

About Health TV with Jeanne Blake
Parenting at a Challenging Time
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JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. Every year tens of thousands of children lose a parent to cancer. Losing a parent is always difficult, but imagine if your parent died and you'd never spoken about it. Or perhaps worse, you didn't even know they were sick. On this edition of *About Health TV* we're going to talk about a program at Massachusetts General Hospital that is designed to help families talk about serious illness. It's called PACT, Parenting at a Challenging Time. Joining us for this program is the founder of PACT, Dr. Paula Rauch. She is the chief of the child psychiatry consultation service at Mass General Hospital. And we're also joined by Suzanne Greenberg, who knows well the pain of losing a parent as a child. Thank you, both of you, for coming in to talk about this program. Dr. Rauch, it's your baby. Where did it come from and what is it?

DR. RAUCH: After many years of working with children who were medically ill and trying to understand and help families to help their children, more and more I was hearing from other clinicians in the hospital. What about the children of adults who had particularly cancer, but also other serious illness? Who was looking into their needs? And I got interested in that idea and was supported by the administration at the Mass General, the head of the cancer center, to pilot a program where I would be available in a consultation format free of charge to adults who had cancer who wanted to talk to an expert in child development about how to make the process of their illness go as well as it possibly could for their children.

JEANNE BLAKE: Now, just to get some perspective, when did this start?

DR. RAUCH: About three years ago.

JEANNE BLAKE: Okay. And what need were you seeing on a very human level? Can you give us an example of someone that you met that really crystallized in your mind that this was definitely something that would benefit families going through such a tragedy?

DR. RAUCH: I can remember some of the first families that I saw. I can remember a mother with a brain tumor who was very concerned about how to talk to her adolescent daughter, who was facing decisions about going off to college in the next few months. Should she tell her daughter about her illness? Should she keep it a secret? She was worried that her daughter learning about her illness

would then change her decisions about colleges. She really profoundly had that sense that the decisions that she made at that point in her illness were going to affect her children long term, and she wanted help to think out loud about what was the best way to meet their needs.

JEANNE BLAKE: I imagine that that creates a tremendous stress, because a mother wants her child to have a life and to not consume her life with her cancer, and yet having a child go away when you're facing a life-threatening disease must be horrifying.

DR. RAUCH: With this mother, and with many other parents that I've met with over the last three years, one of the things that we end up talking about is the way in which not talking about it with your child is an error of kindness. The parent often may feel that by not talking with their child they're protecting them from the sadness of the illness, but in fact they're not giving the child an opportunity to cope with all of their capacities and make decisions that make sense for that child and within that family. As often as any of the things I hear is concern from parents: "Gee, my child is doing so well, should I be worried? He's playing soccer, he's doing fine in school, but he's not talking about my illness." And one of the kinds of support I end up providing is saying, "Your child is coping well." There's sometimes a misconception that children should be completely devastated, completely fall off their developmental line, in the context of a parent with a serious or life-threatening illness, and that's really not our experience.

JEANNE BLAKE: But that was a child that did know about what was going on within the family, right?

DR. RAUCH: That's right.

JEANNE BLAKE: Let's talk just briefly about what the impact is or can be. I imagine every child is different, every family is different, no matter how it's been talked about or not talked about. But if a child does not have the opportunity to talk about it and a parent becomes very ill and dies without that process, without the child being part of that, what is the potential long-term impact?

DR. RAUCH: Often children who never have a chance to have that conversation feel betrayed. They feel that the parent knew this very important piece of information that was going to affect the child intensely and didn't help them to make sense of it, didn't say the goodbye, and people seem to have the notion, with the goodbye that we need, saying literally goodbye, but really the goodbye is talking

with the child about what you've loved about them, what makes them special, what your hopes and dreams are for the child in the future.

JEANNE BLAKE: I imagine that there's the age approach, which we'll get into, but I also would think as a child, just listening to you talk, that in a way it would be not trusting that the child was adult or mature enough to be able to handle it, which sends a very powerful message to a child.

DR. RAUCH: I have learned as much from the parents and children that I've seen as I have brought to the consultation service, and I'll tell you what a 12-year-old boy said to me on the day that his mother died. She was a very wonderful mom but a mom who felt like she could never tell her son that she was dying and didn't want anyone else to tell him. And what he said was – he was in the sixth grade at the time – he said, "I wish I would have known at least two months ago. Maybe I wouldn't have wanted to know last year when I was in the fifth grade that she was going to die, but now I feel like everybody knew except me. I can't understand why she didn't tell me."

JEANNE BLAKE: Wow, 12 years old. And were you able to answer that? Had you known the mother well enough that you could give him an answer?

DR. RAUCH: Well, we said to him -- what his father said to him and what I said to him was that really up until the end of her life she wanted to believe that she wouldn't die, and what she told you is what she wanted to believe even though all the odds were against her.

JEANNE BLAKE: Do you think that helps?

DR. RAUCH: Well, frequently we're in a situation of making the best of a situation. Do I think it was best for this child? No. And I can't think of the child for whom finding out after the fact is the best approach.

JEANNE BLAKE: Suzanne Greenberg, this must all sound very familiar to you.

SUZANNE: Yes.

JEANNE BLAKE: Tell us what happened when you were a child.

SUZANNE: Well, my mother got sick when I was 4 with cancer, and died when I was 9, but she never discussed her illness. She went into the hospital and died, and nobody talked to me about it.

JEANNE BLAKE: Did you have a sense that something was awry?

SUZANNE: Absolutely. I got very visual in my life, getting trained to look for all the clues of things that are wrong.

JEANNE BLAKE: Well, what did you think was going on for six years?

SUZANNE: Well, she was in remission for part of that. Just a secret.

JEANNE BLAKE: Really? I mean, you had no clue that your mother was not feeling well?

SUZANNE: I had a clue, but I didn't understand what it was or how it was going to play itself out. But obviously, you have a clue about something awry. It was unclear, but I think part of my motivation to fund or help fund a program like this is more what happened as an adult. I used to think that my experience was tucked away in a very private family history from the 1950s and that it was a quirk with only my mother and my father and our little system. But as time has gone on I've seen other families go through some more things, and no matter how educated or how sophisticated the parents are, there is a real uncertainty about how to navigate the conversation with kids. And that's what stimulated me at this point to do everything I can to raise money for this program. One example is my sister. She didn't know how to talk to her grandchildren, she didn't know how to talk to her own children when she was diagnosed with cancer, and neighbors and friends. It's tough.

JEANNE BLAKE: Let me ask you, because I've got a million questions. Tell us about the day that your mother did die. What happened? Do you remember?

SUZANNE: It was the day after Christmas, and I went into the living room and I went on my dad's lap, and he said my mom was out of misery. And I thought great, she's well. I was so ...

JEANNE BLAKE: This is heartbreaking.

SUZANNE: It's all right. I'm fine. And then he said no, no, she died. And you asked about that day, and so that's the way the day went.

JEANNE BLAKE: Did you know what that meant? You were 9.

SUZANNE: No, I did know what it meant.

JEANNE BLAKE: And do you remember any feelings that you had? I mean, Dr. Rauch talked about the feelings of betrayal.

SUZANNE: Absolutely betrayal.

JEANNE BLAKE: Really?

SUZANNE: Absolutely problems with trust.

JEANNE BLAKE: But immediately? Do you remember the immediate reaction that you had?

SUZANNE: Relieved that she was out of her misery. I think I did feel that way, but I think I denied the actual death for a long time by dreaming that she still was alive and dreaming of conversations with her a long time after she died.

JEANNE BLAKE: And now transitioning into an adult. I mean, I think this is such a key piece, that especially during those developing years when something so major happens, that of course it's going to carry on to your adult life.

SUZANNE: But if you ask the cast of characters in the 1950s in New York City, they would think they were fine, they did the best they could.

JEANNE BLAKE: Well, of course. I mean, I grew up in Minnesota and they'd say the same thing today.

SUZANNE: To this day they would say, "It's your problem," you know?

JEANNE BLAKE: Well okay, but not pointing fingers ... they can't tell you what to feel anymore. You showed them. You mentioned feelings of betrayal and difficulty trusting as an adult, which is ...

SUZANNE: It's a lifelong problem, it's a lifelong struggle, it's an uphill battle. I mean, obviously, to some extent.

JEANNE BLAKE: That there's a big secret?

SUZANNE: Yes, always.

JEANNE BLAKE: Dr. Rauch, what about the developmental piece here? She was so young when her mother was diagnosed, and 9 years old. I think from some work that I've done, that 9 years old transitioning into adolescence seems like ... you know, you're becoming a woman. I mean, it seems like this is a very complicated time in a young girl's life to have her mother die and then have it be so secretive.

DR. RAUCH: I think even going back further, to the time of her diagnosis, think about it, diagnosis during preschool when you're egocentric and you feel like if anything goes wrong you must somehow be responsible. And if you feel somehow responsible ... you spoke about vigilance ... if you feel responsible for something as calamitous as a parent getting cancer, what a huge burden to carry as a young child.

JEANNE BLAKE: How does it feel to be analyzed on television?

SUZANNE: I don't believe I have received the check. This is great. No, it feels fine.

JEANNE BLAKE: She may bill you yet.

SUZANNE: That's right, I'm writing the check.

JEANNE BLAKE: Suzanne, you are supporting this program through your generosity. Dr. Rauch, you have gotten funding from other funders?

DR. RAUCH: We're starting to see some money, and we're very excited about it. The cancer center itself has been supporting us, which we're delighted about. Amgen is interested in supporting as well, and we've had some family foundations that are interested as well. I think when people hear our message it's one that they can relate to. There's hardly a family that hasn't been touched by cancer. I think every one of us has that sense of "but for the grace of God go I, it could be me, it could be mine."

If this were to strike my family, if it hasn't already, then I would want access to someone who could help me think through how to do this best.

JEANNE BLAKE: Can you explain how ... I'm a very concrete thinker and I like to get a picture in my head of how the program works. I mean, is there a room or do you go to where you need to go in the hospital?

DR. RAUCH: I joke about being the nomad. One of my goals for the program is that we make it as accessible as possible so in fact anyone can consult us. The oncologist can call us, the patient can call us, one of the nurses can call us, social services can call us. Anyone can call and say that they've been talking to this family or a parent, either sick or well, can call and say, "Look, I have these questions," and my response is, "Great, what's the best way to sit down and have a conversation?" Often I go to the chemotherapy infusion unit and sit with people there. Many parents will come to my office in child psychiatry and meet with me there. I do a lot of work over the telephone. The logistics of living with cancer and having children is mind-boggling in and of itself, so that part of being accessible is being flexible. And I've been in patient units as well.

JEANNE BLAKE: Are there other programs like this in other hospitals nationally? I mean, you have founded this program. Two questions, Suzanne: Are there, and will you be sharing it with other hospitals and other physicians?

DR. RAUCH: From looking around the country, we're not aware of any programs like this one. There are social workers who are working with families and doing wonderful work around the country and doing wonderful work at the Mass General as well. The Mass General, as far as we know, is the only place where there is a trained child psychiatrist, a child psychologist available to provide that level of expert care and input to families. Typically, both physicians and social workers who work with the adult patient population are not particularly trained in child development. It's two separate training programs. So the idea of bringing someone in who has particular training in child development and child mental health is a novel idea, particularly in the setting where there's not a designated patient, and that, along with the wish to make it accessible by location. We want to make it financially accessible. We don't want parents to feel like they need to have a diagnosis in order to get this support.

JEANNE BLAKE: You mean a psychological diagnosis?

DR. RAUCH: A psychiatric diagnosis. And the right kind of health insurance in order to get this.

JEANNE BLAKE: Ugh, please. They couldn't even be bothered, right?

DR. RAUCH: It just makes it too difficult. It's also too stigmatizing. It seems clear to all of us that any parent who is parenting in the setting of having a life-threatening illness is going to face very specific and very difficult challenges and may not have the same kind of input that they would have around their other parenting.

JEANNE BLAKE: Just as it's called, parenting at a challenging time. It would seem to me that there would be application for this in a lot of specialties, though, in a lot of different diseases and not just cancer.

DR. RAUCH: And, in fact, we've been consulted by other parts of our hospital and other institutions. I've had opportunities to speak at different conferences and have been impressed with how many physicians and other healthcare providers of different disciplines have come up to me and said, "Oh, this is so applicable for what I do. What can we read about this? What can we see?" So that's also what I hope is coming. We really need to be doing pamphlets, doing articles, making videos, making these lessons learned from our experience more available across the country. Starting July 1, we'll have our first child psychiatry fellow working in the parenting program. By having a training program, that's another way to get the message out.

JEANNE BLAKE: Is there a greater need now than you can serve in the hospital?

DR. RAUCH: Oh, much greater.

JEANNE BLAKE: Is that right? That's sad.

DR. RAUCH: I've described myself as a Poland Springs water cooler in the desert, which is not to say there aren't lots of people doing wonderful things for kids, and the hospital overall is very committed to the needs of children. It's just that there are so many adults living with some serious illness who are parents.

JEANNE BLAKE: You've given us an example of the 12-year-old who lost his mother, and Suzanne we've heard from you. Have you heard stories – I'm sure that you have – from people who did it right that you can share with us, where there was a response that you heard that made you know that it was worth it?

DR. RAUCH: There have been many parents and many kids who have talked about how enormously helpful it's been, how being able to talk out loud about what they don't want to say and what they do want to say gets them beyond the place of using euphemisms instead of saying the cancer out loud, having a conversation. And then they come back to me and say, "Wow, this was so much easier than I thought. Gosh, my child, who wasn't asking any questions before, is now asking questions, and I'm better equipped to get my child to elaborate, to find out what the real questions are. Actually, there are lots of questions I can answer. I felt before like there was going to be nothing I could answer, so I just didn't want to go there." Those are some of the stories, and also from the kids, some of whom parents have brought in because the parent feels that the child is not doing badly enough, so they bring the child in and the kids are saying, "I know, I know what's going on. I feel like I'm hearing things. No, I'm not overhearing the news. We're having the discussions. I'm not happy about it. I'm sad about this, but I'm not thinking about it all the time. School is going okay for me. I'm having a good time with my friends. I know that I can talk to my parents about this. Yes, I believe that they'll tell me the truth."

JEANNE BLAKE: I think that some people might be surprised to learn that the death of a parent doesn't have to be necessarily overwhelmingly devastating to a young child. I mean, that to me is a surprise. I can't even imagine it. I'm very lucky that my parents ... my mother is still alive and my father died when I was an adult. It was devastating enough. I mean, I can't imagine having to deal with that as a child. How is it that some children can go on and do all right? And I'll add to that that a friend of mine died from cancer last year and left a 16-year-old and an older daughter, but her husband kept saying to the 16-year-old, "We can talk about this, it's okay." And he was wonderful, by the way. But the child said, "I'm really okay, Dad, I'm really okay." And I'm wondering, how does a child -- again, child-to-child it's going to be different, but how does a child do okay with that? What's going on there?

DR. RAUCH: I think children are enormously resilient, and as important as a parent is, we have to be humble that we are one of a community of important supports for a child. And children who are supported by a well parent and by a community are receiving all kinds of support in many other places. They have the institution, often, of school for support, they have friends, they have friends' parents, they have extended family. All those things are protective. And the sense that somehow the child would

be acutely in crisis, that after the parent died the child would not be able to function, and then there would be some period of time that people talk about, this magical one year, and then it should be behind you and you should be fine. None of that actually follows the true natural history of grief, if you will. In fact, one study is how children cope with an impending death, and the most symptomatic children is the four months before a parent dies. The four months after, and by eight months if you are using some kinds of measures, those children don't look any different than socioeconomically matched peers. Grief is a personal process, so saying that doesn't capture the fact that there won't be many moments through a person's life, even if a person loses their parent late in life, where there's that moment where you really wish the parent were there, you're grieving at that moment. And some things we can predict. We can predict anniversaries and birthdays. But it's a much more personal process. It's when you get a flat tire and your dad's not there to call for help to change it, or when a woman has her own child and her mom died and she's always envisioned having her mom there for the birth. There are going to be those poignant moments, but it doesn't predict the relationship that a child is going to have in adult life. It doesn't predict what line of work they're going to be in. They're going to face all the things that others do, and Suzanne is a good example of how children who lose parents earlier in life go on to live high-quality, satisfying lives with all the ups and downs that the rest of us experience.

JEANNE BLAKE: Suzanne, we don't mean to be talking clinically about such a personal history that you've had. You mentioned that your sister had been diagnosed with cancer – did you say that she handled it well, or she still struggled, you said?

SUZANNE: She still struggled.

JEANNE BLAKE: Was she younger than you or older than you?

SUZANNE: She was older. She died a few months ago.

JEANNE BLAKE: Oh, I'm sorry about that.

SUZANNE: I saw that same generation ... the new generation repeat what the old generation had.

JEANNE BLAKE: Had your mother talked with her?

SUZANNE: No, no, but she was a lot older. She was 16.

JEANNE BLAKE: She didn't learn from that experience to be different for her family.

SUZANNE: I don't know how it all works out that some siblings just strive to be different and others feel comfort in the same ... Dr. Rauch, you would know more than I. I don't know, we were all very different.

JEANNE BLAKE: Did she talk with you?

SUZANNE: Only at the end of her life, and she really spoke to me at the end of her life. It was wonderful, but I wish she had the capacity to speak that way for longer for her kids, for her grandchildren, and, selfishly, for me.

JEANNE BLAKE: So what would you say to people who might hear this and be struggling with that right now and not knowing what to do or whether to speak in an open way or how to maybe do more?

SUZANNE: Well, what I would say and how people hear it are two different things. I think people have to feel that there's a little bit of a problem and they don't know how to handle it. In the case of my sister, she didn't think there was a problem, so every time I would hint about talking out loud or using the cancer word to her grandchildren or to her children, that was dissident to her. So ideally I don't know how to answer that. I think for people who are open or feel something slightly awry, some of those things go a long way. But for people who are very resistant and so frightened about their own illness that they can't hear it or can't even begin to think there's another way of handling it, the door gets closed, and then for the people around them it's pretty frustrating. You know, you get older and you know more people that have been through this and people that have lost their lives, and it's tough. I see people fumbling all around me, educated people fumbling, some better than others, some are more frustrated, some will get more help, some are more blocked so they don't want to talk about it. Oftentimes, the kids do end up doing really well in spite of it all.

DR. RAUCH: I think the question is how are people supposed to know. One way is by ... in your family there was a model, and the model was mostly to not speak about it.

SUZANNE: Right, right, right.

DR. RAUCH: Frequently, people are fumbling, because where are they supposed to get that information from? When they're doing their other parenting, they can look to their neighbors who are going through similar circumstances, they can draw from their own personal experience, even from the media, and frequently what parents talk about in this setting is they feel so isolated. And I sometimes feel like I'm giving them a series of choices. Some parents say this, some parents say that, does this seem comfortable to you, what do you not want to say, and offering them some choices to pick and choose so they don't feel so alone with it.

JEANNE BLAKE: Or being told what to do. We're out of time. So I hope that our talking about it here models that to some families who might hear it and need the information and the help. Thank you so much for coming in to talk about what happened in your life. Dr. Rauch, best of luck with your program. We know it will touch many people's lives and make them better for your being there.

DR. RAUCH: Thank you.

JEANNE BLAKE: And we'd like to thank you for listening to this edition of *About Health TV*. I'm Jeanne Blake and we'll see you next time.

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