

About Health TV with Jeanne Blake
Autism
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JEANNE BLAKE: Welcome to *About Health* TV. I'm Jeanne Blake. Autism is a severe developmental disorder that is usually recognized in children during the first three years of life. The numbers vary, but the Centers for Disease Control and Prevention estimates that one out of 166 births carries the diagnosis of autism. Those are the numbers. For a moving account of what it's like for a family to live with a child who is autistic, we're joined by Susan Senator. She is the mother of three children, the oldest of whom, Nat, was diagnosed with autism when he was 3 years old. Her book, *Making Peace With Autism*, is her account of her family's life with this common debilitating disorder. Susan, thanks so much for coming.

SUSAN: Thank you.

JEANNE BLAKE: What a moving and beautiful and personal account you've written to help other families. I'm sure it was part of your goal in writing it.

SUSAN: Definitely. The whole goal was to give parents kind of a glimpse of how things could be. Definitely to validate how things are, but also to show them how things could be, and it's not impossible to have a happy family.

JEANNE BLAKE: That's right. I think a lot of people who look in from the outside and say, first of all, how do you do it, and how do you maintain any kind of normalcy of a family?

SUSAN: Right. There's just – normalcy is difficult. But I think that each family has its own style, and it's important for families to figure out what that style is and what their goals are as a family. It might be to take vacations together and have fun together, it might be each child's own sports activities and games. There's a lot of different ways you can figure out how to have a family life.

JEANNE BLAKE: I want to take just one step back, and sometimes on About Health we start with a little bit of a biology lesson, and autism is now recognized as sort of a broad spectrum of disorders. Can you help us understand that, and where Nat is on that spectrum?

SUSAN: The spectrum refers to the fact that autism comes in varying degrees of severity, and also with varying deficits. Most of the time autism is characterized by social, communicative kind of impairments, inability to read other people's emotional states, things like that. There also can be behavioral consequences, where kids act with eccentric behaviors, odd kind of behaviors, but not always, often. There can sometimes be cognitive delays, and sometimes sensory issues as well. My son has all of the above, and he's considered fairly severe.

JEANNE BLAKE: We said earlier that children are usually diagnosed with autism during the first three years of their life, and Nat was diagnosed when he was 3. But you say that you knew from the moment of his birth, almost, that there was something awry, that there was something not right with him.

SUSAN: I felt that, almost right away, that I wasn't needed, that there just wasn't the instant connection and just overwhelming joy and happiness that I expected to feel. I think some of that, of course, could just be normal postpartum stuff, but when I think about how different it was when my second child was born, who's typically developing, there was just this instantaneous rapport. So with Natty, the first, it was just kind of, there were some moments that were flat, there were just moments when I didn't get what I expected. And then, as he grew, there were things like he'd startle easily ... even the way he talked, there were lots of signs before he was 2.

JEANNE BLAKE: And people around you kept trying to tell you that it's normal, that this is OK, that there wasn't something really wrong. You were sort of alone in your belief that there might be something wrong.

SUSAN: I was very alone, in that this was the first grandchild on both sides, no one was looking for autism, certainly culturally no one was looking for autism, because the statistics back then were two in 10,000 births, as opposed to now, one in 166. With my husband, that was definitely a stress between us. He didn't see what I was talking about, he didn't have a lot of experience with babies. Our pediatrician was in love with Nat, only saw all of the brilliant, wonderful things he was doing. I think that nobody wanted to see it and nobody expected to see it, and these days it's a lot more easily caught.

JEANNE BLAKE: And you finally got the diagnosis because you were referred to a new doctor, a different doctor.

SUSAN: Well, I got the diagnosis by taking my pediatrician's referral to a developmental pediatrician, yes.

JEANNE BLAKE: And what was that like? You describe it in the book, the grief that you felt, and any parent can imagine that, but just describe for us what that was like. You said that, in a way, your husband said it almost a sense of relief to finally have something that you could hold on to. When you both knew at that time that there was something wrong, the grief has to be just incredible.

SUSAN: Yeah, I mean, I really kept thinking, Please change your mind, when the doctor said autism. I just, I hated hearing that, because all I knew was "Rainman," to me, this hopeless future and this awful thing. My husband felt relief only in the sense of, Well, OK, now we know what it is. The same way that when you find out it's cancer, definitely. It was just a terrible, horrible time, and we were very lost and didn't know how to go on.

JEANNE BLAKE: You didn't want to tell anyone right away. Did you think that's typical, from other parents you've talked to now?

SUSAN: Yeah, I think that people really struggle with how to tell people, how to talk about it. Even saying the words yourself makes it so much more real. So how do you first start doing that?

JEANNE BLAKE: When you first learned that Nat had autism, what did you expect, looking forward to your future?

SUSAN: I heard that he probably wouldn't go to college. I read in one of these doctor's books that he wouldn't have normal relationships with people. Often people end up being institutionalized. All kinds of terrible things like that that really made me scared. It was not until our doctor said, "Well, with the right educational approach, you never know" – and then I said, "What's the right educational approach?" and he said, "That you have to decide for yourself."

JEANNE BLAKE: So you really kicked into action. I think that, reading this book, your personality really came through. I don't know you, but I have a sense that you would take on any challenge the way you took on your son's autism, and you really kicked into action.

SUSAN: I didn't know myself that way at the time, but yes, I think that's true, that gave me, definitely, a focus. I went to the library right away, I think there were only two books at the time, but I read them both. I looked it up in the Yellow Pages, I looked up autism, and I found an autism support

center in Danvers, and I went to a support group within a few weeks. So I really started to try – even though I was grieving, suffering and crying a lot, I tried to find out information to start dealing with it immediately.

JEANNE BLAKE: One of the things that – your book is full of a lot of tools that other families, and I hope extended family members will read this, too, to give them a better understanding of the disorder. But I loved your strategy – your son doesn't, and children with autism need a lot of structure, and so you developed a very clever way to help your son anticipate something that was going to happen called Crisis Books. Explain how that first one – the first one was about Thanksgiving. I'm going to ask you to share one about vacation, but just tell us how you came up with that idea of these Crisis Books.

SUSAN: The funny thing is, this is a strategy that we had found all educators use, it's called social stories, but at the time we didn't know anything about it, and it was just that my husband and I were trying to figure out a way to get Nat through Thanksgiving, which we knew was going to be hellish for Nat.

JEANNE BLAKE: Because why? I sort of jumped and skipped that part.

SUSAN: For us, about six months prior to that we'd had a Passover dinner with the family, at which Nat would not even enter the room, he just stayed at the front door crying for the entire six hours. It was horrible, and that was actually when we all kind of finally knew that something was wrong. This was when he was 2 1/4. So looking back on Passover, with Thanksgiving looming ahead, I knew that we had to do something, and the only thing I knew that really worked with Nat as something that caught his interest – this is even before he was diagnosed – was reading to him. Instinctively, I knew that he liked books, probably because it's just comforting, you hear the same story again and again, and we could see that he would memorize things, he'd wait for the same parts. So we knew that a book was the way to get to him, and so a book about Nat would really get to him, and a book that explains beginning, middle, and end would be the best thing. And that's exactly what we did, just here's what Thanksgiving is, here's how you're going to feel, here's who you're going to see, what you're going to eat, and here's how it's going to end. As long as he would know the end of something, he would be OK.

JEANNE BLAKE: And it worked beautifully.

SUSAN: He walked right into the kitchen quoting from the book.

JEANNE BLAKE: I love that part in the book. You created these – created, I mean, it was your life – but it was such a relief when something worked well for you. It was such a well written book that I felt so drawn in to your family’s experience and shared your happiness when something worked well. I’ve asked you to bring “Nat Goes on Vacation,” the crisis book, and I’m going to ask you to read it, and we’ll show some of the pictures from it, because I think it’s so clever.

SUSAN: All right. “This is Nat. He is a big boy. Nat’s mommy just told him they were going on vacation. What is vacation? Nat asked Mommy. Vacation is when we go away to a new place for a few days. Vacation is a happy time for all of us, said Mommy. First we drive in the car for a long time. We usually drive to the seaside for our vacation. When we get to the beach, we will set up our blanket on the sand. We will put on lotion and open our sun umbrella. We will play in the sand and eat snacks. We will swim in the cold water and lie in the sun on the blanket. At the end of the day, we will put everything away and get back in the car. We will drive to a house that is different from ours. We will take a bath there and sleep there. It might be scary for a little while, but you’ll soon relax and enjoy yourself. At night, we will drive to a restaurant. We will eat supper there. Chicken, or hot dogs, or fish. Then we will go back to the new place and sleep in the new beds. It will be all right. Every day on vacation we will do mostly the same things: go to the beach, eat at a restaurant, then sleep at the new house. But in a few days, vacation will be over and then we will get back in the car and drive back to our real home, and that makes us very happy after a vacation. Nat thought about it. He looked at his friend Floppy Bunny and said, I think vacation will be a happy time.” The end.

JEANNE BLAKE: And it worked. It helped.

SUSAN: Yes, it did.

JEANNE BLAKE: Though going to the beach wasn’t the easiest place to take your son.

SUSAN: Yes, even with the Nat books, and all kinds of little songs that I made up about what we do on the beach. The beach was very hard for years, because for Nat it’s unstructured, so he doesn’t automatically just start building castles or wading or looking for crabs. To him at that time it didn’t make much sense to be there. And I don’t even know if maybe the sand didn’t feel so good to him, just in a sensory way. This is what you hear about kids with autism. So what we had to do was, we had to really structure his beach time. We’d have to say a few minutes playing with the buckets, then Nat will get a treat. Now we’re going to try swimming, we’re going to play on the raft. All kinds of structuring the day as if it were a school day, because nothing is intuitive for him, and for a lot of people with autism. You have to teach them how to play, you have to teach them everything.

JEANNE BLAKE: You describe the time that he took a bucket of water and poured it into a woman's purse on the beach, and you were like [gasp], because part of having autism is that children will act out or they will scream or cry out of, who knows, frustration or –

SUSAN: Boredom.

JEANNE BLAKE: But to your great relief, this woman responded in a really kind way. You ran up to her – can you describe that encounter?

SUSAN: It was a very surprising thing. It was one of these awful things that you always hope won't happen with your kid. He had been awful even before that, he'd been pushing other little kids down, and he wandered off, just a few moments away from us, and poured his bucket into a woman's handbag. And she stood up, sputtering, "What's the meaning of this?" My husband and I ran over, and my husband said to her, "Well, it's no excuse, but he's autistic." And then the woman said, "Oh, well, I understand. In that case, it's going to be a process." And we just felt so relieved we wanted to hug her. I think that what was so nice about that was that she just kind of, she understood what autism meant, and that meant there's unpredictable behavior, and we're trying our best. By running after Nat, and our demeanor, I think, maybe cued to her that we were in charge, so she forgave us, and that was a relief.

JEANNE BLAKE: Have you had experiences that didn't end up so kindly?

SUSAN: Yeah, I mean, at the playground there were times when, if Nat would be climbing and would step on someone's fingers up on the rope ladder, mothers I would see would sort of rush to take their kids away. There was a time when a dad actually took Nat out of the park, because Nat had pushed his little girl down and the father didn't know who the parents were. It was horrible. These kinds of things are terrifying, and you try your best with this child, but they get away from you sometimes. Especially if you have two others that you're looking after. So things have sometimes been difficult, but we have – my husband and I have really figured out a system. My husband will say, "I'm on," and that means he's on Nat and I've got the other two. We divide. We divide up the labor and the taking care.

JEANNE BLAKE: Susan, you said that the doctor that gave you the diagnosis of autism said that a lot would depend on the school setting that Nat got into. And that has been a formidable challenge for you. But you give parents guidance in your book on how to find the right school setting, and it was a process for you, as so much is with autism, as you said earlier. I want to put each of those points at the bottom of the screen and just ask you to address each one of those one at a time. I hope that in the is

process, as you describe it, you'll tell us a bit about how you were able to do that. Finding the right program. No program is perfect for every child.

SUSAN: With that, first of all, the thing a parent really has to do is legwork. They have to find out from trusted advisors – these could be other parents, these could be therapists, teachers, specialists, doctors – where are the programs for your child in your area and in your child's age range, and visit them. Try to work through the school system to visit these programs so that you stay on the same page. That's the way that you first find out what's out there, and that's how – when I go, I look for a kid who's like Nat, who might be Nat in the setting, and I see how is this kid being attended to, and what is he picking up on. How long is he being left to just be on his own? Is that a good thing? In our case it's not a good a thing. It wasn't back then. What's the ratio of staff to kids? What does the staff seem like? A lot of this is trusting your gut.

JEANNE BLAKE: This is what you talked about, that you were mad at yourself sometimes early on, because the learning curve, I think, for a parent of a child with autism has got to be very steep. And you were kind of tough on yourself for not trusting your instincts earlier, but you learned to trust your instincts a lot.

SUSAN: Right, I did, because I kept seeing, over time, yep, that really wasn't a good setting, and I knew it at the moment and I should have said something. So we did learn. We've really learned what kind of people work well with Nat. They have to really like him, first of all. They have to be centered and unflappable and have a sense of humor, hopefully. They don't always have all of these things. It works out sometimes with just a little of everything, sometimes just one of those things, but ideally you have all of those things.

JEANNE BLAKE: That's why the second point is there will be some disappointments.

SUSAN: Right. That's the other thing. I had to also learn not to be too quick to judge a person or a program, to give them a chance, to ask enough questions so that I had the information I need, the most important point for me to find out. Thing like can I visit the classroom whenever I feel like? What are the arrangements for that? Will you communicate with me in a notebook? Will you read my notebook every single day? How open is the program to my input? Those were important to me. If you don't feel that's all in place, you have to decide how important is one thing or the other, and you really have to weigh it yourself.

JEANNE BLAKE: And that's why to reevaluate frequently is important, which is another point.

SUSAN: The thing is, the kids change, the teachers, teachers leave. A child needs change, so you have to keep figuring every few months, kind of reevaluate. It doesn't mean you're changing the program every few months, it just means you're keeping an eye on your kid and his growth and his changes.

JEANNE BLAKE: And to anticipate and look ahead and visit the next year's classroom, is your next point.

SUSAN: Absolutely. Don't leave that to the last minute, if you can. Keep talking to other moms and find out what's out there, what's new out there. New approaches are developed that are wonderful, and sometimes not. And then also, just because it's out there doesn't mean it's the one for your kid.

JEANNE BLAKE: Right. Is it worth a change? Because it would be very disruptive to everyone.

SUSAN: Right. And any change is difficult for these children, more than the typical child.

JEANNE BLAKE: One of the things that I was so taken with in this book that makes it so authentic and real is that you talk, at one point, about feeling really disconnected from Nat. And I got the feeling, and you actually wrote this, that you loved him, but I think there were times that you felt you didn't like him, almost. It took a lot of courage for you to write that.

SUSAN: I wrote that because I really wanted parents to understand that they're going to have a whole range of feelings about this, and they have to really give themselves a break, and to acknowledge those feelings, however ugly they might be. And to know that it's going to pass, and it doesn't mean that you're not a great mother, it doesn't mean you don't love your child. But you're going to feel some of those things sometimes. Yeah, we definitely went through periods that were horrendous, where Nat was testing us and being aggressive. Sometimes it was really about just trying to put my feelings aside and connect with him, really figure out what is going on here, and follow my instinct again, to end up being on his side. And sometimes those were the best ways that we got out of some of the most difficult times.

JEANNE BLAKE: The description of the time that your eyes locked and that you knew he really did connect, because you had really brought yourself down, calmed yourself down and allowed the two of you to connect, was a really beautiful part of that book. Very emotional.

SUSAN: Right. This was when Nat was doing a lot of his terrible laughing. Laughing, laughing, laughing, just to annoy us.

JEANNE BLAKE: In the middle of the night, keeping you awake.

SUSAN: Yes. It started when he was 7, it's been something that has reemerged. We were given a treatment plan from his school that when he laughs in a disruptive way, we were to have him file cards. That didn't always work. That's a good treatment for redirecting energy, but it didn't get at the heart of it. Why was he laughing? But I could never stop and figure out why is he laughing when it would happen, because it would make me so upset. Except for this one evening, where I was just relaxed enough to just kind of sit down with him and laugh with him. Like I just suddenly looked at him, and he was just so cute and giddy. He was so giddy and giggly. And I started just tickling him and making him laugh more, which is really kind of a no-no, according to the treatment that we were given, but it really worked. It got him looking at me, and it was a real moment. We were connecting, and eventually his laughter just died down naturally. And that's when I knew he does this to connect with us. This real annoying stuff. He wants to connect.

JEANNE BLAKE: You had two other children. I've read about families where all the children are autistic, and I read an article a year ago and I've never forgotten it. It was a decision that you and your husband really labored over, to have one more child, and then another child. And this has had an impact on each one of them in a different way. Do you worry long term – I mean, we all have our goals and our family, and depending on what's going on, but do you worry about the impact of growing up in this environment on them? Or do you think it will be good for them to have experienced this?

SUSAN: It's both. I do worry. I worry that we're not meeting – that's probably my biggest worry of all, that we're not meeting Max and Ben's needs, or that somewhere along the way something's going awry. I worry about that, of course. I do really believe that this is going to be a good and formative experience for them, just by showing them how difficult to grow up the way Nat is, so different and so challenged. They're going to learn compassion. And it's easier for Max, my older one, than Benjie, my younger one, but they're both going to learn that.

JEANNE BLAKE: And finally, the biggest question, probably, that I had is that your marriage has endured this. We only have two minutes, and it would take an hour to describe it, but you have a real partnership around meeting this challenge in your family. What would you say has been the most important thing between you and your husband?

SUSAN: Loyalty to each other, and sense of humor. I could just go on and on, but I definitely think that the loyalty is about taking on what they other can't do and not keeping score, and knowing what our strengths and weaknesses are so that he does what I can't – and the other thing is, too, keep reminding each other of the funny things that happen and the crazy things, and even the bad things, and eventually you find a way to laugh at it.

JEANNE BLAKE: But there has been a lot of turmoil in your home, and somehow you've managed to accept that in each other too.

SUSAN: We accept that in each other, we are each other's best friend, we're very different from each other, and that works for us. I guess in our case opposites attracted. For now, we respect each other's space too, and our needs.

JEANNE BLAKE: Susan Senator, you've written a beautiful book. Again, it's called *Making Peace With Autism*. I can't imagine a family with an autistic child, or if you know anyone who's living with a child with autism, this is an important book to read. It will help you be more sensitive and helpful, I think. And I thank you for coming in today to talk with us.

SUSAN: Thanks.

JEANNE BLAKE: I'd like to thank you, as well, for joining us on *About Health TV*. I'm Jeanne Blake, and I'll see you next time.

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