



# **Discharge Best Practices** *for the High Risk Infant*

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## Overview

The American Academy of Pediatrics (AAP) policy statement on the hospital discharge of the high-risk neonate continues to address 4 categories of high-risk infants: preterm infants; infants with special health care needs or dependence on technology; infants at risk because of family issues and infants with anticipated early death. The rate of preterm births has been on the rise since 2014 with 10% of all births in the United States comprised of infants less than 37 weeks' gestation (Connors 2021).

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High-risk infants are at increased risk for morbidity and mortality following discharge from the Neonatal Intensive Care Unit (NICU). The decision on when to discharge these infants home is complex, without clear supporting evidence and largely based on medical condition (AAP Committee on Fetus and Newborn 2008). However, the discharge readiness of families to assume care is ultimately the piece that can determine the success or failure of transitioning care to home (AAP Committee on Fetus and Newborn 2008, Smith 2013)

Edwards et al (2021 p.6) found that gestational age and weight at discharge increased steadily from 2005 to 2018 for infants 24 to 29 weeks' gestation with undetermined causes, benefits and costs. It is unclear if this delay in discharge and ultimately increased separation from family leads to improved discharge readiness since the most suitable discharge age and weight are largely unknown (Edwards 2021).

Smith et al (2013, p. 415) defines NICU discharge readiness as 'the masterful attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the primary caregivers at the time of discharge' (Smith 2013). Although not as well studied as in the adult population, discharge unreadiness in caregivers of newborns, perceived either by themselves or their providers experience more difficulty post discharge (Bernstein 2002).



For instance, one study of families with preterm infants, discharge unreadiness was associated with more infant feeding related issues in the days after discharge (Smith 2012). In a study of mothers of term infants who felt unready for discharge made twice as many phone calls to their PCP on behalf of their infants, placed their infants in the prone position for sleep more often and had a higher likelihood of a newborn emergency room or urgent care visit during the first 30 days after discharge (Bernstein 2002).

Length of stay has not been independently associated with discharge readiness; however, caregivers of complex infants may require more time to achieve discharge readiness (Smith 2009). Discharge readiness is largely supported by a robust discharge preparation plan. The art of balancing length of stay to avoid increased separation of patient from family, increased health care costs and the risks inherent with a prolonged hospital stay with discharge readiness of caregivers begins at the NICU admission.

Discharge planning for the high risk infant is a multidisciplinary effort that should be initiated soon after the infant is admitted to the NICU and included in the care plan on a daily basis. An individualized approach should be adopted to meet the needs of the various medical and social concerns unique to each patient. Parents or other appointed caregivers must be included in the process with the neonatologists, nurse practitioners, bedside nurses and other multidisciplinary team members involved with the infant's care. When appropriate, input from the hospital and/or community social service departments, lactation specialists, physical therapists, nutritionists, respiratory therapists, and case managers should be solicited. Special situations may require the expertise of medical and/or surgical sub-specialists and other individuals as deemed necessary (AAP Committee on Fetus and Newborn 2008).

Several broad categories of discharge readiness should be incorporated into the discharge plan that include, but are not limited to, specific medical, family and psychosocial criteria. Published guidelines have identified important components that include: attending to parental education, primary care, ongoing medical conditions, home care, social support and follow-up care coordination (AAP Committee on Fetus and Newborn 2008). All of this is aimed at achieving a seamless care transition.

## Medical Readiness

For the premature infant, specific physiologic parameters to be met prior to safe discharge were identified in a large cohort of NICU patients (Silber 2009) that include: maintenance of body temperature fully clothed in an open crib at room temperature (20- 25°C or 68-77°F); coordination of suck, swallow, and breathing while taking an adequate feed volume; sustained pattern of weight gain compatible with the post-menstrual age (PMA) of the infant; demonstration of stability in cardiorespiratory function for a specified period of time; oxygenation status: infant is weaned to room air or is stable on portable oxygen (Kemper 2011) and the ability of the family to care for the fragile premature infant must be evaluated and demonstrated.

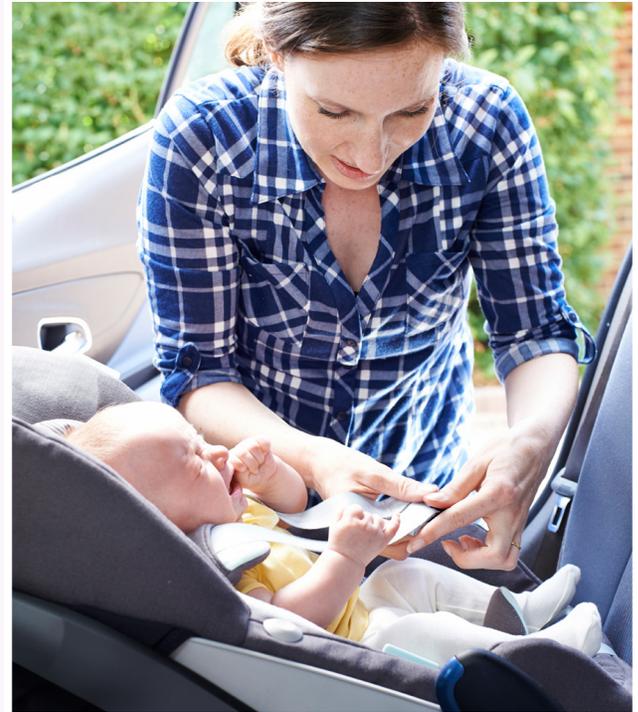
The criteria listed are consistent with previously published guidelines from the American Academy of Pediatrics (AAP Committee on Fetus and Newborn 2008). ProgenyHealth suggests these parameters in conjunction with other proprietary criteria to assess an infant's clinical stability and preparedness for discharge:

1. **Body temperature:** The infant has demonstrated adequate maintenance of normal body temperature fully clothed in an open bed with normal ambient room temperature (20–25°C or 68–77°F) (AAP Committee on Fetus and Newborn 2008).
2. **Feeding/Nutrition:** The infant has established competent feeding by breast or bottle without cardiorespiratory compromise. A sustained pattern of weight gain of sufficient duration has been Demonstrated (AAP Committee on Fetus and Newborn 2008, AAP Section on Breastfeeding 2000). The infant should be capable of nipple feeding adequate calories in order to maintain desired growth and weight gain. Human milk is desirable and support should be provided to all mothers who wish to breast feed. Hypercaloric feedings may be required and/ or supplements as necessary. Lactation consultants or nutrition/feeding specialists will play an important role in this area. One or two days of observation may be necessary for growth restricted or low birth weight infants, whereas near-term babies may require a lesser amount of time. If oral feedings cannot be achieved by 44 weeks PMA, then gavage or gastrostomy tube feedings should be considered as clinically indicated (AAP Committee on Fetus and Newborn 2008, AAP Section on Breastfeeding 2000).
3. **Cardiorespiratory control:** Physiologically mature and stable cardiorespiratory function has been documented for a sufficient duration (AAP Committee on Fetus and Newborn 2008, Kemper 2011).<sup>1,3</sup> The infant's oxygen saturation should be normal for baseline. If being discharged on oxygen, oximetry readings on home oxygen settings should be documented.

## Special Testing

- **Hearing:** Audiologic screening should be performed and follow-up should be arranged for referrals and/ or additional testing as indicated for infants at high risk for hearing loss (Joint Committee on Infant Hearing 2007).
- **Eye exam:** Evaluation by a pediatric ophthalmologist should be performed or scheduled according to published guidelines and rigorous outpatient follow-up should be arranged for at risk patients who require serial retinal examinations (AAP Section on Ophthalmology 2006). The time, date and location of the first post discharge outpatient ophthalmology appointment should be documented in the hospital chart.

◦ **Car seat and car bed:** Per AAP report: “Hospitals should develop protocols to include car safety seat observation before discharge for infants born at less than 37 weeks’ gestation. Some hospital protocols include car safety seat observations for infants at risk of obstructive apnea, bradycardia, or oxygen desaturation other than those born at less than 37 weeks’ gestation. Examples include infants with hypotonia (e.g., Down syndrome or congenital neuromuscular disorders), infants with micro- gnathia (Pierre Robin sequence), and infants who have undergone congenital heart surgery” Bull et al 2009). Infants with documented oxygen desaturation, apnea, or bradycardia in a semi upright position should travel in a supine or prone position in an FMVSS 213 (Federal Motor Vehicle Safety Standard) approved car bed after an observation period. The AAP AAP Committee on Fetus and Newborn does not speak to frequency of apnea and bradycardia events or level of oxygen saturation that would lead to use of a car bed; rather the report states “...deemed significant by the treating physician or hospital policy...” (AAP Committee on Fetus and Newborn 2008 p. 6). Specific information regarding currently available car beds can be obtained from several resources (AAP Committee on Fetus and Newborn 2008).



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Infants documented with oxygen desaturation, apnea, or bradycardia in a semi upright position should travel in a supine or prone position

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**CCHD(Critical Congenital Heart Disease) Screening:** The AAP, American Heart Association (AHA), and American College of Cardiology (ACC) endorse universal newborn screening for CCHD using pulse oximetry (Mahle et al 2012, Kemper et al 2011). According to the 2019 report from the United States Centers for Disease Control and Prevention (CDC) all 50 states and the District of Columbia have implemented critical CHD screening policies (Glidewell et al 2019). All newborns should be screened according to the algorithm adopted by the facility.

## Other Considerations

1. **Jaundice:** Though hyperbilirubinemia may not be an issue for the ELBW infant at the time of discharge, near-term and term infants who are discharged while bilirubin values remain elevated may remain at risk for bilirubin encephalopathy. Therefore, use of established nomograms and guidelines for phototherapy and exchange transfusion should assist the clinician with bilirubin determinations as an outpatient.
2. **Home apnea monitoring:** Discharge of an infant with a home apnea monitor may be considered for infants who have not demonstrated an apnea free period, who require home oxygen or methylxanthine therapy or who satisfy AAP criteria (AAP Committee on Fetus and Newborn 2003). Parents and caregivers should receive basic cardiopulmonary support (BCS) and monitor training and, if necessary, referral to community (BCS) training can be made. Strong consideration should be given for caregivers of all infants discharged from the NICU to receive training in choking prevention, BCS and first aid, even if a home monitor is not indicated.

3. **Medications:** Medication dosing and administration instructions should be completed and the parent should receive a medication instruction sheet confirmed by the medical and nursing staff. The child should be discharged with an adequate supply of medication until a refill can be obtained from the infant's primary care physician (AAP Committee on Fetus and Newborn 2008).
4. **Home oxygen:** Arrangements should be made for the child to be discharged with home oxygen if discharge readiness has otherwise been achieved and other criteria have been met. Follow-up with a physician who can assess and monitor the infant's ongoing need for home oxygen should be arranged on a regular basis (AAP Committee on Fetus and Newborn 2008).
5. **Neurological:** Appropriate follow-up imaging studies such as a cranial ultrasound or an MRI scan should be arranged and referral to a neurologist as clinically indicated. An early intervention referral and appointment in a NICU follow-up program should be confirmed for infants requiring these services (AAP Committee on Fetus and Newborn 2008).
6. **Sub-specialty care:** Follow-up appointments with consultants or other subspecialists who have examined or need to assess the child if services were unavailable in the NICU, should be arranged (AAP Committee on Fetus and Newborn 2008).
7. **Metabolic screening:** Department of Health mandated screening test results should be reviewed and repeat testing performed as indicated (Newborn Screening Authoring Committee 2008).
8. **Immunizations:** Vaccinations should be administered as per AAP guidelines (Pickering et al 2008).
9. **RSV prevention:** Palivizumab should be administered as per AAP guidelines (Committee on Infectious Diseases and Bronchiolitis Guidelines Committee 2014).
10. **Sleep position and behavior:** AAP guidelines regarding supine sleep position in all infants, except under extraordinary circumstances, should be promoted. Use of pacifiers (after establishment of breast feeding) and avoidance of bed sharing should be reinforced. SIDS reduction strategies outlined by the AAP Task Force on SIDS Reduction should be acknowledged (Task Force on Sudden Infant Death Syndrome 2016).



**Relevant state and local guidelines:** These guidelines should be followed related to newborn screening.

## Family Readiness

1. **Home visits:** Home visitation should be arranged as necessary for home assessments and/or outpatient lab testing by a home care nurse. The social status and support network assessment by the social worker should be reviewed and referral to outside social agencies may be indicated for additional input and/or a home environment assessment before discharge. If a home visit is not available then a visit to the primary care physician's office should be arranged.
2. **Smoking:** Smoking in the vicinity of the baby or his/her domicile should be strongly discouraged. Referral to smoking quit lines for family members should be considered (1-800-QUIT-NOW/1-800-784-8669 or in Spanish, 1-855-DÉJELO-YA/1-855-335-3569) (AAP Committee on Fetus and Newborn 2008).
3. **Discharge teaching:** Well baby care instructions should be provided and demonstrated by the caregiver. An "overnight" stay or other extended period of time should ideally be offered to parents of babies who have multiple discharge needs such as home monitors, oxygen, medications or other social situations that would benefit from such an exercise (AAP Committee on Fetus and Newborn 2008). Should this be determined to be necessary, scheduling should take place in advance of the proposed discharge date so that hospitalization is not prolonged unnecessarily.

4. **Financial:** Case managers and social workers can assist by arranging appropriate insurance coverage and assessing additional needs of the family such as access to utilities (e.g. water, heat), phone service and transportation.
5. **Psychosocial support:** Social workers, counselors and chaplains may become involved with the family to provide emotional or spiritual support. Identification of risk factors for the development of post-partum depression should lead to intervention. Awareness by the parent of “shaken baby syndrome” through handouts or videos should be made available and common frustrations of parenthood should be discussed so that the caregiver can recognize the need to seek help. Referral to outpatient treatment centers or physicians for counseling, drug rehabilitation or any other concerns should be implemented as appropriate. Contact information including caregiver’s names and telephone numbers should be confirmed with the family prior to discharge (AAP Committee on Fetus and Newborn 2008).

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Identify a primary care physician prior to discharge regarding infant’s history, treatments and ongoing health care needs.

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## Community Readiness

1. **Primary care:** A primary care physician should be identified and communication should occur with this physician prior to discharge regarding the infant’s history, treatments and ongoing health care needs. An appointment should be arranged within a reasonable period of time, preferably within 3-5 days of discharge. Follow-up should be sooner, within 1-3 days of discharge, for an infant with hyperbilirubinemia or an oxygen requirement. The family should be given the appropriate contact information to reach their primary care physician after discharge. An additional facsimile should be sent to the office that includes a summary of the infant’s current clinical status, followed by a comprehensive discharge summary (AAP Committee on Fetus and Newborn 2008).
2. **Sub-specialty care:** If the infant needs sub-specialty follow-up, appointments should be made prior to discharge and noted in the chart. Follow-up appointment and notation in the chart is especially crucial for ongoing retinal exams (AAP Section on Ophthalmology et al 2006).

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## About ProgenyHealth

ProgenyHealth's 130+ full-time, NICU-specialized physicians and nurses have managed nearly 100,000 cases to-date, working collaboratively supporting their colleagues on the front lines of hospitals across the country. The benefit to our plan partners is consistent and accurate authorizations which ensure that each and every infant receives the right level of care in the right setting, based on their unique clinical circumstances and health care needs.

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