



THE UNTHINKABLE **CAT VASKO**

When her two-year-old son, Luke, woke up in the middle of the night with a terrible fever in July of 2008, Meghan Anderson knew immediately what was wrong. The former oncology nurse felt her son's stomach and knew he had a tumor. "Luke was always the one with the little pot belly before he hit his growth spurt," she says. "We never thought much about it before then, but when I felt it that night, I just knew."

Ask virtually any parent whose child has had cancer, and they'll tell you right away that they knew something was wrong long before the official diagnosis. Dharshini Wallooppillai and her husband, both internal medicine physicians, knew from the moment their three-year-old daughter Ishani tumbled from a playscape. Wallooppillai felt a lump in Ishani's calf that would soon be diagnosed as rhabdomyosarcoma.

Jonna Ewing, mother of Karoline Ryder, diagnosed at 18 months with brain cancer, says, "The date of diagnosis is kind of like a birthday. You know in your heart something isn't right, and when you finally figure it out, you thank God, because now you can finally do something."

For Jamie Deibel, diagnosed at age 12 with leukemia, the most alarming aspect of cancer treatment was the possibility of losing her hair. "That was the thing that made me most nervous," she recalls. "I have really long hair. I didn't really realize that was going to happen. When I first found out I was going to lose my hair, I stopped brushing it because I was so afraid of losing it."

Children like Luke, Ishani and Ryder, diagnosed at much younger ages, are often unaware of what's happening to them. In some cases, this ignorance truly is bliss. "You can't stop this child," says Wallooppillai of her daughter. "They fight so hard. As an adult, if I was going through what she was, I'd be feeling sorry for myself. But they don't. They rebound and just keep going. Whenever we feel down, we just look at her and think, 'Okay, I better get over it.' She's so strong."

But in many cases, children's lack of understanding of what's happening to them can lead to problems with treatment. Chemotherapy is a lengthy, painful process, as Luke and his family quickly learned during his first few months of treatment for Wilms' tumor. "He had a really anxious time," Anderson recalls. "There was a needle they put in that he called

the butterfly. He'd say, 'Butterfly hurts Luke,' and then he'd start screaming and crying. What two-year-old can tell you, 'I'm tired' or 'I'm nauseous?'" To help Luke adjust to the anxieties of treatment, Anderson bought him a toy doctor's kit. "We'd roleplay with him so he would feel some control over that was going on," she says. "He may be the only three-year-old who knows exactly how to listen with a stethoscope."

Luke finished his treatment on April 14 of this year, and now has scans every three months to be sure the cancer is gone. "Every little cough he has, my heart goes into my throat," Anderson says. "We call it scan anxiety. You go in and just hope they'll give you another three months with your child."

Ryder, now 8 years old and three years beyond treatment, is coping with a different kind of long-term stress. Though her follow-up scans are clean, the side effects from her years of treatment continue to impact her life. "We did two and a half years of chemo," Ewing says, "and developmentally Ryder was two years behind. They told me she needed to go into an institution. The treatment just tore her up. Her breathing is the most difficult thing. Now she's on oxygen all the time. And things are hard for her. She has to constantly be reminded about stuff like math, or the definitions of certain words. It has to be repeated and revisited constantly, and it's challenging."

Now Ewing fights to give Ryder a normal life with her twin sister, Mackenzie. "She's wise in the oddest ways," she says. "She gets adult humor where her sister doesn't, and she says really dry things. It's uncanny out of the mouth of an eight-year-old. I don't know what kind of personality she would have had. She missed a lot of kid stuff."

Ewing hopes that by age ten, Ryder will be able to go all day without oxygen, though she will still need support at night. In the meantime, she has done everything within her power to help rebuild her daughter's throat muscles to get her off her feeding tube, which she has been on for six years. "For the first time in six years, she is able to have regular water and regular drinks," she says. "I am really pushing it. The child has to drink. I want her to be able to drink champagne at her wedding one day."

Deibel, now a junior in the University of Eastern Kentucky's nursing program, has also had to cope with long-term side effects of cancer treatment. "For a while, chemo can mess with your coordination, and I had trouble with that the first couple of years after treatment," she recalls. "I broke my foot this past year, and they said that some of the steroids thinned out my bones and that's why it broke so easily."

And there are other, intangible side effects as well. Deibel, who is still close with one friend she made during her years of treatment, remembers how many of her friends passed away during that time. "The first three years, we went to probably fourteen or fifteen funerals," she says. "I grew up a lot during those years."

Following Luke's treatment, Anderson brought him to a child psychologist to work through some of the trauma of chemotherapy. "He was still anxious in certain situations," she says. "At that age they're just starting to get their independence, and

Luke didn't have any . . . all of a sudden I now have two boys who are having fun and happy. My husband didn't realize how anxious he was until now that he's acting normal and super-social."

For Wallooppillai and her family, the struggle continues. A year and a half after completing her treatment for rhabdomyosarcoma in April 2007, Ishani was diagnosed again with the disease. Nine cycles of chemo later – with three still to go – her scans look good, but Wallooppillai maintains a physician's sense of realism. "The first time she was treated, there was a written protocol, but there is no protocol for a relapse," she says. "There is no standard. Every doctor will probably give a different opinion, and that's really scary. We were eighteen months out of treatment. We had started to let our guard down a bit. When it came back, it was a real shock."

Because rhabdomyosarcoma is a comparatively rare disease, chemotherapy combinations for treatment have been ill-researched over the years. "Every child seems to get a different combination, which is very disheartening," Wallooppillai says. "Nobody knows what to do. The numbers make it harder to find money for the research. All the money goes into cancers that are more common. But when it's your child, it's not rare. It's your child."

Anderson concurs. "This experience opened our eyes to everything," she says. "Pediatric cancer is not very well funded. We were blessed; Luke's cancer is well researched, but a lot of families aren't facing those odds because the research just isn't there. I can't even imagine."

While Anderson, Ewing and Deibel cope with the long-term side effects of cancers past, Wallooppillai finds herself focusing on Ishani's cancer in the present. "I'm almost 43 years old, and while I don't think of myself as old, I think I have pretty much experienced everything life has to offer short of retiring," she says. "And I look at Ishani. She's still waiting for her first kiss. She asks me, 'When do I get to start driving?' or 'Next year, can I get swimming lessons?' Most parents can just say yes or no, but me, I don't know."

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