

# NCCN Roundtable: Talking to Children About Cancer

Presented by Martha Aschenbrenner, MA; Bruce Ham; Paula K. Rauch, MD; Zoraida Sambolin; and Maya Silver; moderated by Lillie D. Shockney, RN

## Abstract

A roundtable presentation at the NCCN 19th Annual Conference focused on the child's experience when a parent has cancer and concluded that honest communication, appropriate to the child's age and temperament, is essential, and that oncology providers should institute programs that help families deal with the illness. (*J Natl Compr Canc Netw* 2014;12:777–779)

The NCCN roundtable discussion titled, “The Child's Experience When a Parent has Cancer,” left attendees with a better understanding of the child's experience and a greater commitment toward those left in the wake of a parent's cancer diagnosis and, in some cases, death.

Moderated by Lillie D. Shockney, RN, Administrative Director of the Johns Hopkins Breast Center and Director of the Johns Hopkins Cancer Survivorship Program, the panel explored how parents and clinicians can and should communicate sensitively but honestly with children whose parent has cancer. Proper preparation is not only critical to the child's emotional health and future well-being, but is needed by the parents, too, panelists agreed.

Ms. Shockney was first diagnosed with breast cancer when her daughter was 12 and was diagnosed in the contralateral breast 3 years later. She described her daughter's reactions and questions as revealing (“Mommy, are you going to die?”), touching (“Let me be a kid a little longer”), and even funny (“Will the doctor let you bring the breast home?”).

She incorporated lessons she learned into her work and her life. “Without realizing it, our daughter found our sense of humor, and every day my husband and I made sure we found something funny about the fact that I had been diagnosed with cancer,” she said.

In those dark days, it was important to punctuate these conversations with hope, she added, which takes

many different shapes along the cancer journey but always includes some concern over the wellbeing of families once the patient is gone. Honesty does not erode the hope, she emphasized.

## Be Open and Honest

In fact, *honesty* was the word spoken most often by the panel. Parents, other caregivers, and the oncology team should approach children with openness and honesty about the cancer diagnosis, and even about the possibility of death, they agreed. This means welcoming the child's questions, thoughts, feelings, and fears.

“Talking about death feels abnormal, but when children are forewarned, it does not raise their anxiety,” explained Martha Aschenbrenner, MA, a palliative care counselor at The University of Texas MD Anderson Cancer Center who is also a child life specialist, a pastoral counselor, and a cancer survivor herself.

“Our goal is often to protect children, but honest information is the best predictor of how well children will cope, will understand what they are seeing and have it match what they are hearing, and will trust in the people caring for them,” she explained.

Maya Silver, who co-authored, *My Parent Has Cancer and It Really Sucks*, with her father, agreed that honesty is critical when talking to teenagers, and the sooner the better. “Withholding the news often results in teenagers hearing the news accidentally, and this creates a perceived breach in trust. It's better to create trust from the beginning.”

## It's Your Job

It is a sad fact that most communities and hospitals offer little support for families dealing with cancer. In the absence

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of structured programs, the person usually charged with speaking to the children “is you,” Ms. Aschenbrenner told NCCN attendees, referring to physicians.

To Zoraida Sambolin, former anchor of CNN’s “Early Start” and a breast cancer survivor, support from the oncology team was so important that she selected her oncology providers based as much on their communication skills as their clinical expertise. “I knew that if I had difficult conversations that needed to happen,” she said, “they would happen in a setting where I would feel more comfortable.”

Bruce Ham, widowed with 3 young daughters, also urged oncology providers to assume this responsibility. “You, more than anyone, are in the position to prepare families for what could come to be,” he said.

His wife Lisa was 39 when diagnosed with metastatic colon cancer, and their daughters were 7, 9, and 12. Lisa lived only 6 months after the diagnosis, and her short journey came as a shock to the family. “It’s great that we maintained hope,” he said, “but I wish I would have had more time to ask my wife questions, to get her perspective on life, for her to make memories for my girls. I wish I had her counsel before she was so riddled with drugs that these conversations were trying for both of us.”

In the aftermath of her death, Mr. Ham, who is Chief Development Officer for a YMCA in North Carolina, did find a community support group—Single Fathers Due to Cancer—where, 3 years later, he continues to draw strength.

“Unfortunately, I think this is the only group of its kind in the nation,” he said. “There were no resources to help any of us think about how to handle

our children—not during the illness and not after. In fact, most of us never heard from the hospital again, except through our insurance carriers.”

Mr. Ham writes about his journey in the book, *Laughter, Braids and Tears*, the cover of which features his three daughters with beautifully braided hair. “See that? It’s a reverse French braid!” he boasted, to applause. He blogs about his experiences on <http://www.therealfullhouse.wordpress.com>.

At least 1 center is trying to fill this resource gap. Massachusetts General Hospital Cancer Center has a program, Parenting at a Challenging Time (PACT) ([www.MGHPACT.org](http://www.MGHPACT.org) [see sidebar]), which is staffed by child psychiatrists and psychologists and supported through philanthropic grants. PACT is a “parent guidance consultation model,” individualized based on the parent’s description of the child.

“Our program respects that the parent is the expert on his or her own children but needs help in addressing the challenges of living with cancer,” said Paula K. Rauch, MD, the founding director of PACT and Associate Professor of Psychiatry at Harvard Medical School.

### What Do You Tell the Children?

The panel agreed that conversations with children should be tailored to the child’s age and temperament. PACT staff consider the child’s developmental level and temperament when determining how best to talk with that child. The manner in which the child has coped with other troublesome issues is also informative, said Ms. Aschenbrenner.

### The Marjorie E. Korff PACT Program at Massachusetts General Hospital Cancer Center

The Marjorie E. Korff PACT Program at Massachusetts General Hospital Cancer Center offers guidance to parents with cancer receiving treatment at the Massachusetts General Hospital Cancer Center. PACT staff clinicians (psychiatrists and psychologists) work with parents, drawing on their combined knowledge and experience to develop a plan that parents can follow to support their child’s continued healthy development. PACT staff also helps identify additional support systems within the family and community.

PACT clinicians provide individual consultations with parents (the parent with cancer and/or a healthy parent or partner) for one to several sessions, as needed. The PACT staff seeks to learn from the parent about the child’s age, temperament, behavior, and concerns he or she may have expressed. These consultations help prepare parents for talking with their children and dealing with issues and needs that might arise. The program is open to inpatients and outpatients.

Additional information about the principles that underscore this program is found in the book, *Raising an Emotionally Healthy Child When a Parent Is Sick*. This book represents the collective experience and wisdom of the PACT clinical team. The site also offers a toolkit for educators. These resources can be very useful to providers interested in developing similar programs for their patients.

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“You need to know your own child,” agreed Ms. Sambolin, whose son was 14 at the time of her breast cancer diagnosis. He rose to the occasion with unexpected resiliency by educating himself and creating a network of support among his friends. While her son became her advocate and caretaker, her 9-year-old daughter was far less inquisitive, she said.

“My son chose to walk the journey with me. It taught me that kids can handle a lot more than we think they can handle and that when he faces adversity, he is going to be able to handle it,” she added.

Maya Silver agreed that dealing with her mother’s cancer (which her mother survived) helped her prepare for future crises. As a 27-year-old adult she said she is able to differentiate “big problems from small problems” and apply personal coping mechanisms. “It taught me a lot about what not to do,” she said. “I’ve learned how helpful organized communication strategies would have been back then.”

In brief, the panel’s advice for talking to children of various ages is:

- Children younger than age 6 have a poor concept of time and do not understand the meaning of “forever.” Use concrete language, including the word “die,” rather than “go to heaven,” “not make it,” and other euphemisms. Explain that death means the parent will not “breathe, eat, hurt, or come back.” Start describing this process early-on in a terminal illness.
- School-age children express their thoughts more easily, understand that sickness can lead to death, and are likely to ask, “Is Daddy going to die?” Answer them honestly, as they can sense the truth; repeated affirmations that “everything will be ok” will be confusing. Virtually all children worry about their parent dying, and their fears should be openly addressed.
- Teenagers view dishonesty as a lack of respect and trust, and when information is withheld they feel lied to. Assure them that the information they receive (they will “google”) is accurate. Hold “family meetings” or give updates on Mom’s condition and treatment, and be “honest within reason.”

## Creating a Legacy

Many parents feel that creating a legacy for their children is important. This can be in the form of

### Meet the Panelists

**Lillie D. Shockney, RN**, Moderator, Administrative Director of the Johns Hopkins Breast Center, Director of the Johns Hopkins Cancer Survivorship Program, and 2-time breast cancer survivor

**Martha Aschenbrenner, MA**, counselor for the acute palliative care inpatient unit at The University of Texas MD Anderson Cancer Center. She is also a child life specialist and a pastoral counselor.

**Bruce Ham**, Chief Development Officer for the YMCA of the Triangle Area in North Carolina. He is the author of *Laughter, Braids and Tears*.

**Paula K. Rauch, MD**, Founding Director for the Marjorie E. Korff PACT Program at the Massachusetts General Hospital Cancer Center, Boston, and Associate Professor of Psychiatry at Harvard Medical School.

**Zoraida Sambolin**, cancer survivor, Emmy Award-winning journalist and former co-anchor for CNN’s “*Early Start*.” Living in Chicago now, she is heavily involved in cancer outreach projects within Spanish-speaking communities.

**Maya Silver**, co-author of *My Parent has Cancer and It Really Sucks*. Living in Colorado, she currently is an editor for *DiningOut* Magazines.

letters, videos, scrapbooks, or cards, and it should be started while the parent is still up to the task.

“We tell patients to think of it as an umbrella you bring with you in case it rains, ie, if things don’t turn out as we hope,” said Dr. Rauch. “Write a letter about what you see in your child that is special, share a unique parenting memory.”

Ms. Shockney encourages her patients to leave cards for their children to be opened on significant occasions. She recently received a call from a 24-year-old newly married young woman whose mother she had cared for 10 years earlier. The woman told her, “For all my milestones, there’s been a card from my mother. When my aunt placed my veil on my head she handed me a card. It was beautiful, and I loved seeing my mother’s handwriting once again.”

“My mother’s card said, ‘When your dad lifts your veil and kisses your right cheek, you will feel me kiss your left,’” she said. “Lillie, I called to let you know that I felt my mother’s kiss. Thank you for arranging for her to be at my wedding.”