

The Challenges of Discharging an Infant from a Neonatal Intensive Care Unit When Home is Far from Specialized Care

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Discharging infants with complicated problems from the neonatal intensive care unit (NICU) is always a challenge, but it is even more difficult when the family lives in a rural area where health care resources are limited. Rural areas have shortages of pediatricians and other primary care providers and almost no specialty care providers, such as speech and physical therapists and home health nurses. Families often must travel long distances to obtain specialty care at considerable personal and financial costs. The cost of travel and time away from work is especially burdensome because children in rural areas are more likely to live in poverty. Though parents from rural areas learn how to take care of their infants at the NICU before discharge, this is just the beginning of a difficult adjustment for these families.

Preparation For Discharge Begins at Admission

Social workers are key to planning and preparing for discharge, beginning with an assessment of the family's resources and needs when their infant is admitted. Social workers also assist in obtaining financial support as well as providing emotional and mental health support, when needed.

Education is essential to ensure that parents are capable and confident in caring for their infant at home. Everyone helps prepare parents for discharge: nurses, social workers, physicians, nurse practitioners, respiratory therapists, pharmacists, physical and occupational therapists, nutritionists, and lactation consultants.

As discharge nears, parents often room with their infant and provide most of the care in order to anticipate what the process at home will be. Usually both parents learn how to care for their infant though this may be difficult or impossible for parents with limited resources who live long distances from the NICU and have other children to care for.

A Complicated Home-Coming

Prior to discharge from the hospital, home health care agencies need to be contacted



and arrangements made for medical equipment to be delivered to the home and for the family to be taught its use. Discharge, travel time, and equipment delivery must be carefully coordinated. Home health nurses can be very helpful in the transition from hospital to home life, but pediatric home health services in rural areas are limited.

The most important aspect of post-NICU care is establishing a patient- and family-centered medical home. This involves identifying a primary care provider who is comfortable taking care of an infant who may have complex medical needs and requires coordination of care with multiple specialists. Because pediatricians have extensive training in anticipating problems and caring for these infants, we generally

an ophthalmologist at least every five years throughout life. Infants also may need to see a pediatric surgeon for follow-up if they have had bowel surgery or if they need hernia repair.

In Summary

Having a premature infant or infant that requires care in a NICU is very difficult for families. If their home is far from that NICU, the challenges of separation and travel begin at birth. Most NICU graduates do very well, but they are at higher risk for ongoing medical problems and learning difficulties when they reach school age. It takes a team of health care workers along with federal, state, and local public health programs to support these families. ◇

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suggest that parents find a pediatrician. However, in many rural areas, there are no pediatricians.

Fortunately, most family physicians are great at coordinating care and accessing resources, but parents need to partner with their family physician and also be proactive in getting care. If parents participate in an early intervention program, their service coordinator will be able to help them. (For more information about early intervention, Individuals with Disabilities Education Act Part C, see articles on pages 13-15.)

Pediatric Specialists

Most pediatric specialists practice in urban areas though they may establish outreach clinics in moderate-sized communities in rural areas. Unfortunately, specialists are usually available only once or twice a month so clinic appointments may be difficult to obtain. Pediatric pulmonologists are the most common specialists seen by NICU graduates, helping manage chronic lung disease in infants needing oxygen or ventilators.

Most infants discharged from the NICU, especially the most premature infants, should have on-going formalized neurodevelopmental follow-up in addition to developmental screening by the primary care provider. Very premature babies should be examined by

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RESOURCES

The Center for Children with Special Needs
Seattle Children's Hospital
<http://cshcn.org/>

Early Support for Infants and Toddlers
Washington State Department of Early Learning
www.del.wa.gov/development/esit/Default.aspx

National Center for Medical Home Implementation
www.medicalhomeinfo.org/

National Rural Health Association
www.ruralhealthweb.org/

Washington State Medical Home
<http://medicalhome.org/>

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