

All grown up and no place to go

For young special-needs patients and their parents, transitioning from the pediatric health care world can be a difficult journey

By CHRISTINE FACCILOLO • Special to The News Journal • September 21, 2010

Terri Hancharick knew it would be a challenge to find a medical home for her special-needs daughter, Brigitte, in the adult health care system. But she never expected the process to be so frustrating.

Brigitte had been receiving care at Alfred I. duPont Hospital for Children since infancy. But the hospital limits treatment to patients younger than 21, so Hancharick had to assemble a new medical team two years ago.

Hancharick soon discovered that few doctors were taking new patients and the ones who were did not feel confident treating a patient with a medical history as complex as Brigitte's. The 23-year-old has severe cerebral palsy and seizures and is visually impaired and nonverbal.

"I went through two primary care doctors," said Hancharick, 52, of Newark. "The first said Brigitte would be better served by a specialist and didn't need a primary care doctor, and that's not true. The second retired."

Moreover, the specialists Hancharick was able to locate were in Philadelphia, Baltimore and New Jersey. "We were traveling all over the place," she said.

Transitioning children from pediatric care to the adult health care system can be difficult for any family. But for the parents of a child with special medical needs, the responsibilities are greater and the challenges more complex.

To help make that process easier, duPont Hospital established the Transition of Care division, which began accepting patients earlier this year. The goal is to help patients develop self-management skills, prepare patients and families for the differences between pediatric and adult care, and identify appropriate adult health care providers. Financial, psychosocial, educational and vocational needs are also addressed.

"Some people look at transition from a disease-

specific viewpoint," said Dr. Rita Meek, chief of the Transition of Care division at duPont Hospital. "But we are taking the approach of how do you transition an entire population of young adults with special health care needs, and that really puts us in a very different framework."

Growing demand

Transitioning from pediatric to adult care is a subject that has received increased attention in recent years as hospitals establish programs to meet the growing demand. Medical advances over the past three decades have increased the survival rates for diseases that used to kill children well before adulthood.

For example, the median length of survival for cystic fibrosis has increased from seven years in 1970 to 32 years. Fewer than a third of patients with spina bifida lived until 18 in 1970, but now more than 80 percent do. Similar successes have been achieved in congenital heart disease, sickle cell disease and childhood cancers. In fact, more than 90 percent of children with complex chronic or disabling health conditions are expected to live more than 20 years, according to the National Center for Medical Home Implementation.

"We created this problem by having such great improvements in pediatric care but there's not a really good solution yet," said Meek, who is also a pediatric hematologist.

A successful transition is one that takes into account how the patient fares medically, financially and socially, Meek said. One of the major challenges the program addresses is the cultural change patients and children will encounter as they move from pediatric to adult systems of care.

Pediatric health care provides family-centered, comprehensive services in a single location, where parents control decisions. In the adult health system, care is episodic and individualistic.

"In the adult world the expectation is that the family and the patient are going to steer the ship, where in the pediatric world the providers often assume that role," said Cory Nourie, patient transition social work coordinator at duPont Hospital.

Meek agreed. "We have the luxury in pediatrics of having social work support. We have child life specialists," she said. "When you get to the primary care provider on the other side, they don't have these supports nor is it reasonable to expect that they would."

Doctors hard to find

As a result, many parents fear that their child's needs will not be met by an adult provider. Indeed, many physicians whose practices focus on adults aren't familiar with disease processes that have

historically been considered pediatric illnesses.

"In pediatric hospitals there are mostly rare diseases, whereas in the adult world they treat things that are relatively common," said Dr. Eric B. Levey, director of the Center for Spina Bifida & Related Conditions at the Kennedy Krieger Institute in Baltimore.

Hancharick recalls how hard it was to find an orthopedist who was willing to treat her daughter's cerebral palsy.

"They kept asking if it was her hip or ankle. I said it's her whole body," said Hancharick, who served as chair of the Adult Transition Services Committee of the Governor's Advisory Council for Exceptional Citizens when recommendations for duPont Hospital's new division were being solicited.

Robin Russell worries about finding doctors who will have the patience and expertise to deal with her son Joseph's behavioral problems brought on by hydrocephalus.

"We went to see a dermatologist recently but we weren't able to get very far because Joseph wouldn't cooperate," she said. "Sometimes it takes five people just to get blood work done."

Still, experts maintain that transferring patients to the adult health care system is critical to their psychosocial development.

"Historically, society tends to infantilize people with disabilities in general, and keeping somebody in a pediatric system is just adding to that stereotype," said Nourie.

Moreover, pediatric doctors may not be comfortable addressing the adult issues that will crop up during a patient's lifetime.

"About 30 to 40 percent of cystic fibrosis patients will develop diabetes or osteoporosis," said Dr. Peter Joseph Mogayzel, director of the cystic fibrosis center at the Children's Center of Johns Hopkins Hospital in Baltimore. "And there is almost universal male infertility."

Special training

Coordination of medical care is crucial to a successful transition. Patients with complex medical histories need a primary care provider to maintain records, manage their subspecialists and conduct routine screenings.

The duPont Hospital and Christiana Care Health System are collaborating on a pilot program that uses med-peds, physicians trained in both pediatric and adult medicine, to care for transitioning patients.

"What's special about our training is that it allows us to learn about the kinds of issues and treatments for kids with cystic fibrosis and congenital heart disease, but it also allows us to start thinking about what can hurt them in adulthood, such as cancer and coronary heart disease," said Dr. Allen Friedland, director of the med-peds program at Christiana Care.

Robin Jones, for instance, was surprised to learn that her 20-year-old daughter, Chrystal, who suffers from spina bifida, seizures and hydrocephalus and is wheelchair-bound, is susceptible to arthritis and osteoporosis.

"Those things I never knew were a problem or could be a problem," said Jones, 48, of New Castle.

In addition to the medical issues, the program seeks to direct families to resources to meet patients' social needs. While increasing numbers of community programs provide resources, accommodations and opportunities for individuals with disabilities, many families are not aware of these programs in their communities.

"We have lots of community-based organizations and services in Delaware but they are not well connected with one another, so for families or young adults it's sometimes very difficult for them to find their way through the maze," said Ilka Riddle, health director for the Center for Disabilities Studies at the University of Delaware.

Jones was delighted to learn that her daughter was eligible for paratransit services. "It's hard to get her around," she said. "We just got her signed up."

The program also alerts families to important legal and financial issues that take on added significance when young adults cannot make decisions for themselves.

Russell said setting up a guardianship for her 21-year-old son, Joseph, is next on her to-do list. "I'm still a little nervous about that," she said.

One of the biggest challenges to a successful transition is the patient's ability to maintain continuous insurance coverage.

"There's a significant change at 21," said Meek. "They change from being entitled to only eligible, and there are very different criteria for what is considered eligible and many families have no clue that this is coming."

Ann Vannucci worries about dental expenses for her 20-year-old daughter, Lauren, who suffers from tuberous sclerosis and is deaf and blind. She's also had extensive dental issues.

"If they have dental benefits through Medicaid, they lose it all when they turn 21," said the 51-year-old New Castle resident. "We'll be paying out of pocket."

Meek stressed that duPont Hospital is not the only institution faced with this issue. But because of the strict age limit on admission and treatment, the hospital had to look at its options.

"I'm not saying this is perfect. I think it is a work in progress," she said. "But we are starting and if you don't start, you have no possibility of making an impact."



For Newark mom Terri Hancharick, finding care for her daughter in the adult health care system was frustrating. Brigitte, 23, has severe cerebral palsy and seizures and is visually impaired and nonverbal. (The News Journal/GINGER WALL)



Joseph Russell with mom, Robin (left), and coach Kristal Hall. Robin Russell said finding care for her son has been difficult. (The News Journal/WILLIAM BRETZGER)



Brigitte Hancharick has severe cerebral palsy. "We were traveling all over the place" to find specialists, her mother says. (The News Journal/GINGER WALL)

ELEMENTS FOR A SUCCESSFUL TRANSITION

1. Start early. Experts recommend starting discussions about transitioning around age 11 and having a plan in place by 14.
2. Support new pediatrician/parent/patient relationships. Pediatricians and parents should gradually move from a director to a consultant role, while patients should move from a recipient to a managerial role.
3. Educate patients on managing their health needs. Pediatricians should help patients with chronic conditions learn more about their disease and medications and treatments. Patients should also be taught how to refill prescriptions and get care.
4. Create a portable medical summary. A good medical summary should contain an active problem list, current and past medications, equipment and devices, plans for emergency care, functional limitations and health care providers.
5. Address health insurance issues. Consult with a social worker or other benefits specialist as eligibility requirements change dramatically when the patient turns 21.

Source: American Academy of Pediatrics



Joseph Russell gets an assist from Challenger League coach Kristal Hall. Russell suffers from hydrocephalus. (The News Journal / WILLIAM BRETZGER)

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