

Physician

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In recent years, advances in medical technology have made it possible for more children to be cared for at home rather than in hospitals. At the same time, with the high cost of inpatient hospital care, the home care industry has seen an increase in technology-dependent patients being discharged to the home environment.

In addition, both families and medical professionals often feel that children who require life-sustaining equipment and services will do better at home than in a hospital. The Committee on Children with Disabilities of the American Academy of Pediatrics has stated that home care for technology-dependent children "may offer the advantages of supporting the child's growth and development in a more nurturing family environment without compromising comprehensive health care delivered in a cost-effective manner."

The convergence of these factors means that it is now more important than ever to provide coordination of care for children who are discharged to the home with supportive technology, whether it involves feeding tubes, catheters,

From hospital to home

Team care for special-needs children

By Judy Giel, RRT, CRTT

mechanical ventilators, monitors, or other devices. Some conditions may require the use of rather simple technology for only a short time, while others require lifelong support on more than one complex device.

Helping technology-dependent children—and their families—make the transition from hospital to home presents a number of coordination, communication, and education challenges. A team approach to planning and care for these children can help achieve positive outcomes for the children and reduce frustration and anxiety for families and medical professionals alike.

St. Paul-based Pediatric Home Service (PHS) has developed such an approach over the past 17 years. During that time, the greater Minnesota pediatric health-care community,

payers, schools, and families have partnered with the PHS staff of respiratory therapists, nurses, pharmacists, dietitians, and educators to create coordinated and individualized plans of care for thousands of children with special needs and their families.

Hospital-based care is provided by a multidisciplinary health care team of professionals, led by physicians. The physicians develop a level of trust in these professionals through day-to-day personal experience. Home-based care requires the physician to extend that trust and to rely on "outsiders" to implement treatment plans and communicate on key issues that regularly occur. In order to make appropriate decisions, physicians must receive reliable and timely information to ensure the child's access to emergency and urgent care

treatment, timely implementation of critical changes in care plans, and effective training and skill building for caregivers.

Beginnings

In the early 1990s, Logan, a ventilator-dependent child, might have faced growing up in an institution rather than in his home. For his physician and hospital clinicians, such a future for Logan was unthinkable. The hospital team contacted PHS to work with the physician, hospital staff, home-care nursing agency, and family to bring Logan home to his family.

Attaining the desired outcome of bringing Logan home required more than exceptional health care. Many obstacles had to be overcome before discharge. PHS focused on Logan's individual needs by working closely with the hospital care team to develop a plan of care.

Because of the highly specialized medical life-support equipment and technology required, the plan of care was designed to cover customized, hands-on training for the home-care nurses and family caregivers. A simulated home care set-up was created in the hospital

so that caregivers could learn and practice while under the supervision of the pediatric pulmonologist, critical care nurses, and respiratory therapists. Ensuring the ability to respond immediately to an emergency and providing technical support, customized written educational materials, and 24-hour on-call clinicians were key elements of the plan of care.

While clinical professionals prepared the “medical home” environment, employees at the Minnesota Department of Health and the Department of Human Services worked with the federal government on payment and services. They helped obtain a waiver that would allow adequate payment for in-home nursing, medical equipment, supplies, and services that were paid for in hospital but not to the extent required in this home-based model.

In the end, the team effort was a success. Logan lived with his family and progressed to living in a group home. He will always be ventilator-dependent because of his neuromuscular trauma, but he has participated in community life as normally as is possible with his disability.

Key components of care

Relationships are the foundation for taking care of children with special medical needs. This type of care requires a dedicated team that embraces the value of possibilities in caring for these unique children, rather than dwelling on the difficulties. In addition to

this “care from the heart,” the following key factors are essential.

Safety. A care plan focused on safe medical care provides the framework for achieving positive outcomes. The team approach to developing a coordinated care plan involves the hospital and health care providers, payers, and family members, as well as the patient. The plan incorporates needed services, such as pediatric and neonatal respiratory care, infusion therapy with on-staff registered nurses and pharmacists, medical equipment and supplies, nutrition care provided by dietitians, and asthma management by certified asthma educators.

Planning for care begins when a PHS clinician visits the hospital to review the child’s medical history and current status and assess the needs of the child and family. Once the equipment, supply, and service requirements have been identified, an in-home environmental assessment is conducted to ensure safe operation of sophisticated medical equipment; safe storage of medications, supplies, and formula; and emergency back-up plans for extended power failures, severe weather, and potential community catastrophes. This information is given to the treating physician. When the safety issues have been addressed and resolved to the physician’s satisfaction, discharge planning can proceed.

Primary care. Assigning a PHS primary care clinician (e.g., a respiratory therapist, nurse, dietitian, or

social worker) to the child’s case facilitates communication, continuity of care, coordination, and advocacy for the child. The clinicians gain the trust and confidence of the family by serving as consistent and reliable members of the care team. Physicians work in tandem with the clinicians, who have gained an understanding of the child’s status by working with the child and family over time.

Payers have access to the medical rationale and individual requirements to authorize payment for care outside the hospital setting. In addition to PHS reimbursement specialists, insurers’ care managers have access to a knowledgeable clinician to consult with on payment and medical issues.

Education and training. Clinical education and hands-on training on sophisticated medical equipment, supplies, medications, and delivery devices begin as soon as the home caregivers are identified. Educational materials are written for the family and other caregivers based on clinicians’ first-hand experience, matching the appropriate technology to the prescribed plan.

Emergency response procedures and equipment troubleshooting are practiced in controlled settings before the child is discharged from the hospital. PHS regularly offers classes for clinicians who become a part of the team post-discharge.

Technological support. PHS employees are trained according to manufacturer

specifications to evaluate sophisticated medical equipment performance on a regular basis. Those involved in caring for special-needs children have immediate, around-the-clock access to employees who can answer questions and address concerns.

Electronic medical records. EMRs enable physicians to access privacy-protected patient information. EMRs also allow caregivers to provide patient-specific details only once; they don’t have to repeat them to each care team member. Once patient information is entered in the PHS database, the physician has easy access to all the information.

Social services. As part of the coordinated care plan, PHS social workers connect families with community resources and help families manage crises.

Special needs, special teams

Caring for children with special and often complex medical needs requires treatment plans specifically designed for them. A coordinated team works with the family, physicians, and other caregivers to plan care and acquire the necessary equipment for patients and their families. Positive outcomes for these children are the result of meticulous planning, coordination, communication, and education—and care that comes from the heart. ▣

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