

CONTENTS

Straight Talk

BY ERIK NESS

What kids need and want to know when a parent is diagnosed.

Little Joanie had a hard question: “Who’s going to be my mommy?”

“I’m your mommy,” answered Janice Hayes-Cha.

But that wasn’t the whole question. “I’m too scared to say it!” said Joanie.

“Can you whisper it in my ear?”

She could: “Who’s going to be my mommy if you die?”

Kids ask hard questions all the time, but for parents facing cancer it can be even harder. Fortunately, Hayes-Cha was ready.

“All I could think of was my kids,” she says of her initial diagnosis with advanced breast cancer. “I was really freaked out.” Then her doctor at Massachusetts General Hospital Cancer Center suggested the Parenting At a Challenging Time, or PACT, program. “It was a huge relief to have that expertise at my disposal.”

Joanie wasn’t even sad that day, says Hayes-Cha; she was just working things out. “Her main issue was, ‘Who is going to take care of me?’ ”

Hayes-Cha countered that she didn’t think she would die soon, and that Joanie might even be all grown up when she did. “That never occurred to her,” she says. Then they went through all the women in Joanie’s life and chose a just-in-case mother. Both of them felt better.



Janice Hayes-Cha and her husband, Jang-Ho, found their children (from left) Joanie, Leo, John, and Denis, each had different concerns about her cancer. Photo by Johnny Arguedas

“The degree of distress felt by cancer patients around their kids has been vastly under-acknowledged in the medical community,” says Paula Rauch, MD, a child psychiatrist who founded and directs PACT. A quarter of all cancer patients have a child under 18. “I think most parents need guidance to manage this,” Dr. Rauch says. “Every cancer center ought to have designated people who are experts in the needs of children and in the challenges that families with dependent children experience.”

Most people get their parenting advice from family and friends. But when a parent gets cancer, the treatment and recovery cycles put life into a compressor that a peer group may not well understand. PACT provides specialized peer-group knowledge that is savvy to the vagaries of child development. For example, while the preschooler may be clutching to the apron strings, the adolescent is often looking to cut them. “How do you support a child’s daily routine?” asks Dr. Rauch. “How do you help parents—in the context of understanding normal development and mental health issues—advance parent-child communication?”

How Much to Share

Every family is different, every child is unique, and every cancer follows its own twisted course. That makes communication perhaps the most important element for a family dealing with parental cancer. PACT’s website (www.mghpact.org) has a list of 12 lessons learned; eight focus on communication.

“Not sharing information excludes kids,” says Dr. Rauch. “It leaves them feeling undervalued and not important. Nobody copes best when they are surprised. Parents need to name the illness. You can’t begin a conversation if you don’t know what you’re talking about. As soon as kids can talk, parents should use the real diagnosis. ‘Mommy is sick’ is actually much more frightening.”

Dr. Rauch says if a patient wants to model that honesty is a value in the family, “then you need to show [children] how to have hard conversations. It’s the combination of communication and loving intent. You don’t have to get it exactly right, but kids need to feel that they are lovingly included in what’s going on in the lives of their family.”

Communication approaches don’t translate across various age groups. What a 5-year-old understands and experiences will vary greatly from the mindset of a 16-year-old, and thus their needs and styles for coping will differ as well.

You can’t force children to talk. Don Fisher’s daughters were in fourth and ninth grade when their mother, Susan, was diagnosed with osteosarcoma. He coped by developing a dual persona: the optimist, who hoped fervently for the cure, and the realist, who heard the doctors’ grim reports. For the last six months of Susan’s life she could only lay upon her side, her bones unable to support her.

☒ You don’t have to get it exactly right, but kids need to feel that they are lovingly included in what’s going on in the lives of their family. ☒

—Paula Rauch, MD

Fisher watched his daughters with concern, as one became a caregiver and another fled the house at every opportunity. One was stoic in the face of grief, the other wept openly. As the only one in the family who communicated with the

doctors—Susan didn't want to know the prognosis—he struggled with what to tell his kids.

“To engage them I'd have to convince them that she was going to die, and I couldn't and wouldn't do that,” he remembers. “How do I communicate that to them in a way that lets them absorb it as best as they can but does not beat hope out of them?”

He saw a therapist for his own stress and grief, and he wanted his daughters to see one too. But the PACT counselors concluded the girls probably didn't need professional help—their coping raised no warning signs. PACT “let hope live,” Fisher says, “giving me hope that the girls would be OK, and would be better than OK.”

Other cancer centers, as well as nonprofits, offer help for children and adolescents dealing with a parent's cancer. At every Gilda's Club (www.gildasclub.org), a program called Noogieland employs activities to help kids cope, and Hurricane Voices (www.hurricanevoices.org/list) offers helpful tools and information. The Children's Treehouse Foundation (www.childrenstreehousefdn.org) provides a partial list of hospitals that offer support groups for kids who have a parent with cancer.

A Really Good Question

Not all children can go it alone. Research led by Josette Hoekstra-Weebers, MD, senior researcher at the University Medical Center Groningen in The Netherlands found that about a quarter of adolescents whose parents have cancer require professional assistance. They found that recurrences and other complications seem to indicate a higher probability that kids will need help.

Adolescent girls and elementary school-age boys are also at higher risk. The concern for adolescent girls was not surprising since girls tend to take up many parental roles, and other studies have found this pattern. But the concern for younger boys is a new insight, Dr. Hoekstra-Weebers says. Because boys of that age tend to be less advanced in their language skills than girls, she thinks “boys at that age are less able to communicate their emotions and fears.”

Younger children sometimes experience unexplained headaches or tummy aches. “Take them seriously,” Dr. Hoekstra-Weebers advises. Withdrawal at any age is a concern, as is aggressive or delinquent behavior. Common sense says that children who have had previous problems, such as anxiety, stress, depression, or other mental health issues, are probably at greater risk when cancer strikes a family.

Surprisingly, Dr. Hoekstra-Weebers has found no evidence that communication helps, but she trusts her instincts. “I still think children are helped when the parents talk about their illness.”

It's also useful when kids do the talking. “Welcome all questions,” Dr. Rauch says, and probe a bit to make sure you know what's really being asked. “The process of elaborating questions helps you understand what they're asking,” she explains. Some suggestions: “That's a really good question, what were you wondering

about? Let me be sure I really understand What got you wondering about that?"

Answer too fast and you risk missing the real question. Research has shown that when time elapses between question and answer, the answers mean more to the kids.

Hayes-Cha and her husband spent some time talking with their four kids about how she got cancer to make sure they knew it wasn't their fault. Her elder son was under the impression that cancer spread by hugging. Joanie blamed it on her infant twin brothers. "Their world is so different. The way they think about things is just amazing," Hayes-Cha says. "Those conversations were the most enlightening as far as getting inside my kids' heads."

Harriet Berman, PhD, a child psychologist with The Wellness Community, suggests this conversational ploy should work at any age. "Ask your kid: 'What is this like for you? Because I've never been 10 years old and had a parent with cancer. I really want to learn from you what this is like.' " Even if they won't talk about it, it at least gives them tacit permission to talk with somebody.

Some kids know exactly what they need. Hillary Nelson's son Ryan was 6 when she told him about her breast cancer and the treatment plan. He quickly set some ground rules: He didn't want his friends to know, and he wanted her to wear a wig around him. In a letter to another boy, he confessed that he thought he'd laugh at her because she would look silly without hair.

Experts can speculate, says Berman, "but we can't know the deep emotional impact without hearing it from them I don't think there is any great wise way to know what your kid's experience is, and to reconcile all of this. It's about being patient and going through this experience together."

Parents and children both need to process, she says: "Again and again. Because as we grow, the meaning of things changes dramatically."