



THIS STORY HAS BEEN FORMATTED FOR EASY PRINTING

PEDIATRIC PERSPECTIVE

The Boston Globe

Help when red tape snarls a patient

By Dr. Darshak Sanghavi | April 24, 2006

The first thing to understand about 22-year-old Bethany Sabbag's struggle to live at home is the sheer volume of stomach fluid -- almost half-a-gallon -- that her body makes each day. The second thing to understand is that it all drains from a tube implanted in her abdomen into a plastic receptacle that Bethany indelicately calls her "bag o' barf."

A few months ago, MassHealth, the state program that pays for Sabbag's medical care, abruptly announced it would slash the allowable number of bags to only three per month. Rather than throw out the old bag when full each day, Sabbag and her mother would have to clean out and reuse each rancid bag for 10 full days.

While dealing with health insurance bureaucracies can bring almost anyone to their knees, Sabbag's family was already overwhelmed dealing with her complex medical condition -- a rare genetic disorder affecting the energy-generating areas of the cells, called mitochondria. Sabbag and her mother needed a way to cut through the red tape and avert the cut in her bag supply.

Help came from a novel program recently funded by MassHealth to assist the families of children and young adults with multiple medical problems in maneuvering through the disjointed healthcare system.

As Cindy Sabbag puts it, her daughter is an "adult living in a child's world." Now 22 years old, she is developmentally more like a 13-year-old. Her condition affects almost every body part. Cindy counts 15 different pediatric subspecialists who care for her daughter, ranging from cardiologists to ophthalmologists to pulmonologists. To manage her extraordinary medical needs, Bethany requires 96 hours per week of individualized nursing care at home and at school.

Two weeks ago, I visited Bethany and Cindy at their modest Medford home. Cindy poured coffee for us, and I watched Bethany stir in sugar and spoon the hot drink into her mouth. With each swallow, the food went down her esophagus, into her stomach, and then drained into the bag, which was hidden under her shirt. Because her small intestine is essentially paralyzed, Bethany can digest no food, and her nutrition must be given intravenously. She puts food in her mouth mostly for social reasons -- it's only when one can't eat normally that one sees how much of ordinary socializing involves food -- and to enjoy the flavors and textures of food.

As we spoke about Bethany's recent art projects (she is a student at Minuteman Regional High School three days a week and wants to be a graphic designer), five different intravenous pumps mounted on a milk crate infused medications into a catheter implanted in Bethany's chest.

Cindy explained that hooking up Bethany to all her medical equipment at night takes two hours. The bedroom resembles an intensive care unit. As Bethany sleeps, a nurse administers scores of medications and intravenous feedings (Bethany calls the concentrated-fat solution dripping into her veins the "bag o'blubber"). On nights when Bethany's nurses call in sick, Cindy forgoes sleep and manages the pumps herself, since she's the only parent who lives with Bethany.

Like Bethany, hundreds of children and young adults in Massachusetts have extraordinary medical needs requiring parents to coordinate countless doctors' visits, home nursing agencies, medical equipment suppliers, and insurance paperwork. The vast majority of these medically complex patients live either at home or, if they cannot be handled there, in medical foster care.

MassHealth recently funded a two-year, \$2.5 million program, Community Case Management, or CCM, to help the families of 550 of these patients navigate the system. Each family was given immediate access to a case manager, a nurse who could help with any care needs.

Dr. Julie Meyers, a pediatrician who is the program's medical director, told me that the service is "just the right thing to do" to serve exhausted families.

Consider how the program, which costs taxpayers about \$5,000 per child each year, helped when Bethany's bags were suddenly cut. Immediately after getting the news, Cindy called her case manager, a nurse named Debra Bourn-Hammerle. Within a day, the case manager worked through the MassHealth bureaucracy to restore the bag supply. It turned out that most people used the bags to manage urinary incontinence, and no one at MassHealth realized that Bethany needed more since she used them for a different purpose.

Cindy Sabbag said her case manager has also made it easier to schedule nurses and find replacements when someone calls in sick. The program lets her focus on "mom things" like running Bethany's Girl Scout troop, she said. Most important, the program has helped Cindy, who is legally blind, create a fulfilling life for Bethany in her own home and school.

Letting Bethany live at home, said her mother, has helped nurture her unflagging spirit, and the knowledge she has a home to return to has given her the will to pull through life-threatening complications.

Her mother recalled that when Bethany was 15, she developed septic shock from a fungus that got into her blood from her IV and entered her blood. In the intensive care unit, doctors told Cindy that Bethany could die and needed to be on a breathing machine and put into a medically induced coma. As sedatives entered Bethany's veins and her consciousness drifted into twilight, Bethany looked to her mother and spoke, in gasping breaths. "Mom," she wheezed, "for Halloween, I want to dress up as Darth Vader."

When she woke weeks later, her friends and family had filled her hospital room with Darth Vader masks and action figures.

That's Bethany, her mother said: When everyone else was wondering if she'd die, she was planning her Halloween costume.

Bethany continues to surprise her mother with her fortitude. One recent night, as she was preparing for bed, Bethany got a serious look on her face. "Mom," she asked, "can doctors sometimes help people die if they're suffering?"

Taken aback and somewhat frightened, Cindy answered as well as she could, explaining that doctors take an oath to protect life and relieve suffering. But perhaps in some extreme cases, she said, doctors might help people die if the pain were just too great.

"Well," Bethany said as she smiled, "that would never be for me. My life is just too wonderful now."

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