

About Health TV with Jeanne Blake
Author, Dr. Paula Rauch,
Raising an Emotionally Healthy Child When a Parent is Sick
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JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. Parenting is challenging when a mother or father is well. But when a parent is seriously ill, it takes on new dimensions in difficulty. On this edition of *About Health TV*, we'll discuss how parents who are seriously ill can raise children who are emotionally strong and healthy. Our guest for this edition of *About Health TV* is Dr. Paula Rauch, the founder of the Massachusetts General Hospital care center parenting program and author of this book, *Raising an Emotionally Healthy Child When a Parent is Sick*. Dr. Rauch, thank you for coming in, and congratulations on your just published book.

DR. RAUCH: Thank you.

JEANNE BLAKE: This book really formalizes, or puts into print, what you've been doing for many years through the program you founded at Mass General called Parenting at a Challenging Time. How did you start to put it into book form?

DR. RAUCH: We were hearing from our patients that in these particularly difficult times, it's hard to remember everything that's being said to you in a clinical interchange, and they would sometimes be sitting there taking down notes and trying to be sure they've gotten every important word, and they were wishing there was something they could read themselves. They were also wishing that there was something their best friend could read, their sister could read, that they could pass off to the nurse at school or a guidance counselor. We heard it over and over and over again from our patients, then we had an opportunity through Harvard Medical School to write this book, and we jumped at the opportunity.

JEANNE BLAKE: Also, I think that, as you described a patient taking notes, they too want to be understood at home or by their friends. That's really who this book is written for, is for the parent who's sick, but also for spouses and friends and relatives, so that they can really understand, because you can't really understand unless you've been there.

DR. RAUCH: Absolutely. I think sometimes the people who care most about someone who's ill, their friends and family, may have ideas about what their children need that aren't really based in developmental understanding, and so the kinds of common sense information that we provide to parents, they're wishing they could expand outside our clinical space and, in fact, across the country, because we also receive phone calls and e-mails from people across the country asking for someone like us to help them in their communities. Unfortunately, not every cancer center, not every general hospital has access to trained child psychiatrists and child psychologists who have become particularly expert at how to help kids when they're parents are ill.

JEANNE BLAKE: You're sort of it, nationally, because you started the program how many years ago?

DR. RAUCH: It's about eight years now.

JEANNE BLAKE: It's been that long. I know you were here probably five years ago talking about it. I'm kind of going backwards, but tell us, then, what inspired you to start the actual program, rather than just doing your job as a psychiatrist, meeting with families. Why did you then start the national program?

DR. RAUCH: I think lots of times we have a personal story that launches us into doing something new. I had a close friend with children the same age as mine, who was diagnosed with breast cancer, and through our friendship we would go walking on Tuesdays when she completed her chemotherapy, and she had a number of questions, including asking me who could she see who has this as a particular area of expertise. And I said, so confidently at the time, No problem, I'll get back to you tomorrow. And then discovered that there really was no one in our community, and our community had lots of child and adult psychiatrists in it who had really made this area particularly their own and had been looking at the nuances. When there's something that's very emotionally charged, it's particularly important to have people who have a particular skill set around it. Otherwise, people sometimes think, Oh, everything is normal under the stress of having an ill parent, and that's really not true.

JEANNE BLAKE: That's a disservice to a child. They need limits to grow up, which is really what you get into from the first page. Describing, and you do so beautifully, take the reader through every stage of a child's life. So regardless of how old a child may be at a time that a parent becomes ill, there is a place in this book where they can go and say, OK, this is the good model for me to follow. This is

going to help me do the least amount of damage to my child, and actually raise a child who is resilient and strong. And you start with toddlers. You were very clear about the fact that – I came away with two things, really, in the beginning part of the book. That toddlers need a structure – every toddler needs a structure, regardless of whether their parent is ill – but it's particularly important when a parent is ill. And also, key to the caregiver is tremendous organization, which doesn't come naturally to people. Can you just help us understand a little bit more of why that structure is so key?

DR. RAUCH: Absolutely. In fact, the first third of the book talks about normal development, and where normal development meets the particular challenges of having an ill parent, and I hope that the information that's in all the development chapters would be useful to a parent whether they were sick or well, because it's good parenting advice, I hope. When addressing the issues around toddlers, toddlers are experiencing the world not so much through words but through experience, and part of what helps a toddler to feel secure is having a regular schedule, a familiar environment. It's not so much what you say, but it's what you do that gives a child that sense of security. What sometimes happens in the setting of the commotion that surrounds a parent's illness is that a toddler is being moved from place to place to place and their schedule is disrupted. In the initial diagnosis, all bets are off, and people really need time to get themselves organized. But after that first phase, what you want to help people to do is to have as much structure and consistency in the youngest child's life, and to help them remember that part of what makes them self-confident is realizing that they can manage bearable frustration, and that life is OK if you don't get the yellow cup even though you love the yellow cup. Sometimes kids at this age will ask for their third and fifth and ninth breakfast choice, and knowing that there are two choices is really enough, and then helping them to feel comfortable with those choices.

JEANNE BLAKE: As you said, that is just good parenting. You're talking about a toddler who can demand a yellow cup over a red cup. What about an infant, a six-month-old infant? Does a six-month-old pick up the vibe if something's off?

DR. RAUCH: Maybe. It would be a little hard to know because it's hard to check back in with six-month-olds to know. But certainly they are going to be aware of a disruptive routine and being put down at different times for a nap, eating different foods. So if a parent can focus on those specific things that make the environment familiar – and one of the clinical recommendations we make is to have parents have their child take their afternoon nap in a porta-crib. That way, if a parent has an unexpected trip to the hospital or a meeting that runs late, the child has a porta-crib all set up that's familiar ... a little space that they recognize as their own.

JEANNE BLAKE: As I was reading the book, I thought, How can I hear you, Dr. Rauch, if there are probably a thousand of those tips in this book. I decided to take sort of a broader approach. And the other very key element that I wanted to have you talk about today was the importance of being able to ask for help. I think that's – number one, it's hard for some people to ask for help. But being sick and being a parent of a child of any age is exhausting. You have some very creative ways of helping people ask for that help and designate the people they think can be of the most help.

DR. RAUCH: We've heard from family after family of how emotionally draining it is to try to organize the well-wishers. They very much appreciate people's kind thoughts and actions, but meeting people and talking to them about what you need, all those things actually taking away from your own children. So we actually talk about assigning somebody the job of being the captain of kindness. When the parent – the sick parent or the well parent – runs into someone, for example, at the supermarket who says, "What can I do to be helpful?" you refer them to the captain of kindness, and then the parent can let the captain of kindness know what kinds of things would be helpful. It might be taking their child to ballet or to soccer. It might be mowing the lawn. There could be really specific things. It might be that instead of sending flowers when someone's in the hospital, sending phone cards, if the mom is far from where her children are, would be more helpful. So that capacity to welcome support but not have to differentiate to people what each individual person –

JEANNE BLAKE: It just creates a whole new job, really. I remember when a friend of mine died, her mother – she was in her 20s when she died, and her mother said, "People are calling they want to help." She said, "I just want to tell her, just clean the refrigerator." So I think this is what you're saying, that there's so much that needs to be done, some people will have a hard time saying, "Well, you know, could you mow the lawn?" And yet people really do feel helpless and they want to be able to contribute in some way. So I love your suggestion for that.

DR. RAUCH: And there are ways you can set your house up so that it's actually easier for somebody to come in and be helpful. So it may be that a sick parent will sit at the kitchen table while a good friend takes snapshots of the insides of their cabinets and tack them in, so that if somebody wants to put away the dishes in the dishwasher, they can actually put them away in the places where they belong.

JEANNE BLAKE: And you mentioned being on the phone with someone, being in the room when a mother was on the phone when her sister was putting Post-its on the cupboards: Bowls go here, plates go here. There are so many of those tips in this book, and it's incredibly helpful. Dr. Rauch, we talk

about the developmental stages, and I think for parents in general there are always a lot of questions about what kids are ready to hear when. When you're talking about a serious illness, and in particular death is what you're addressing in this part of the book, I just would like to go through – because I think people will find it helpful to understand this – what the concepts are around death for, let's start with infants and toddlers and then we'll go up to adolescents.

DR. RAUCH: What we know is that infants and toddlers don't have any concept of forever, at all, so that as they come to want to know someone as important as a parent, who may have died during those first couple of years of life, they're going to need all kinds of records. They're going to need the photographs and the videotapes and stories from family members to come to get to know that parent who died. So really what you want to do is create the paper trail, of a sort, albums of information. Sometimes at memorial services people will be asked to bring a photograph of the parent as a child along with a story. We especially encourage people to tell the funny stories. Sometimes when someone dies, they become sort of sacred, and you think they did everything perfectly, and there's nothing that's better than to hear the stories about when parents were less than perfect.

JEANNE BLAKE: I'm sure we're still like that, right. The second one, the second age that you address is preschool age children.

DR. RAUCH: Some kids that are in the sort of 3- to 6-year-old age, they also don't understand forever, so they think that death is reversible. It can be particularly painful for a parent, a surviving parent who is deeply grieving, to come home from a funeral with their preschooler and have the preschooler say, "So, when is Daddy coming back?" or "When is Mommy coming back?" and not have actually understood that this is forever. In some ways it makes us feel like they're a little protected, that they don't sit with forever with the same intensity as we do. But preschoolers also think, because of the way they use logic, they imagine that everything happens for a cause, and because they're egocentric, they imagine they're the cause, and those two things come together to be what we refer to as magical thinking, which means that when a parent dies it's very common for preschoolers, and even early grade school kids, to feel like they did something to cause their parent's illness.

JEANNE BLAKE: So how does a parent – is it simply a matter of saying – how do you start to have that conversation? How do you have that conversation of assuring a child it wasn't their fault?

DR. RAUCH: It's not one conversation, it's many conversations, but it's important to ask a preschool age child, Do you ever wonder what caused Mommy to die? Do you ever wonder how come

Daddy died? or How come Daddy died of cancer, or Mommy had her heart attack, or Mommy's kidneys didn't work? whatever the illness is, and then we listen to the things that they tell us. We also look at their play. You can often see ... playing out a story line in which the child is responsible for the parent's death. You let them complete their play, you don't want to interrupt that, but you make sure that at a later time, say, "You know what? I wonder if you wonder what caused Mommy to have her kidney problem. Let me explain it to you." It's not because we think that a 4-year-old is going to have a nuanced sense of what causes kidney disease, or what causes cancer. But the clear message is, it's nothing kids thought or did that made their mom have problem kidneys or gave their dad a heart attack.

JEANNE BLAKE: It makes me feel so sad, because I think so many parents – people who don't access a book like this or get professional help when a parent dies, they would never think to say that to a child, or to watch for that, and to reassure them on that. It just makes me feel so sad. I did feel very sad at times reading the book. OK, elementary school.

DR. RAUCH: Grade school kids really are looking for cause and effect. Everything is supposed to happen for a reason. They have the zeal of those who have just learned that rules rule, and so they have some basic ideas about what causes illness, and may sometimes think they're complicated. So they'll often think that all cancers are caused by cigarette smoking, and of course that's not true. They'll think that germs cause illness. For example, with our cancer patients, many of them are on chemotherapy, they have immune system issues and there's a lot of talk about washing your hands and not sneezing on Mom. So it may seem to a child that what the parent has is contagious. So it's important to correct that image. It's very important for grade school kids to understand that everybody did everything they could possibly do. The parent did everything he or she possibly could do to live as long as possible, or they're currently doing everything they can, which means going to medical care that they have confidence in. It's very upsetting to grade school children, elementary school age children, to feel like somehow what could have been done wasn't done. Actually, sometimes the media will leave grade school kids thinking that. I've now met with a number of children in elementary schools who hear the advertising on TV for cancer centers and imagine that if their parent had gone to that cancer center they would have survived. That's a very uncomfortable place to leave a kid imagining.

JEANNE BLAKE: That's for sure. I think, also, that that age children, 7 to 12, still need to be reassured that they have nothing to do with it, that it wasn't their sneezing around Mom when she was immune suppressed.

DR. RAUCH: Absolutely. And parents want them to continue to do as many of their regular activities as possible, to support them in doing at least a few of their favorite things. Sometimes what can happen is, kids are overextended – often kids are overextended – and in the setting of the parent's illness they're only getting to these activities in a spotty way, and then feeling unsuccessful at them. So we try to help parents to sort of shrink the number of activities down to the ones that are the most important for a child, and work really hard, with support from the community, to get their child, in a consistent way, to whatever that activity is with the equipment they need, including school. Again, another one of those helpful things. In elementary school, often there are projects that kids have to do, and those of us that have parented children through those years realize that some of those projects, it would be good if you were an architect, it would be nice if it was your full-time job, but particularly in the setting of having a parent who's ill, there's nobody to go out and buy those supplies and spend hours and hours making that Native American village. And so that's the kind of thing that someone else in the community could offer to do, or be alerted, "You know, it would be great if you could build the fort out of popsicle sticks, because we have some other things going on." And it's hard for a child at that age, if they go to school and they don't have support.

JEANNE BLAKE: That's where I was going to go next, because then you also have a child who, it would be perfectly normal for a child to feel a resentment that they are somehow being left behind because of this illness. I would imagine that it's important for them to be able to express those feelings.

DR. RAUCH: Absolutely. Then, to recognize that when a parent dies, everyone at every age is going to have regrets. And grade school kids will very often say, "If I knew Dad was going to die, I would have gotten better grades," and it's important to give them the message back that [inaudible] and that their parents were happy with the hard work they did, and reading was not going to change the outcome.

JEANNE BLAKE: What do you think, as a psychiatrist, what is it about regret? Because adults feel that too. Every person that I know that has lost someone, including myself, though I've learned to anticipate it after my father died, and then when my mother died I had less, because I was able to say, Well, look at as it was. What do you think regret is about?

DR. RAUCH: I think it's when we have this emotional [inaudible] There's something about the regret that's almost trying to rewrite history. It feels like problem solving of a sort: If only I hadn't done this, then it would have been this way. What if I had done that. And it is natural to replay experience after experience when you lose someone, and it's only natural, then, that if you had it to do again, you

might do something differently. When you're engaged in it you're sort of in the moment, and you're rewriting the script all the time, and you can change what you're doing. If you didn't like what happened at 2:00, you can see them again at 5:00 and make sure to try to do it a little differently. Once that person dies, all you have is to rewrite the history and wonder about how it could have been different. It is absolutely normal. I can't think of anybody losing someone that can't think of something they wish they had.

JEANNE BLAKE: I've been so curious about it that I've talked with people about it. And part of me thinks that it's almost a function of not wanting to let go, too. Because if you're rolling that around in your head – but what I have found, my ability to let go of the few regrets that I did have around my mother, was that it actually helped me get faster to a place of just feeling her love. I try to share that with people when I know they've lost someone, because in my work, and I've been around many people who've died, I've just seen it a billion times. It's so sad to me, because it's such a draining emotion. And for families. Let's go on to the next age group, so that we don't skip this one, because it's very important, adolescents. They understand that death happens.

DR. RAUCH: They do, and it sits with them very heavy. At the same time, adolescents are very preoccupied with their own lives, and that combination of abstractly understanding the enormity of an illness one minute, and from a parent's perspective sometimes not applying that understanding, so the same child can be very tearful about being afraid that they're dad is going to die will only 15 minutes later say, "Oh, I don't want to be here for dinner tonight. My friends are going out to do this and this." And often parents wish their adolescents would step up to the plate, and have an unrealistic concept of the executive function of the household that a teenager would assume. The fantasy that a 17-year-old is going to come home and walk into the house and go, "Whoa, I think I'll put the dishes in the dishwasher, and after I do that I'm going to run upstairs and do a wash," it's not realistic. Often adolescents will talk about feeling that their parents are mad at them all the time, that they have expectations higher than what the teenager can manage, and part of why teenagers turn to their friends and do their age-appropriate activities out in the world is because they can't bear the full intensity of anticipating the possibility of losing somebody they love. And when you think about it, hopefully the majority of the families that we work with, the parent will survive, and there will be plenty of time to repair those relationships. But for those that don't, we really want an adolescent to have a strong friendship group to turn to during that grieving process. So finding some balance between parents being clear: Tuesdays and Sundays are family night, you really need to be at home for those, and everything else, maybe other evenings, are negotiable. But having real expectations that recognize that

balance between family and friends, and school. But not doing the kind of guilt-provoking stuff like saying, “Fine, go with your friends for the weekend, but you’ll be sorry when Dad’s gone.”

JEANNE BLAKE: Could you imagine? I mean, as you just described, that would put later upon layer ... We won’t get to all 12, but there are a dozen lessons learned from the parenting program, and just as we’ve gone through – the wisdom that you impart is incredible. I’d like to just go through a few of these, because then I think folks that are listening will learn a lot. OK, lesson number one. Everyone deserves to know what’s going on. I shared with you before, last time you were on the program, that I had a friend who absolutely, positively refused to talk with her teenage children about the fact that she was dying. Would not do it. They knew she was sick and she was going to die, but she wouldn’t be the one to talk with them. That makes me feel sad to this day. Why is it so important to talk about it?

DR. RAUCH: I think of honesty as a family value. We’re trying to teach our children to tell us things that may be hard for them to tell us, and things that we don’t feel that good about hearing, but it’s better to work it out within the family, to have that kind of honest dialogue. And when parents aren’t honest with their children, the children feel excluded, they feel undervalued, they feel deceived. While it’s easy to understand why parents – it feels to a parent, often, like it’s hurtful to their child to assault them, almost, to deliver this bad news. But delivering it crying together and then making plans for the future is a wonderful, loving thing to do.

JEANNE BLAKE: I think that in the case of my friend, it was too painful for her. I came to understand that more and respect that more, though I still wish that she’d been able to do that, because I know how valuable it was, for me at least, to be able to have that conversation with my mother and father, and I think that you are, in writing this book, making it possible for way more people that will do it than wouldn’t have done it, and through the work you’re doing.

DR. RAUCH: Sometimes we work with families and the sick parent can do that. We think about how it would work, we try, whatever. But sometimes what a parent can do is to let the other parent, or let a grandparent or another person, talk with the child and then do the follow-up with the parent. So there’s not one right way to do this. But facilitating the communication and having that dialogue be open.

JEANNE BLAKE: To do it at least.

DR. RAUCH: With someone, somehow, and then, if possible, to reconnect up with the parent.

JEANNE BLAKE: We have time only for one more of these, believe it or not. Overhearing the news is the worst possible way for a child to hear it. It's almost obvious, but I want to hear what you have to say about that.

DR. RAUCH: It speaks to the same issue, which is that it doesn't feel respectful. This is so important in the life of the child. It's a terrible way to find something out, it's the most likely to be mixed up, it feels like the child is less important than whoever else the parent is talking to, or someone else is talking to, or one of the awful scenarios that they learn from another child on the playground who heard it from their parents. So there is something really not respectful about being left to overhear important.

JEANNE BLAKE: Dr. Rauch, you've written a beautiful book that I know will help many families. Thank you for coming in to talk about it.

DR. RAUCH: My pleasure.

JEANNE BLAKE: Again, the book is called *Raising an Emotionally Healthy Child When a Parent is Sick*, by Dr. Paula Rauch. We should also mention that Dr. Anna Muriel, a colleague of yours at Mass General, was a co-author of the book. We want to thank you for joining us on *About Health TV*. I'm Jeanne Blake. I'll see you next time.

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