, approximately 50% of preterm infants <37 weeks' GA at birth are discharged home directly from tertiary NICUs; the remainder are transferred to community hospitals before discharge.(2,3) When transfer occurs, working cooperatively toward shared discharge criteria and goals enhances the family's feeling of support with the discharge process.

Although the NICU is a life-saving environment, prolonging stay may not be beneficial. Prolonged hospitalization has been associated with poorer parent–child relationships, failure to thrive, child abuse, and parental grief and feelings of inadequacy.(6) The NICU environment of noise, bright light and lack of day-night cycling can have adverse effects on infant growth and development. Preterm infants are uniquely susceptible to nosocomial infection and multidrug-resistant pathogens. Randomized trials of early discharge programs for stable preterm infants have demonstrated not only safety but also better parental emotional well-being and quality of home life.(7-9) Shortening length of stay reduces hospital costs (although costs of postdischarge services must be included in economic analyses)(7,8,10) and increases the availability of NICU beds. A shorter hospital stay may not only benefit families socially and psychologically but also financially, by reducing costs for visiting and child care, and decreasing time off work.

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DISCHARGE READINESS

Infant competencies (physiological maturity)

Discharge readiness of preterm infants is usually determined by demonstration of functional maturation rather than weight or PMA criteria. Many infants achieve these physiological milestones between 34 and 36 weeks' PMA, although there is individual variability and extremely preterm infants often require more time.(11) Once they attain physiological maturity, most preterm infants are observed to allow a margin of safety before discharge. The four most important physiological competencies are:

- Thermoregulation
- Control of breathing
- Respiratory stability
- Feeding skills and weight gain

Thermoregulation

Although newborn preterm infants cannot regulate their body temperature as well as term infants, their thermoregulatory ability improves with maturation. Often, the ability to increase metabolism and generate heat reaches that of a term infant before 40 weeks' PMA. Weight criteria for transfer from an isolette to open cot vary among centres,(12) with little evidence to guide practice. A 2011 Cochrane review of four studies comparing transfer to cots of medically stable infants at lower weights (<1700 g) versus higher weights (>1700 g) concluded that transfer to a cot at 1600 g did not have adverse effects on temperature stability or weight gain, but did not necessarily lead to earlier discharge.(13) The room temperature in these four studies was at least 22°C. Overheating is a risk factor for sudden infant death syndrome (SIDS) and must be avoided.(14)

Control of breathing

Apnea of prematurity is defined as cessation of breathing for ≥20 s or 10 s to 20 s if accompanied by bradycardia (heart rate <80 beats/min) or oxygen saturation (SaO_2) <80% in infants <37 weeks' PMA.(15) Although most preterm infants are free of apneic and bradycardic spells by 36 weeks' PMA,(11) very preterm infants show more variability in resolution, and apnea may persist up to 44 weeks' PMA.(16) When caffeine is used to treat apnea of prematurity, many clinicians discontinue its use before discharge. The half-life of caffeine is prolonged in neonates (approximately 100 h) and infants may be at risk for recurrence of apnea for several days after it is discontinued.

Practices regarding a 'safe' apnea-free period before cessation of cardiorespiratory monitoring and discharge home vary among nurseries, likely because there are no data to support a specific period of time; such variation is one reason for differences in discharge timing.(17,18) In one survey, 74% of neonatal specialists required an apnea-free period of five to seven days before discharge, and 9% observed infants for at least 10 days.(19) Darnall et al(19) attempted to define a minimal safe period using a retrospective chart review and noted that 5% of otherwise healthy preterm infants continued to experience apneas separated by as much as eight days after the last documented episode. A more recent observational study reported that 96% of preterm infants did not experience recurrence of apnea or bradycardia after seven days from the last spell.(20) Recurrence rates were higher for infants <30 weeks' GA and for infants in whom the last spell occurred at >36 weeks' PMA. For infants <26 weeks' GA, 13 days were required for 95% to remain apnea-free. Rigorous definition of clinically significant apnea and bradycardia, and accurate and consistent documentation are crucial.(18)

Apnea of prematurity is not considered to be a risk factor for SIDS,(21) nor is there evidence to support routine home monitoring to prevent SIDS.(22) Apneic episodes noted during cardiorespiratory monitoring of otherwise stable preterm infants resolved over time and were not related to SIDS or acute life-threatening events.(23) Home cardiorespiratory monitoring is rarely indicated; it is occasionally considered for infants with unusually prolonged and recurrent apnea, bradycardia and hypoxemia, following discussion with parents about risks and benefits.

Cardiorespiratory events associated with feeding are common in preterm infants due to incoordination of sucking, swallowing and breathing. The severity of these events (ie, bradycardia, colour change, intervention needed) should be assessed individually and events that are considered to be significant should be resolved before discharge.

Recognized strategies to reduce the risk of SIDS should be emphasized with parents(14) and preterm infants placed in the supine position before discharge. Even infants with BPD maintain cardiorespiratory stability in this position.(24) Preterm infants are at increased risk of apnea and oxygen desaturation when placed in a semiupright position in an infant car seat.(25) SaO_2 monitoring of preterm infants while in their car seat may detect such events before discharge home.(26)

Respiratory stability

Some very preterm infants require prolonged ventilatory support because of BPD and may be >34 weeks' PMA when such support is discontinued. Observing these infants is important to ensure that cardiorespiratory stability without ventilatory support is maintained.

Approximately 25% of surviving preterm infants with birthweights <1500 g receive oxygen beyond 36 weeks' PMA.(3) There is little evidence to guide clinicians in setting appropriate SaO_2 targets for infants with prolonged oxygen dependency. Two trials comparing low (89% to 94%) versus high (95% to 99%) SaO_2 targets for growing preterm infants(27,28) did not show differences in growth or neurodevelopment. Respiratory morbidity (pneumonia, acute exacerbations of chronic lung disease, rehospitalization for pulmonary causes and the need for diuretics, methylxanthines and/or oxygen) as well as duration of oxygen therapy were greater in the higher SaO_2 groups. The only benefits conferred by higher SaO_2 targets were a nonsignificant reduction in progression to threshold ROP(27) and a modest decrease in retinal ablative therapy for severe ROP.(28) No studies have examined the impact on complications associated with BPD, such as pulmonary hypertension. It is important to note that the SaO_2 value of 88%, used in the physiological definition of BPD as the lowest acceptable SaO_2 for preterm infants, is not intended as a guideline for oxygen administration for these infants.(29)

Most authors suggest a target SaO_2 of approximately 90% to 95% for infants with BPD.(30-33) This allows a margin of safety for times when infants may experience oxygen desaturation, such as sleep and feeding. Oxygen is weaned and discontinued when infants consistently maintain this target SaO_2 in room air. Many centres monitor SaO_2 in room air for approximately one week before discharging to home.(33,34)

Some infants with prolonged oxygen dependency may be candidates for home oxygen therapy. In making decisions about home oxygen, each family's needs should be considered individually, balancing the burden of prolonged hospitalization with the impact of caring for an infant on home oxygen.

Feeding skills and weight gain

Safe oral feeding requires infant maturity and readiness to coordinate sucking, swallowing and breathing to avoid aspiration and respiratory compromise. Preterm infants, especially those with BPD,

often experience difficulties transitioning from gavage to oral feedings that can delay discharge.(35) Early introduction and advancement of oral feeds based on the infant's individualized cues, state and behaviour, rather than a predetermined feeding schedule, have been shown to lead to earlier attainment of full oral feeding and decreased length of stay.(36,37)

Infants with prolonged respiratory issues may experience disruption of oral-motor skills because of abnormal tactile stimulation of perioral and intraoral tissues resulting from their long-standing needs for endotracheal and nasogastric tubes, and/or nasal prongs.(38) It has been suggested that there is a critical period during late gestation and early postnatal life when manipulation of the facial area may lead to oral aversion and delay attainment of oral-motor skills and transitioning to oral feeds. Offering non-nutritive sucking during gavage feeding significantly shortens length of stay in hospital and also facilitates transition from tube to oral feeding.(39)

Although breast milk provides many benefits for preterm infants, breastfeeding rates are lower for preterm than term infants. Many clinicians try to avoid bottle feeds during establishment of breastfeeding, but there is insufficient evidence that using tube feeds alone to supplement breast feeds increases breastfeeding success for preterm infants.(40) Supplementation with cup feeds may increase the number of babies discharged home fully breastfeeding but also delays discharge by approximately 10 days.(40)

Preterm infants often have nutritional deficits at discharge and may require hypercaloric feedings and nutritional supplements for catch-up growth.(41) Iron deficiency is a risk, and iron supplementation during the first year improves hemoglobin levels and iron stores.(42) Vitamin D is important for adequate bone mineralization; however, optimal supplementation during the first year of life is not yet established. The American Academy of Pediatrics recommends ensuring a daily intake of 400 IU/day, up to a maximum of 1000 IU/day.(43) Although study findings have been promising, further trials are needed to support the routine use of multinutrient fortification of breast milk after discharge.(44,45)

Gastroesophageal reflux (GER) is likely physiological in most preterm infants, with minimal clinical consequences.(46,47) The evidence suggesting an association between GER and apnea is variable, with studies both supporting and refuting a causal relationship.(48) A small number of preterm infants demonstrate significant problems associated with GER, including aspiration and recurrent vomiting. Treatment may be warranted for such infants, although the efficacy of most antireflux strategies has not been extensively studied in large clinical trials.

Family and home

Although parents assume full responsibility for their infant's care following discharge, many do not feel fully prepared for this role when they take their baby home.(49) As well as providing basic infant care, such as feeding, bathing and temperature-taking, parents of preterm infants may need to administer medications and nutritional supplements, and meet specific medical needs. They should be able to recognize early signs and symptoms of illness and know how to respond. Emotional readiness for discharge is equally important. Parents must feel confident in their ability to parent.

Preterm birth and prolonged hospitalization are family stressors that can place vulnerable infants at risk of neglect, failure to thrive and adverse developmental outcomes. Demographic factors, including low educational level, poor socioeconomic circumstances, young maternal age, language barriers and inadequate housing, as well as inadequate prenatal care, the use of illicit substances or alcohol, depression, isolation, lack of family support, unstable parental relationships and infrequent family visiting during NICU stay may increase this risk.(50) Assessing the physical and psychosocial environment at home is an important component of the discharge process. Involving all members of the health care team – especially nurses and social workers – early in the NICU course in providing emotional support, assessing risk and advocating for financial and community resources is critical to ensure the safe discharge of high-risk neonates.

PREPARING FOR DISCHARGE

Discharge planning begins at the time of NICU admission. Promoting family involvement in their infant's care, ongoing communication, enhancing parental understanding of their infant's medical issues, along with anticipatory guidance on preterm infant development and behaviour, all help to decrease parental stress and anxiety and facilitate safe transition to home. Family-centred care maps, developmental care, facilities where parents can stay with their infant (single-room design or family rooms) and programs to help parents interact with their infant are strategies that enhance communication and parent–infant interaction, improve family satisfaction and mental health outcomes, and decrease length of stay.(51-56) Clarifying parental benefits helps working parents to plan employment leave during their infant's hospital stay. Ongoing parent education at the bedside, in parent groups, and with electronic and printed resources is essential. If infants are transferred to community hospitals before discharge, preparing parents for the transfer engenders trust and confidence.(57)

As the infant approaches physiological maturity, the health care team should discuss an anticipated time of discharge with the family. Mothers (and fathers) who have returned to work should make arrangements for parental leave commencing one to two weeks before anticipated discharge, so they can spend more time with their baby and so mothers may establish exclusive breastfeeding. Specific parental education needs include SIDS prevention and supine sleep positioning, cardiopulmonary resuscitation, car seat safety, minimizing infection risks and their infant's specific medical needs. Parents who smoke can be offered smoking cessation help, if available. Parents should choose a primary care physician for their infant with guidance from the discharge planning team.

The health care team should review the infant's hospital course to determine whether there are unresolved medical issues and to develop a discharge and follow-up plan. Immunizations should be given in accordance with the provincial/territorial schedule at the appropriate chronological age. Preterm infants with a birthweight <2000 g who receive hepatitis B vaccine require four doses.(58) Appropriate investigations and screening tests, including newborn screening, assessment for respiratory syncytial virus (RSV) prophylaxis,(59) cranial imaging, ROP screening,(60) a hearing screen,(61) and car seat SaO_2 monitoring(26), must be completed before discharge.

Coordinating follow-up is the responsibility of the discharge team. Transitioning medical care can be enhanced through discussion between the team and the identified primary care physician, and by providing written information about the infant's hospitalization, medical issues and ongoing care plan. It may be helpful for the primary care physician to visit the infant and family before discharge. Following discharge, ongoing neonatal/paediatric support for the primary care physician should be available. The initial appointment should be booked before discharge. Follow-up appointments with other medical and surgical specialists depend on the infant's needs. Specific recommendations for RSV prophylaxis(59) and ROP screening(60) are available. In Canada, neurodevelopmental follow-up for high-risk preterm infants is

provided by neonatal follow-up programs; criteria for follow-up vary among individual programs.(62)

Services, such as predischarge visits from community service agencies, in-hospital care-by-parent rooms, parent support groups and collaborations with experienced NICU parents, are an invaluable component of discharge planning. They provide emotional support and help dispel feelings of isolation and loneliness.(63) Permitting families to take babies home on a day pass, having a team member accompany the infant home, and follow-up phone calls and home visits by public health nurses may also facilitate the transition from hospital to home.

Discharge planning for the preterm infant requires a systematic and interprofessional multidisciplinary approach. Parents have an active role in discharge planning and require support both before and after discharge. Health care providers are responsible for ensuring that the family achieves these competencies along the continuum from NICU to home.

RECOMMENDATIONS

The following recommendations address a broad spectrum of neonatal care and are generally drawn from Level 2 or 3 evidence.(64) They were developed from the best available evidence, by consensus, and are consistent with evidence-based practice.(65)

- Nurseries caring for preterm infants must implement strategies to educate parents about their infant, promote parental involvement with their infant and prepare parents for their infant's transition to home.
- Preterm infants should be considered ready for discharge home when they are medically stable and have attained physiological maturity, including the following measures:
  - maintenance of normal body temperature (approximately 37°C) when fully clothed, in an open cot;
  - an apnea-free period of sufficient duration (at least five to seven days is suggested);
  - maintenance of SaO_2 >90% to 95% in room air;
  - sustained weight gain; and
  - successful feeding by breast and/or bottle without major cardiorespiratory compromise.
- Before discharge home, preterm infants must be completely evaluated, including:
  - provincial newborn screening;
  - assessment for RSV prophylaxis and administration, if indicated;
  - cranial imaging at near-term, if indicated by gestational age;
  - retinopathy of prematurity (ROP) screening, if indicated by gestational age or birthweight;
  - hearing screening;
  - successful SaO_2 monitoring in their car seat;
  - immunizations according to chronological age and provincial/territorial schedule; and
  - predischarge physical examination, including measurement of weight, length and head circumference.
- The discharge team must determine each family's caregiving and psychosocial readiness for their infant's discharge, including assessment of the home environment. The family should receive predischarge education that includes safe sleep practices and SIDS prevention. Infant cardiopulmonary resuscitation training is highly desirable.

  Parents should be able to:
  - independently and confidently care for their infant;
  - provide medications, nutritional supplements and any special medical care;
  - recognize signs and symptoms of illness and respond appropriately, especially in emergency situations; and
  - understand the importance of infection control measures and a smoke-free environment.
- The infant's health care team must ensure that an appropriate follow-up plan is in place before discharge, and that all aspects of the plan are communicated to and understood by the parents. Follow-up may include:
  - identification of and communication with the identified primary care physician, and providing a written or electronic summary of each infant's birth history and care;
  - follow-up by a qualified health care professional within 72 h;
  - medical and surgical follow-up appointments as required, including ROP screening;
  - neonatal neurodevelopmental follow-up, if indicated;
  - follow-up of hearing and newborn screening results;
  - RSV prophylaxis, if required;
  - community resources and supports; and
  - a neonatologist's or paediatrician's advice and support to the primary care physician, as needed.

Note: Information for parents, 'Your newborn: Bringing baby home from the hospital', can be accessed at www.caringforkids.cps.ca.

ACKNOWLEDGEMENTS: This position statement was reviewed by the CPS Community Paediatrics Committee and by the College of Family Physicians of Canada.

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