minnesota MEDICINE

VOLUME 91 NUMBER 10

The Case for House Calls

Ed Ratner, M.D., believes they're a better, less-expensive way to care for the frail elderly.

Home Care for Kids

The Difficulty of Dying at Home

Virtual Home Visits

Plus
The Biology of Trans Fats

MINNESOTA MEDICINE

OCTOBER 2008

MINNESOTA MEDICAL ASSOCIATION | OCTOBER 2008

Photo courtesy of Pediatric Home Service

Nurse Doreen Carson administers infusions of Myozyme during her home visits to 2-year-old Ira Brown.

Pediatrics

Intensive Care at Home

High-tech equipment sized for little bodies, specialized providers, and two decades of experience have made it possible for kids with the most complex medical problems to be home.

Doreen Carson, R.N., sits on the floor with her right leg draped over 2-year-old Ira Brown's knees, a syringe in one gloved hand, and the other on the toddler's bare chest. "This isn't as bad as it looks," Carson says with a smile, explaining that she's about to draw blood through a port inserted under the skin on the boy's chest, and she doesn't want him to move when she inserts the needle. Ira's mother holds his arms. Carson has found that plopping down on the floor next to the boy and using her leg like an extra pair of hands to keep his lower body still is the best method for doing blood draws and administering his medication infusions. If they did the procedure on a bed, she explains, it would be harder to hold him still. If he were on a table, he'd be uncomfortable.

Carson concentrates to keep the needle, the boy's chest, and her gloved hands sterile. She scrubs his skin a second time with an antiseptic solution—just in case, she says—before rubbing it with a numbing cream, and then inserting the needle. Ira's used to this routine and doesn't flinch when the needle goes in.

Born on July 23, 2006, with Pompe's disease, a neuromuscular disorder that can lead to cardiac, breathing, and feeding difficulties as well as motor delays, Ira spent most of his first year and a half in the hospital. When he finally went home at 15 months, he had a tracheotomy tube in his neck, a G-tube in his abdomen, and a port in his chest. Along with him went thousands of dollars of sophisticated medical equipment.

Although his condition is rare, Ira is typical of many pediatric home care patients today: He has multiple problems requiring complex therapies and a battalion of caregivers to administer them. Carson is one of two nurses from St. Paul-based Pediatric Home Service who visit Ira to give him infusions of Myozyme, an enzyme replacement therapy that not long ago was only administered in the hospital. Respiratory therapists from the agency monitor his breathing and adjust his ventilator equipment. Nurses from other agencies provide extended care nearly round the clock. And a host of specialists from Children's Hospitals and Clinics of Minnesota track his progress when he goes back to the hospital for checkups.

Home Care Grows Up

Children's has been sending home kids who need ventilator and other high-tech support since 1987. But over two decades, several things have changed, according to John McNamara, M.D., director of Children's chronic ventilator, home care, and hospice programs.

For one, the level of complexity of the kids' conditions has increased. McNamara explains that the change in the population of pediatric patients needing technology assistance and nursing support at home is in large part because of the introduction of surfactant replacement therapy in the 1980s. Before then, many premature infants and children with multiple health problems either died or required long-term ventilator support and likely stayed in the hospital. Surfactant therapy has allowed more children with neuromuscular diseases and congenital disorders to survive and healthier children to be weaned from the machines earlier. Thus, the children who now need ongoing ventilator support—and home care—tend to have more complex problems. McNamara says Children's sees about 45 such patients a year.

Another change since 1987 is the amount of equipment available for home use. Kids like Ira go home with ventilators, batteries, chargers, CO_2 monitors, pulse oximeters, feeding pumps, nebulizers, and suction machines. "We have more technology in the home now to monitor these children than I had as a resident in the ICU [during the 1980s]," McNamara says.

Transitioning children who have multiple health problems and need such technology support from hospital to home is a complex undertaking. "I liken it to a NASA launch," McNamara says.

Transitioning children from hospital to home can be complex. "I liken it to a NASA launch."

—John McNamara, M.D.

At Children's, a discharge planning service helps organize the move home. The child might be transferred from the ICU to a step-down unit where staff can begin to simulate the home environment weeks or even months before discharge. There, the patient will be transitioned from the equipment used in the hospital to that which will be used at home and from the doctors who took care of them in the hospital (likely neonatologists or pediatric critical care specialists) to the doctors who will follow their care at home (likely pulmonologists). Medication timelines and care plans are set up during this period, and parents and other family members are trained to use the equipment, administer medications, and spot signs of trouble.

"It takes a long time," says Children's pulmonologist Roy Maynard, M.D., pointing out that one other factor can slow the process even further—finding skilled home care nurses to care for a child on a ventilator who might need nursing care 24/7. "The more rural [the home of the patient], the harder it is to find them," he says.

The Right Thing to Do

Finding in-home care for kids is easier in Minnesota than many other states. McNamara says the state as a whole—families, policymakers, payers, and the medical community—has always supported the notion that kids with multiple health problems belong at home rather than in a hospital or long-term care facility.

As a result, a branch of the home health industry has grown to meet the needs. One agency whose lifespan parallels the advances in neonatology and pulmonology that have led to survival for more kids is Pediatric Home Service. In the late 1980s, founder and current president Susan Wingert, R.T., was working for a company that provided respiratory services for adults when she saw that hospitals were beginning to send children home with ventilators. She also noticed that no home care providers were geared up to work with them, so she decided to start her own agency. Now the company's 50 clinicians—respiratory therapists, social workers, and nurses—and an in-house pharmacy and medical supply unit serve about 2,000 patients.

Elk River-based Accurate Home Care, which specializes in providing extended-hour care for kids, also was conceived when its founder, Amy Nelson, noted the growing demand for pediatric services. Nelson was doing office work for two other home health agencies and going to nursing school when she decided to quit school and start her own agency in 2002. In five years, it has grown to about 1,000 employees and serves about 425 clients around the state.

Such growth has been fueled not only by advances in neonatology and technology but also by payers' desire to keep costs down. Although it's not cheap to provide 24-hour skilled nursing care at home—it can cost as much as $1,000 a day, according to Carol Cantleberry, R.N., director of nursing at Accurate Home Care—it's less expensive than hospital care. An ICU bed can cost $5,000 a day, according to McNamara.

The biggest industry driver, however, has been the consensus that kids belong at home. All the sources interviewed for this story said it's fundamentally better for a child to be at home, to interact with siblings, and to be integrated into their family's daily life. "We know that children who go home have much better developmental outcomes than children who are institutionalized," McNamara says.

Yet, caring for kids at home is not easy on their loved ones. "It's very stressful to the families to take these children home," McNamara says. "It's a lot of work, a lot of machinery, a lot of alarms going off and strangers in your home. But families really want their children home, and children belong at home."—Carmen Peota