Transitioning Newborns from NICU to Home:

A Resource Toolkit

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Overview: Improving the Quality of the Transition Home from the NICU

Infants born preterm or with complex congenital conditions are surviving to discharge in growing numbers and often require significant monitoring and coordination of care in the ambulatory setting.

This toolkit includes resources for hospitals that wish to improve safety when newborns transition home from their neonatal intensive care unit (NICU) by creating a Health Coach Program, tools for coaches, and information for parents and families of newborns who have spent time in the NICU.

Although the transition of the fragile infant from intensive care specialist to the ambulatory care provider begins prior to hospital discharge, it is incomplete until the infant receives appropriate outpatient followup with their designated primary care provider. Over the days or weeks after discharge from the hospital, the infant is especially vulnerable to errors related to poor care coordination and incomplete communication because the responsibility for care is often not clearly specified. During the discharge planning and transition process, a Health Coach can help prepare the family to meet the needs of their fragile infant competently and confidently.

The Health Coach serves as a teacher, facilitator, and coach, remaining sensitive to parent/caregiver needs as they enact all these roles. This connection, void of bedside clinician responsibilities, offers the parent/caretaker an environment to openly express their fears or concerns that will ultimately create an improved partnership with the direct care providers.

This manual is designed to be adapted for any institution that cares for fragile newborn infants.

The aim of this program, which was originally developed and tested as the "Safe Passages" program at Texas Children's Hospital in Houston, is to facilitate care transition from the NICU to ambulatory followup by enhancing the discharge process. The primary components of the intervention are:

- Tools for Hospitals to Create a Health Coach Program
- Tools for Health Coaches
- Information Packets for Families
- Clinical Materials to Share With Primary Care Providers

Tools for Hospitals to Create a Health Coach Program

Basic Components of the Health Coach Program

Achieving a high degree of care coordination and communication is critical to assure the safety of the discharge process and as a result achieve good outcomes. Collaboration occurs in four areas.

1. The Health Coach teaches caregivers how to coordinate care for their infant, which fosters independence.
2. The discharge process is standardized to include the use of an enhanced personal health record (PHR) and specific instructions, including handouts tailored to the needs of individual infants and families, so that caregivers recognize and respond appropriately to common problems that infants encounter in the post discharge period.
3. Information technology (IT) is used to enhance communication with caregivers and with community providers, in particular the primary care provider. Health IT has the potential to facilitate communication and coordination of care among the several disciplines and settings of ambulatory care but is not a required component of this intervention.
4. Clinical materials, specific to each infant, are provided to primary care providers (PCPs) to enhance their knowledge and skill in managing the common problems of NICU graduates. This information should be provided electronically if possible.

The structural elements of the discharge process are the organization and system, caregiver, infant, NICU team, and PCP. Better outcomes result from effective processes, and poor outcomes result from ineffective processes (poor communication, poor understanding by caregiver, lack of knowledge and skills by PCP, and non-standardized discharge process).

Key processes include:

- Family (caregiver) education/empowerment
- Use of IT
- Toolkits
- Standardized discharge templates (if these are part of the electronic records management system in use)
- Well-informed PCP

Key outcomes include:

- Healthy, safe infants
- Fewer emergency department visits and missed appointments

- Competent, confident caregivers
- Enhanced caregiver satisfaction

The Health Coach is a skilled, sensitive professional who helps families to become competent and confident caregivers who can advocate for the needs of their infant. Thus, the role of the Health Coach is as an educator, not as a caregiver. While the background of the Health Coach could be in nursing or social work, in our experience, an experienced, master's-prepared health educator may be better able to "coach" parents rather than "do for" them. Previous experience in patient education is vitally important. Training in specific skills in the NICU can be accomplished during the orientation period.

Training and Scheduling of the Health Coach

Once identified, the Health Coach should be properly trained on the enhanced discharge process. During orientation, introduce the Health Coach to the entire NICU health care team. Familiarize the Health Coach with local PCPs and family advocacy groups. Attending staff meetings; hosting "meet and greets;" and placing signage in the units, newsletters, and emails are all effective methods to get the word out about your new Health Coach.

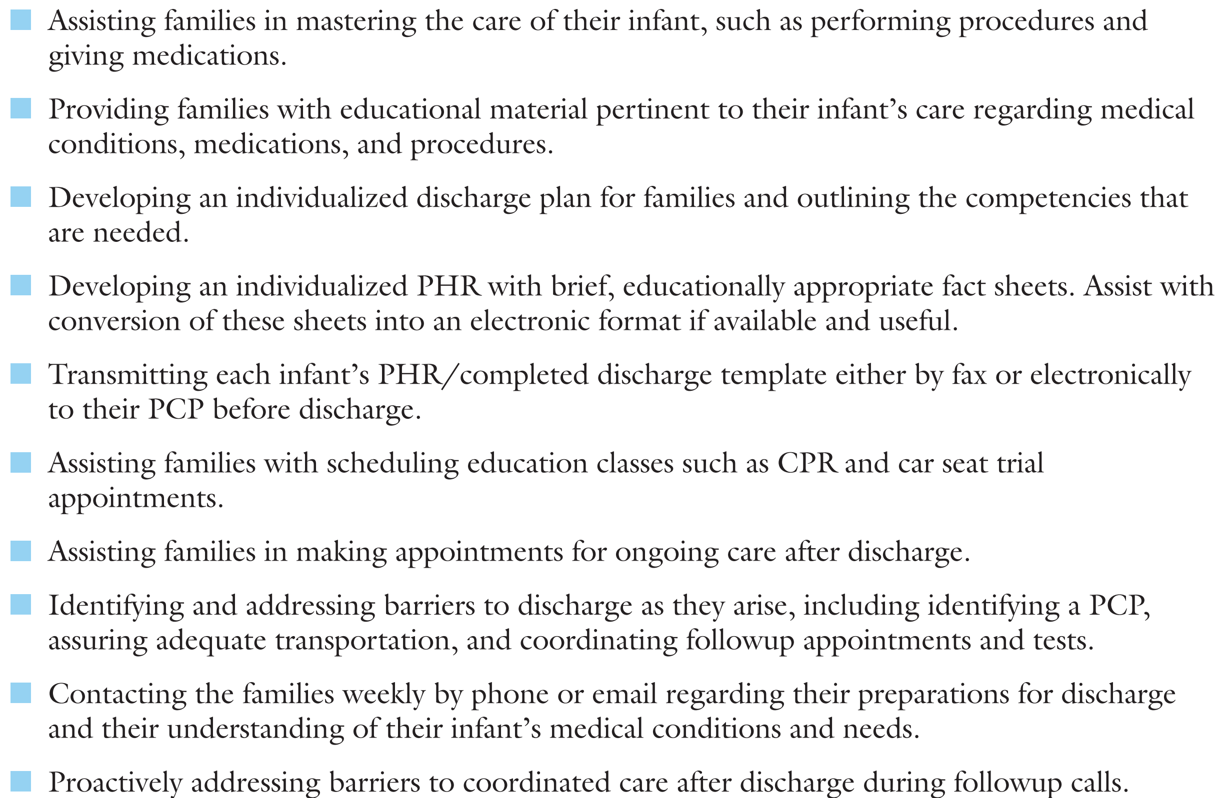
It is important for the Health Coach to be accessible to the familes and health care team, whether by pager, phone, or email. Some families visit only in the morning, some only at night, and some stay throughout the day.

The Health Coach should be available during non-traditional hours to accommodate families. For example, the Health Coach may have 2 late days per week to meet with families that visit in the evenings. Also, the Health Coach may have a mid-shift of 11:00 a.m. to 7:00 p.m., as opposed to a traditional 8:00 a.m. to 5:00 p.m. schedule.

Elements of a Health Coach Job Description

The activities of the Health Coach in the NICU setting include the following:

- Acting as a teacher, facilitator, and coach, remaining sensitive to family/caregiver needs to foster the development of families into competent caregivers for their fragile infant.
- Coaching families/caregivers to positively care and advocate for their infant.
- Coaching families to collaborate with the health care team, including participation in rounds.
- Being accessible to families and NICU staff by phone, pager, or email.
- Using effective communication techniques, including read-backs, to educate families.
- Interviewing families to assess their understanding of their infants' medical conditions, procedures, and required medications.



- Assisting families in mastering the care of their infant, such as performing procedures and giving medications.
- Providing families with educational material pertinent to their infant’s care regarding medical conditions, medications, and procedures.
- Developing an individualized discharge plan for families and outlining the competencies that are needed.
- Developing an individualized PHR with brief, educationally appropriate fact sheets. Assist with conversion of these sheets into an electronic format if available and useful.
- Transmitting each infant’s PHR/completed discharge template either by fax or electronically to their PCP before discharge.
- Assisting families with scheduling education classes such as CPR and car seat trial appointments.
- Assisting families in making appointments for ongoing care after discharge.
- Identifying and addressing barriers to discharge as they arise, including identifying a PCP, assuring adequate transportation, and coordinating followup appointments and tests.
- Contacting the families weekly by phone or email regarding their preparations for discharge and their understanding of their infant’s medical conditions and needs.
- Proactively addressing barriers to coordinated care after discharge during followup calls.

Sample Tools for Health Coaches

Coaching in the Hospital

As a Health Coach, your job is to provide families with the tools and support they need to promote knowledge and management of their baby's transition as they prepare for discharge. The primary goal of a NICU discharge education program is to have a safe transition from the NICU to home. For a discharge to be safe and successful, make sure the health care team clearly knows and understands the health needs of the infant and discharge needs of the parents/caregivers. The families must fully understand their infant's health condition and how to properly care for their infant. You will visit the unit on a daily basis for initial introduction visits with the families of newly admitted babies, needs assessment, discharge module teaching, and scheduling followup visits. These visits may be completed individually or combined into one visit to accommodate the family's schedule.

It is better to conduct several brief, uninterrupted visits with the family rather than a long visit that may be interrupted by other health care team members, feedings, or visitors.

Suggestions for Daily Rounds

- On a daily basis, determine which babies are newly admitted to the unit.
- Determine whether any babies have had a significant change in status, such as acute deterioration, transfer to another area in the hospital, or discharge.
- Prioritize patient visits for the day.
    - New patients – while discharge planning should always "begin at admission," any infant whose expected remaining length of stay is less than 2 weeks should receive priority for health coaching.
    - Already enrolled patients – monitor status and anticipate discharge needs.
- For new patients, make an appointment with the family to provide an initial needs assessment.
- Round briefly on all patients daily to assess for changes in status and new needs.
- In most locales, the sooner information regarding insurance status can be obtained, the easier it is to arrange followup.
- Determine, from families and health care team of the new patients, whether families need your help with finding a pediatrician and insurance.
- If families of new patients are not at the bedside, make telephone contact as soon as possible.

Planning for Needs Assessment Visits

- During the needs assessment visit, you will systematically take into account all of the infant's discharge needs as identified by the family and health care team by using a needs assessment form that covers the topics below (available in Appendix C). After reviewing answers to the assessment, provide, if needed:
- Information regarding insurance resources.
- List of pediatricians who accept the family's insurance and who are located near their home.
- Contact information for agencies and/or specialty clinics.
- Answers to questions asked during the initial visit.
- Additional discussion of family's discharge goals.

Considerations when looking for a pediatrician for the infant are:

- Type of insurance.
- Out-of-pocket cost.
- Distance of pediatrician's office from the family's home.
- Personal preference of the caregiver.
- Type of facility (large network of doctors vs. a few doctors).
- Office hours.
- Emergency procedures.
- Onsite labs and test equipment.
- Hospital affiliation.

Initial planning is important. Make an appointment with the family for discharge teaching within 2 days before planned discharge.

Tips for Teaching Visits

If time permits, conduct discharge teaching during a separate appointment after the patient's needs assessment. During this visit, provide the family with diagnosis- /disease-specific materials, general health handouts, and clinical information. The needs assessment and teaching visits may be combined if necessary to accommodate the family's schedule.

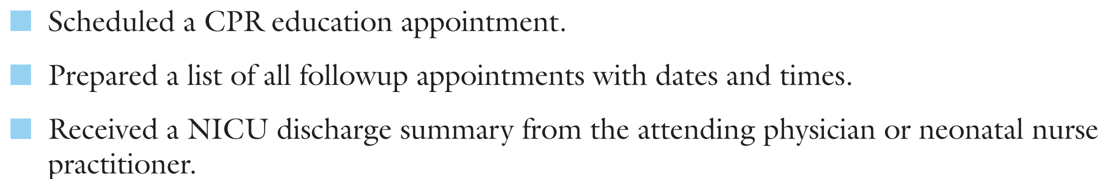
Tips for the teaching visit:

- Provide general health handouts to the family and review during the teaching visit. These modules include disease prevention education (signs and symptoms of illness, crying, colic, preventing infection, and respiratory syncytial virus [RSV]).
- Review the diagnosis- and disease-specific materials with the family. Additional handouts may need to be reviewed and added to the packet as the infant receives specific orders or diagnoses. These materials include specific medications and immunizations, breastfeeding or specialized bottle feeding, managing breathing, bronchopulmonary dysplasia, or gastrostomy (tube or button).
- Tell the family that clinical material specific to their infant is included in their information packet so that the information can be shared with the PCP after discharge if necessary. Explain that the information will be provided to the PCP electronically as well.
- Include read backs, specific examples, and pictures for the family during teaching sessions to ensure that they fully understand the information.
- Adjust the teaching to fit to the family's comprehension, educational level, and cultural background.
- Maintain patient confidentiality at all times if teaching in an open setting.
- Use an interpreter or translator during the visit if the family's first language is not English.

Final Visits and Appointment Scheduling

During the final visit, which should take place at least 2 days before discharge if possible, focus on having the family schedule followup appointments as indicated by the infant's health care needs. If necessary, combine with the other needs assessment and teaching visits to accommodate the family's schedule. Followup care needs often include appointments with the PCP and various specialists for the infant's specific conditions. Be careful to only coach the family and not do the scheduling for them. At the end of the final visit, ensure the family has:

- Obtained insurance coverage.
- Identified a pediatrician and made a followup appointment.
- Identified appropriate specialists for the infant's diagnoses and made appointments.
- Received hands-on teaching regarding specific diagnoses.
- Completed discharge teaching.



- Scheduled a CPR education appointment.
- Prepared a list of all followup appointments with dates and times.
- Received a NICU discharge summary from the attending physician or neonatal nurse practitioner.

Each infant should have his or her own PHR, which includes both general information about newborn care and specific information about the problems facing that particular infant. The PHR should identify and explain all of the infant's diagnoses, procedures, medications, and appointments. For each infant, the Health Coach solicits specific information to be included in the PHR through discussion with the health care team and families to decide what information is most needed for appropriate followup care.

Encourage the family to keep all documents, appointments, and information together in a packet. Emphasize to the family the importance of keeping all followup appointments and taking a list of medications to all appointments. In addition, the family should be provided instructions regarding what to do in case of an emergency.

Highlights of the Family Information Packet

The Health Coach will provide brief, easy-to-understand information materials outlining common discharge needs and clinical information specific to each infant. The materials are developed by the Health Coach based on the examples provided in Appendix A. Thus, an individual infant's family would receive only the materials pertinent to that baby, assuring that families are not inundated with information that is not relevant to their infant.

The Health Coach develops information for family caregivers (see Appendix A) that:

- Is written at 5th grade level.
- Explains each of the most frequent medical conditions, procedures, and prescribed medications that are encountered in the local NICU.
- Includes a brief description of the condition and its management, warning signs and symptoms of worsening conditions, and when to contact the health care provider.
- Focuses on feeding, sleeping habits, and infant temperament, which can be developed according to usual local practices.

Topics include tips for:

- Getting care
- Understanding signs and symptoms of illness
- Medicines and immunizations
- Managing breathing problems
- Feeding

If resources permit, the Health Coach may also want to develop additional customized information that:

- Includes pictures and a description of how a procedure is done and/or the equipment is used.
- May include pictures of needed medications and how to administer them, a description of what the medications are for, and signs and symptoms of adverse effects.
- May include video/DVD modules, which are welcomed by parents/caregivers.

Optional topics that families may find helpful, depending on time and resources available to the Health Coach to develop these:

- Important contact numbers to departments at the hospital.
- Helpful information about the NICU and hospital (e.g., hospital maps, cafeteria hours, visiting policies).
- Available hospital resources (e.g., daily rounds, primary nursing, change of shift report, lactation support, milk bank, child life, sibling support, food areas, parking, library).
- Support groups in the local area.
- Journaling/scrapbooking—newborn photos and videos of procedures.
- Medical terms dictionary.
- Discharge planning (insurance coverage, pediatrician contact information and appointment date, CPR education, car seat safety test and education).
- Followup appointments (detailed lists with phone numbers and addresses).

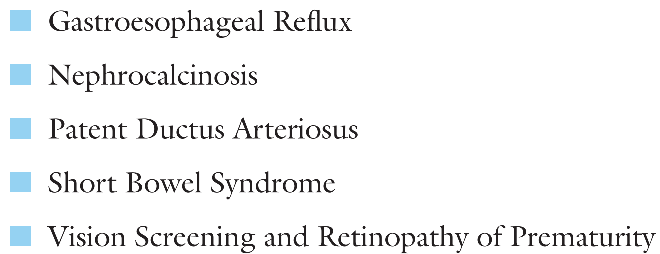
Highlights of Clinical Materials to Share with Primary Care Providers

The purpose of the clinical material is to assist PCPs in their ongoing care of NICU graduates. While the modules included in this manual address many of the ongoing medical conditions that PCPs will need to manage in the ambulatory setting, additional clinical materials may need to be developed depending upon local practices. The optimal way to ascertain what modules are useful is to survey local PCPs regarding their perceived needs.

Appendix B contains material on diagnoses and conditions; care, treatment, and development; and feeding:

Diagnoses and conditions include:

- Anemia of Prematurity
- Apnea of Prematurity
- Bronchopulmonary Dysplasia



- Gastroesophageal Reflux
- Nephrocalcinosis
- Patent Ductus Arteriosus
- Short Bowel Syndrome
- Vision Screening and Retinopathy of Prematurity

Clinical materials on care, treatment, and development include the following:

- Medications
- Neurodevelopment
- Ostomy Care
- Sleep in Preterm Infants
- Tracheostomies

Feeding information covers the following topics:

- Breastmilk
- Feeding Tubes
- Formula Feedings
- Growth
- Weaning

Putting It All Together

The Health Coach will need to identify the appropriate materials and include them in information provided to the family and PCP. To do this, the Health Coach will need equipment to create a PHR, family information, and bedside reminders to support the care transition. To create the information for families, the Health Coach should have access to computers, copiers, and office supplies to customize the materials for each infant.

The Followup Process

The followup process includes sending clinical information materials to the PCP electronically through email, fax, or a shared electronic program. To evaluate the effectiveness of the discharge, conduct a followup phone call with the infant's family.

The last step of the enhanced discharge process is followup with families by phone call within 3 days of discharge. This step is done using a survey tool that was developed based on the Care Transitions Measure of Eric Coleman.[1] This survey (Appendix D) addresses the common pitfalls of the discharge process. In addition to using the survey to monitor the effectiveness of the discharge process, you may wish to ask about followup appointments, medical equipment, and prescriptions.

Hospitals may find it useful to administer the survey again a month after discharge. The survey is included in Appendix D and takes about 10 minutes to administer.

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[1]Coleman EA, Smith JD, Frank JC, et al. Preparing patients and caregivers to participate in care delivered across settings: The Care Transitions Intervention. J Am Geriatr Soc. 2004;52:1817-1825.

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