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Health & Science

How one couple's loss led to a push for psychological care for kids with cancer

By Brady Dennis December 29, 2015

What has stuck with Vicki and Peter Brown for years, beyond the enduring grief of losing their only child, Matthew, are the emotional traumas they all suffered during his struggle with a rare form of bone cancer.

Living in a hospital for months on end, Mattie grew anxious and depressed. He feared CT scans and dreaded the sight of another phalanx of white-coated doctors marching down the hall to deliver what invariably was bad news. His parents, frantically trying to save him, struggled with sleepless nights, mounting financial worries — and overwhelming silence that engulfed their Foggy Bottom home when he died at age 7 in 2009.

The Browns often felt lost and alone. "It was just a horrific experience," Peter Brown said. "And we recognized that the value of psychological, emotional, social support was just as important, if not more important, than the medical treatment."

The couple ultimately launched a years-long effort to try to ensure that children with cancer and their families get the help they need for the non-medical aspects of the disease. Last week, their hard work paid off with the publication of the first national standards for the "psychosocial" care of children with cancer and their families.

The standards, published in a special issue of the journal Pediatric Blood and Cancer, are a road map for health-care providers from the moment of diagnosis into survivorship or bereavement. The Browns hope the rigorously researched standards will mark the first step toward putting in place a consistent level of care around the country, from massive cancer treatment centers to small-town community hospitals.

One recommendation is that young people with cancer and their families — including siblings — receive regular assessments of their psychological needs, not only when a crisis occurs. Another urges officials to be aware of the risk of financial hardship, and to help families find ways to address those concerns before the situation becomes dire.

The standards say families should be educated early on about palliative care and its role in helping to "reduce suffering throughout the disease process." And they say children with cancer should receive "developmentally appropriate" information to prepare them for the treatments and procedures they will undergo.

More of that type of care, the Browns say, might have better prepared Mattie for the challenges he endured. They included two excruciating surgeries on his limbs and an aggressive procedure to remove tumors from his lungs.

“My ultimate goal,” said Peter Brown, “is that I can never again find a family that can identify with some of the experiences we had.”

No evidence-based standards

Many hospitals have psychologists, psychiatrists, social workers and “child life” specialists who help young cancer patients cope with the fear and unfamiliarity of the medical world. But there were no uniform, peer-reviewed standards for the psychological and emotional side of pediatric cancer, as there are for medical care.

“There are beautiful, well-written summaries and guidelines out there, but none of them were based [entirely] on evidence. Nobody had really done this kind of rigorous evaluation of the evidence out there for psychosocial care,” said Mary Jo Kupst, emerita professor of pediatrics at the Medical College of Wisconsin and an expert in pediatric psychology. Kupst is one of the key authors of the new standards.

After a young person is treated for cancer, the new standards say, a health-team member should help prepare the patient to return to school after an extended absence — and also talk to teachers and other administrators about how to provide support. When a child dies, someone should check to see what kind of help the family might need.

Many top-tier centers have programs designed to help children and their families in those and other ways. For example, the Dana-Farber Cancer Institute in Boston has a pediatric psychosocial oncology team, which includes social workers, psychologists and other experts.

But many hospitals have fewer tools to help families, either because of a lack of resources or expertise. “There’s a lot of variability ,” Kupst said.

Lori Wiener, head of the Psychosocial Support and Research Program at the National Cancer Institute and a leader in the national standards process, said that some experts might find the standards more obvious than revelatory. “But we needed to set the bar low,” she said. “We had to make it broadly implementable and sufficiently general. I’d rather everyone get the minimum than nothing at all.”

At best, it will take years for the voluntary standards to become commonplace across the country. Their adoption depends partly on the willingness of public and private insurers to pay for staffing to provide the extra care. The Browns hope to put in place an accreditation process, but that also will take time.

‘Did he really exist?’

Vicki and Peter Brown never lose track of how long it has been since Mattie died.

On a recent morning, he had been gone 2,275 days, or 325 weeks. By February 2017, he will have been dead more days than he was alive. As time passes, Vicki Brown says, it becomes harder to summon exactly what life felt like with Mattie. “Your mind plays tricks on you,” she says. “Was I really a mom? Did he really exist?”

The Browns are quick to acknowledge that their work on the new psychosocial standards is partly an effort to find meaning in their own tragedy.

“We can’t undo history. But what we can do is try to help those who are going through this, or are going to go through this,” Peter says. “This gives us an outlet to do some good. I wish somebody 20 or 30 years ago had done this. It wouldn’t have necessarily changed the outcome for Mattie, but it might have made it less worse to live through.”

Most mornings, Vicki Brown sits at her small desk in Mattie’s old bedroom, which has become the headquarters of the Mattie Miracle Cancer Foundation, the organization the couple founded to focus on improving overall care for childhood cancers.

For years after Mattie’s death, it seemed nearly impossible to walk into this space. But these days, Vicki finds comfort working there, amid his rubber alligators and model sailboats and the fake cockroach he once used to scare his nurses.

From the window, she can see the sun rising over the city. She knows there are other children out there wrestling with cancer, other families struggling, other parents mourning. So she signs in online and goes back to work.

Brady Dennis is a national reporter for The Washington Post, focusing on food and drug issues.

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