

Home Care for the High-Risk Neonate

Success or Failure Depends on Home Health Nurse Funding and Availability

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As a professor of nursing, ethics, and health policy, Dr. Catlin heard of the Caldwell family when reading an article in the local newspaper. The article stated that their daughter was ready to come home after her hospitalization in a tertiary center but could not do so owing to a lack of home care nursing. This sparked interest in the provocative topic, and a meeting with the family was set.

Dani, a corporate attorney, and Colin, a middle-school instructor, are parents of 3-year-old Hailey, a healthy child. They are happily married, thriving homeowners, and participants in their community. Dani has a healthy second pregnancy and childbirth. Tired after successful pushing and a healthy delivery, she looks at her new full-term daughter, Maura. Maura appears a little blue to her, and the physician also agrees to this. The child is taken to the in-

tensive care nursery, and unexpectedly, life changes. Suddenly the Caldwell's professionally competent lives are left behind; their abilities to solve problems, find answers, and effective solutions are no longer helpful in this single instance. Maura is diagnosed with central congenital hypoventilation syndrome and must live most of her life on a ventilator. And at this moment, the Caldwells have joined 60,000 other American families parenting a child

with a long-term acute and chronic illness and living on technology (Martinson in Fleming, 2004). For a mother's account, see the sidebar on page XXX.

Owing to advances in technology, children who previously, and in other countries, would not survive are being saved in the United States. Parents, led by the media to believe in miracles, and physicians, committed to scientific progress, want to believe that infants will improve, that conditions are fixable, and that unlimited funding for inpatient intensive care is warranted. Rarely are the complex long-term issues considered while the families and infants are enmeshed in ventilator support, feeding tubes, and tracheotomies. As time passes and successful "saves" occur, all are thrilled with the outcome (except the perhaps niggling feeling in the back of the mother's mind of "What about my life, my career, my work?" and the father obsessing silently over "How much is this all going to cost, and will we meet the mortgage and car payments?"). The child stabilizes with the use of technological support, and the families are told that they can begin to think about taking the child home. In the hospital, where now there are scores of staff members involved in caring for the child (round-the-clock

nurses, specialty physicians, residents, fellows, attendants, respiratory therapists, speech therapists, occupational therapists, physical therapists, child life specialists, and nutritionists), parents will be taught how to manage the condition at home, alone or, if they are lucky to find someone to fund it, with home health nursing support. Upon discharge, parents will begin to plan what their future path will be: searching for and fighting for services for their special need child. They will learn that despite seemingly limitless resources for inpatient care, both public and private health insurance plans contain limited levels of home health services, and that the glorious technology of rescue is not always followed by ongoing support.

For the family bringing home a high-risk infant, there is (and will be) no greater challenge than obtaining reliable and capable home care services. Whether the child suffered a birth accident, was born prematurely, or has a congenital condition, families taking home infants who require high-level support will need nurses. The home health nurse will be needed to teach parents to care for their child and to monitor equipment and medications; assess respiratory, nutritional, and developmental issues; and provide nighttime relief for the parents. Although home health and hospice agencies may be experienced in obtaining reimbursement and finding nurses trained to support the adult patient, finding them to care for infants at home is more complex. For the home health nurse transitioning to pediatrics, a core curriculum in pediatrics exists

(Broome & Rollins, 1999). Ray (2005) reported that there are many barriers to obtaining home healthcare for newborns, such as failure to inform parents about available services, unstable funding, and nonavailability of technological machinery for home use. Yet without the availability of home health services, such children are forced to grow up in the hospital or in long-term care facilities (Britton & Johnston, 1993; Catlin, 2006; Smith & Uphoff, 2001).

Catlin (2006) identified 422 American children spending between 6 months and 6 years in the hospital. Extreme prematurity, respiratory distress, and necrotizing enterocolitis were the main contributors to long-term stays. The greatest percentage of children (33%) were dependent upon ventilators, tracheotomies, and feeding tubes. Home healthcare was often not available for these children with highly technological needs.

Hummel and Cronin (2004) delineate the comprehensive planning requirements for home discharge of a technologically supported infant. They provide anticipatory guidance to potential problems such as discharge criteria and medical stability, parent's ability and readiness, home assessment, transportation issues, medical equipment, and emergency medical responses. Gracy et al. (2004) describe how to choose a home care service. Romanko (2005) specifically presents the care a child on a ventilator at home will need, stressing the protection from respiratory syncytial virus and the importance of nutritional issues. Fleming (2004) discusses evidence-based initiatives to support technology-de-

pendent infants, with emphasis on financial planning needed to apply for social security benefits and finding respite care services. Bondurant and Brinkman (2003) describe the intense developmental support that a high-risk infant will require at home, stressing the need for developmental intervention from the very beginning. Davis and Tessler-Stein (2004) emphasize the need for parents to build an attachment with their infant even in the face of chaos. Parents will need significant support (Ahmann, 1996; Davis & Tessler-Stein, 2004; Doucette & Pinelli, 2004). Doucette and Pinelli suggest that families be treated as a unit and encouraged to garner their resources and seek counseling as needed. Ahmann (1996) and Giardino (2001) provide good home care guides to be shared with families.

Another group of infants who will need home healthcare are those with terminal conditions and who come home for hospice and palliative care (Catlin & Carter, 2002; Carter & Levettown, 2004; Gilmer, 2002; Rushon, 2005). Supportive palliative care provides prevention of and relief from any pain or suffering on the part of the child, and support for the parents who have their own psychic pain and grief. Infants dying at home may present special challenges. For example, although family and staff may support a dying adult who is unable to swallow or chooses to stop eating, many have problems in withholding artificial fluids from a dying infant unable to suck or swallow. Carter and Leuthner (2003), in a comprehensive review of evidence, found support for a child's increased comfort when

Tonight Is Going to Be a Long Night

Dani Caldwell, Attorney at Law, Wife, Mother, Caregiver



After several months of sporadic night nurses, we have finally gotten to the point where we have a nurse “scheduled” every night to monitor our 1-year-old daughter, who has a tracheotomy and is on a ventilator while she sleeps. Up until recently, my husband, myself, my parents or mother-in-law, or some kind volunteer stayed up all night, every night, to monitor our daughter. Those were long nights, followed by long days taking care of an active 1-year-old and her older sister. My husband would pull triple-duty being a night nurse, a dad, and a junior high school history teacher. Looking back, I am not sure how we survived the sleep deprivation on top of all of the other issues that come with caring for a child with a chronic condition. Looking back at where we came from, I almost feel bad about complaining about having to pull one night shift tonight.

I know, though, what spending tonight without a nurse will mean. The anxiety started about 3 pm this afternoon. Every day, at some point, I wonder, “Will the nurse call in sick?” “Do we need to prepare for a long night?” My husband, thinking about the same thing, speaks his worries aloud: “I am so tired, I sure hope we have a nurse tonight.” I feel the rock

in my stomach when I have to tell him, three hours later, that the nurse called in sick. The anger flashes quickly. Then, because we know we have no choice, we make our plan for the night—I will stay up until 4 AM, he will take over until 9 AM. As we are putting our 4-year-old to bed, she tells us that she wishes she had wings so that she could fly away to another home. We know that we haven’t been successful in keeping our fears, anxiety, and exhaustion from reaching her.

So, tonight, we hold our youngest daughter’s life in our hands. It is a responsibility we never, ever would have chosen. We know that we must be awake, must be aware, and if needed, must act. We hope and pray that we don’t have to act.

It is not so easy when there is a nurse here, though, either. We welcome people into our home while we sleep. We begin by telling them about anything new medically, our daughter’s day, and about her. “She took her first steps today.” “She learned to shake her head ‘No.’” Our nurses often hear “news” about our daughter before her grandparents do.

After we have given our parents’ “report,” we ascend our stairs, hoping that the nurse doesn’t have to act. Hoping that we can just go to sleep and just wake up the next morning. We sleep with monitors in our bedroom and our house is small enough that I wake to every alarm that goes off during the night. I cringe when the alarm goes off and pray that it is minor and that our daughter is in good, competent, caring hands. Sometime shortly after the alarms go off, my oldest daughter crawls in bed with us. We stay there, us three—with our younger daughter always missing, the one always apart—until our alarm clock goes off and it is time for the nurse to go home. Those are the good nights.

I hope that tonight I can quietly sneak into my bedroom at 4 AM, wake my husband, and fall asleep and get as much sleep as possible before tomorrow begins again. I allow myself a few moments in the quiet that only happens in the odd hours of the night, to think how we—my husband and daughters and I—are alone, sleeping in our home for only the fourth time in the last 7 months. This is how life is supposed to be. Almost how it used to be. And yet, it will never be the same.

foregoing technologically provided nutrition. The VITAS Innovative Hospice Care Model (Meister, 2005) provides a guide to every service at home needed for palliative care of infants and children.

Payment for home care nursing is complex. Most insurance carriers pay for home health nursing for transitional care only. The purpose of the transition is to train the family caregivers to assume a 24-hour responsibility for the care of the patient at home. After training, continued home care would be funded only if no one in the home can safely provide the care. This may be dependent upon individual state regulation. Language in the California regulations, for example, states that "Unwilling, unable or unavailable family members do not constitute the qualification for home care nurses." If a family needs nurses at night so that they can sleep, this is considered "respite," and respite care services are not covered by most insurances. (Although long-term home care insurance is available for purchase to cover adults and elders, this insurance has not been extended to newborn infants or children.) Families must depend on the funding by state Children's Services (formerly Crippled Children's Services), the assistance of state Regional Centers, or both. Local charity groups may step in, but cannot be depended upon to sustain months and years of the needed support. Very limited federal funding may be available, but the application of Medicare or Medicaid takes weeks to process, and parents must pay out-of-pocket until the funding comes through. In addition, MediCal/Medicare reim-

bursement for a home care nurse is less than half of what a hospital nurse can earn; thus, it is very hard to secure nurses who will work outside the hospital. Also, MediCal, Medicaid and Medicare reimburse very slowly, necessitating home care companies to cover expenses in the meantime. Because of this, many agencies are forced to limit patients who are insured by federal or state assistance plans.

The need for home health nursing coverage for infants has never been greater. Lobbying is essential to make home ventilator care more than "respite" for families. Available funding for reliable and consistent home healthcare nurses can make a difference between success and failure in keeping a child at home. There are models of care that help keep children in their family home. For example, facilities that provide short-term inpatient respite such as the George Mark House in San Leandro, California, are extremely helpful to families. The family that is rested, supported by their community, and that has enough help to keep their child safe and stable, will have a better chance to thrive. When families cannot obtain a stable caregiving staff, they may become distraught, as was the Kelso family (Naseef, 2000; Wellner, 2000). Dawn and Richard Kelso, wealthy, articulate parents, brought their 12-year-old son, his medical equipment, wheelchair, and respirator to the emergency room during one holiday season in which home health nurses were not available, and after 12 years of caring for him at home said, "We tried this, but we give up." The present political agenda that sup-

ports life-extending technology and viability must also support sufficient funding and regulation for appropriate home health-care for people of all ages, including infants and children. Unless these policies change, we may be known as the country that rescues newborns at birth only to abandon them as they grow. ■

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