



Autism and Family: Taking Care of Everyone's Needs

Robert Naseef

Wednesday, December 8, 2010

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Moderator: Nancy Bernotaitis

Guest Speaker: Robert Naseef

It is actually 9 o'clock so I'm going to go ahead and introduce myself. I'm Nancy Bernotaitis. I am the moderator here at *momsfightingautism.com*. If you're new here, our phone number is 949-333-4806 and once you get there, you enter ID number 168978# and that will get you on the phone with us. You will be muted so we won't be able to hear you but later on in the webinar, we'll be allowing people to ask questions so I'll tell you how to ask questions at that point and I will selectively unmute you as you raise your hands. The website is *momsfightingautism.com* and you can listen in either via phone or web. You can ask

questions through the website. There is a box on your screen that will allow you to ask questions. So yeah, later on we'll be asking live questions of people so if you have a question you'd like to ask Dr. Naseef, you can either enter it through the website or hold on to it and we'll have a chance later to ask your questions in person.

Okay, let me go ahead and introduce our guest. Tonight, we have with us Dr. Robert Naseef. He is a psychologist in independent practice. His first book, *Special Children, Challenged Parents: The Struggles and Rewards of Parenting a Child with a Disability*, has received international recognition. He has lectured internationally and he has appeared on radio and television. He is the co-editor of *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism*, and *Professionals Share Their Wisdom. Living Along the Autism Spectrum* is a new DVD which features him along with Stephen Shore and Daniel Gottlieb.

Dr. Naseef's specialty is working with families of children with autism and other special needs. He has published many articles in scholarly journals and other publications. He has "a foot in each world" as the father of an adult child with autism. He has a special interest and expertise in the psychology of men and fatherhood. Through his experiences as a parent and as a professional, Robert relates to both audiences and is a sought after speaker around the country.

Nancy: Welcome Dr. Naseef.

Robert: Hi Nancy, it's good to be here.

Nancy: I'm so glad you're here with me tonight. You want to tell me a little bit about Autism and Family Life: Taking Care of Everyone's Needs?

Robert: Sure. Oh yeah. We can start out that way and be a bit of introduction.

Nancy: Okay.

Robert: Having a child who is different and then in addition like, my slide isn't coming up on the screen like I'm on it, but is that coming up—the airplane slide?

Nancy: Let me see. I don't see it on the *momsfightingautism* site so go back over to my event on the left hand side and make sure you are in the correct events.

Robert: Alright okay. And now go to, sorry about that. Go to Control Panel.

Nancy: You click on My Events.

Robert: I clicked on My Events and I went to Control Panel.

Nancy: Autism and Taking Care

Robert: Okay.

Nancy: There you go.

Robert: To the left now.

Nancy: Let me take a look. Are you in the correct webinar?

Robert: I have to be.

Nancy: You went out to My Events and you click the red button.

Robert: I went to My Events, I clicked the red Autism and the Family.

Nancy: Where the arrow is pointing.

Robert: Right.

Nancy: Under Control Panel and then up at the top where it says Slides.

Robert: And then Control Panel.

Nancy: Up at the Top.

Robert: Alright, because I have the slides showing. They're now on...now I'm on Slides.

Nancy: Go at the Slides at the top.

Robert: Great. Okay. Now loading the slides.

Nancy: There you go.

Robert: It's coming in now?

Nancy: There's a slight delay to if you see the slides and you're ready to roll, it would

just be a matter of a couple of seconds before we can see.

Robert: Alright. Well I'm just going to start talking about this and hope the slides will come in. So what often happens and I have an adult child with autism myself as you mentioned so I've been living this life for a long time and particularly in the beginning, parents and maybe moms more than dad get, you know, pretty much totally immersed in taking care of their child and sometimes, they're just kind of working on firms, or a fuel tank is empty, and be you know, just the stress and strain of it can be overwhelming and I use this concept of airline safety to you know, kind of illustrate this theme of family life. When you get on an airplane, when they give you the safety spill, the flight attendant or the video always has to, if the air pressure and the oxygen mask come down, put it on yourself first because you can't help anybody else if you're not.

Nancy: Let me interrupt you just a second, Dr. Naseef. So those of you who are on the website, if you click the tab that Slides at the top of left hand side, you will be able to view the slides with us as we go along. So there's a box that says, Welcome, Listen In, Slides, and Ask a Question. Click Slides and it will load. It will take a couple of seconds but the slides will load. Okay, sorry for the interruption.

Robert: Okay. And I have mine up now too. This is great.

Nancy: It gives me that visual there so it's in an airplane with the mask on.

Robert: Okay. We're cooking now. So the idea being that when we have a family member with autism, we do need to pay attention to everyone's needs especially the needs of moms and dads because we're the one to take care of everybody else. Sometimes, it feels like a little hard to make space for that like there isn't much space and truthfully, there often is having a child with autism can be consuming especially in the beginning but learning how to balance things is what's going to help us to the long hall, help our children as fully as possible, and help us have a decent life in the process.

So this is the metaphor or way I think this kind of works introduces to people because it just makes sense in a very basic way that if we can't breathe ourselves, we can't help somebody else to breathe. So that's the starting point in a lot of my dealings with people.

And each child is different so tonight, what I'm hoping to give some insight into

is how a family's life changes and we might go through some stages in terms of having a child with autism, learning to take care of that child and having a full life for everyone. We'll talk a little bit about facts and fictions, facts versus fiction in marriage when there's a child with autism. We can talk about issues facing siblings and we can talk about coping with stress and acceptance.

So another idea that I think is helpful is you know, going back to the book of Proverbs and I think you should see that slide at the moment, it talks about "*Educate each child according to his ways.*" It's ancient wisdom. It's also the concept that underlies our public education laws when we have an IEP, that's starting where the child is and educating him or her step by step to have his full life as possible.

So my child's first child psychiatrist, Dr. Rutenberg, talked about starting where the child is and making contact, learning to be with your child. Sounds simple but it can be complex when a child has autism because our child may not be easy to engage with and this is often what happens particularly in the beginning and somewhat throughout life with autism.

So are there, you know, some specific questions people would like me to address, that would be better than just talking for a long time.

Nancy: We're having a lot of questions coming in about siblings. Helping siblings understand their sibling's autism and how to help them relate with that sibling.

Robert: Okay. So the way I'd like to get to that is first talk a little bit about the feelings that parents have and then bridge right into some of the issues faced by siblings. And that's what we might be hearing and you could feed me when we get to that some of the questions.

So right now, what you'll see on the screen is a picture of me with my son at 1 day of age and I think you can see he's making eye contact with me. Most children with autism, a fairly large percentage were born seemingly typical. And then somewhere in the first 2 years of life when the autism bomb strikes, we see a gradual fading of the relationship and the child is more self-absorbed and the characteristics that we now know are called autism—difficulty relating and communicating, stuck on one thing doing things over and over, and just becoming more and more remote at times. But most of our children were born normal and we wished for it and celebrated their births.

So siblings like parents want to have a healthy normal sibling. They want to play with their kid. But what happens when a child with autism doesn't want to play with you? What happens for a mom? What happens for a dad? Siblings are going through the same thing at their level in their way. So I'll show you a few quick slides of my son growing up. Here he is just putting his head up about 4 to 5 months of age. Here I am throwing him up in the air.

Nancy: So he's making eye contact, he's meeting milestones.

Robert: Right. He's making eye contact. He's doing what little toddlers his age are doing. So here you see, he's making eye contact with me. I'm the photographer in this slide called Everyday Joy. Do we have that one up?

Nancy: Yup. I'm seeing it.

Robert: Yeah, yeah. So everything is really seeming great and a lot of moms and dads have this experience of the typical development in their early month. But some don't. Some babies are, you know, sometimes the autism emerges earlier but often the first year of life seems pretty typical, pretty normal. So my son walked at 1 year of age. I mean he was just a lot of fun. Here he is like looking at me and all these pictures, I'm the photographer. He's looking right at me, he walks on his birthday. There we are.

So and then, when a child is diagnosed or when the autism emerges and is eventually diagnosed, those typical moments are seemingly lost. The connection has gotten more and more strained. It's harder to connect. A lot of parents, moms in particular will talk about feeling rejected because their baby doesn't want to cuddle her, isn't making eye contact, isn't engaged and mother and child aren't enjoying each other.

Nancy: Yeah, we have that same experience, Dr. Naseef, where my husband said that the baby doesn't like me.

Robert: The baby doesn't like me. And what can be sort of more profound and more profoundly disturbing. Why did he say that if we could just talk about this in a minute?

Nancy: Because he doesn't make the eye contact with him, he didn't react when he made noises at him and he just seems aloof and like he didn't want anything to do with his father.

Robert: Right. And dads who were spending less time on the average with their kids have even more of this experience because moms are having the same kind of experiences but spending more time with the child and finding ways to connect but it's not so easy to connect. So what I'm putting up next is a slide about the emotional turmoil that might happen with these feelings of rejection. Here it is. So there's rejection, there's fear, guilt, sometimes depression, certainly anxiety. What is this all about? What does it mean? Will it go away? When will it go away? And a profound sense often of alienation or loneliness that is happening to us, is happening to our child. Even though autism is about 1 in 100 now, which means it's about 1 in 50 families, when it happens in your family, there is a profound sense of being alone. If there was one word that I hear the most with how alone people feel in the beginning part of this journey.

So in order to help our typically developing siblings, it challenges us to be into our own experience. And like you just mentioned Nancy, your husband felt rejected. How can a little person, the child, a little boy or a little girl, not feel rejected when their sibling isn't interested in playing with them? There's nothing you want more as a little kid than a brother or sister to play with to be your companion. People that are only children want a brother or sister and it's such an important experience in life.

So I think what's important is to talk to children at their level, at their developmental level about what's going on about the differences between them and their brother and sister. So do you want to give me a question that's coming in?

Nancy: Actually I do. One just came in from Christine from San Clemente, California. Christine asked, "How do I cope with my son who prefers my husband?"

Robert: And this is her son with autism?

Nancy: Yeah. And she says, "I do so much for him and I love him but it's hard not to feel resentful and hurt when he rejects me."

Robert: Well, I think the first step is just your courage in putting that out here, Christine, that's a very deep feeling and your first step in coping with it is to give the name, put it out in the open, talk about it, and acknowledge that that's what it

feels like and it just kind of takes my breath away to think about this and feel the heartbreak. Without knowing your situation more, I'm not sure why your child prefers his dad more, but it's a profoundly disturbing experience to a mom. Most little kids, you know, certainly run to their moms. But it might be, if I can just speculate a little bit that you're home all day and you are challenging your child a lot and then when your husband comes home, he might be, you know, more just having fun, you know, which is a great thing, but your child might prefer that. Now of course, he needs structure, but what I would suggest is that you pay attention to the times you are having fun with your son and developing your relationship that way in things that are mutually enjoyable. And notice your feelings, notice what's going on, but realize that this is changeable although painful and there can be ways for you to connect with your son. He may need a break from you when his dad comes in. I mean it might be as simple as that. It's certainly something that might be worth talking to a therapist about or a professional working with your child. Without knowing your situation specifically, it's hard to comment further. But I hope that's helpful.

Nancy: We actually had the same situation in our house where I am the person who makes him do all the hard work and then dad comes home and he is a playmate.

Robert: A-ha. So you related to that.

Nancy: I could do. But what I found was yeah, I do all the hard work and I get none of the glory but I do get that break when dad comes home and I know that Sam is having a great time with his dad so that's, you know, I've come to terms with that. That's okay with me. I don't have to be the safer parent. It's not a contest, you know.

Robert: Right.

Nancy: I've got a job to do and I'm doing my job.

Robert: Right. I'm sure your child....

Nancy: Right. He loves me, I love him. He loves his dad. He's a great clown. You know, that's okay. It is what it is.

Robert: Right. And you wouldn't want to take that away.

Nancy: Absolutely not. I can't be everything though. If I have to be the person who makes you do all the hard work, that's my role.

Robert: Whoever is with them more is going to have that.

Nancy: Yeah, exactly. Paula from Redmond says, "How does a parent of a child with autism cope with isolation?"

Robert: Oh okay, we're into another issue here. Okay, that's great. I think one of the main ways is connecting with other parents who have kids on the spectrum and there's really a vibrant autism community out here all around the country in the world for that. So I would look for organizations in your area where you can meet other parents, have play dates with other families who also have kids on the spectrum. Hang out, you know, do things together. Autism is now you know, more than 1 in 100 and it's 1 in 50 families as I mentioned before. So the way to cut down the isolation is to reach out to other people and to some extent, get involved in the community but also to reach out to the people around you the people that care about you and that love you and your child and ask them for some support they need when they were at the hospital. A lot of people don't know what to say or do but when you're able to ask for something, they'd often respond.

Nancy: That's true. Getting support, I think, is a huge key. I felt so isolated before I got connected with the autism community and now, I don't feel so alone. It's huge support.

Laura from Aledo, Illinois asks, "How do we handle people that keeps downplaying the anxiety and complete time-consuming job that a family has with an autistic child? We have 2 autistic kids and people do not get it."

Robert: Well, one of the things that helps people to get it is spending time with kids and I don't know that there is any shortcut to people getting it. It's a hard thing to understand. I think it's hard for all of us and the further away we are from the situation, the harder that's going to be. So, but certainly having 2 children on the spectrum is an extremely difficult life for you and certainly you need support and certainly you need people who do get it. But again, the autism community is a great place for that. It's a place where you can feel normal. It's a place

where people don't judge you or your kids and you can be embraced. So I would urge you to find your local autism society chapter or other organization or families of children with autism and other special needs and I think you'll be at home there and having that kind of home, having some support of people who do understand or even makes my point of helping you bridge the gap until other people in your life understands. It's a journey and it's a long one. Depending on where you're at it, I think you will find more support as you go.

Nancy: Yeah. I have to say it in our situation. We really don't have any friends that don't have special children anymore. Our friendship with people with other special needs kids and it's because we all get it.

Robert: Yeah, it's a home. They're your buddy.

Nancy: Yeah. We're our support system and we have each other at least so. And we teach other people trying to get connected to others. You know, it doesn't have to be autism. It can be anything that gets connected.

There's a couple of questions here about relationships. Did you want to do more slides talk?

Robert: Well let me cover a few more things about brothers and sisters.

Nancy: Sure.

Robert: Because since that's a common question. So just, let's imagine that it's you, that you have a brother or sister with a disability with autism with some kind of special need but we're talking about autism. Think about if your brother or sister had this condition, what problems would you face? How would you want your parents to handle it? And when we change places, it's often when you know, we can see the answer, we could see what's going on.

So I'm putting up a slide now that's based on what siblings have told researchers and what they've said in interviews. So, and you'll see a slide of my son, Tariq, and we were having pizza together. So now, here is the one I want you to see. Siblings really talk about wanting parents to notice them, to notice their accomplishments because parents are you know, very much absorbed in taking care of their brothers and sisters who has autism. They want more attention,

some fair amount of attention. Is it possible for them to be equal? Not really. Not in any family is it possible to give equal attention because everyone is different but it is possible to give some special attention to each child and I think if we think of it that way, this is going to be a little smoother. Typical siblings want a time alone with their parents. Like us, they get worn out. Autism can be exhausting. They want some time alone with their parents. They want some time alone with their friends. They don't want to have to be with their brother or sister all the time. That's also true of typical siblings with their typical brothers and sisters but it's also true of the siblings of children with autism. They need the freedom to complain, talk about their feelings, and that can be hard to listen to their complaints. And they may echo similarities about the difficulty of life, the stress of life. They want a family life that is normal as possible. And the way to help them adjust is to be giving them information about the brother's and sister's condition at their level. There's a lot of good children's books about autism more and more to them all the time.

I saw a question that came in earlier about, "Should I talk to my child who has autism and then tell them what their condition is?" And my answer would be yes. Give them information on their level. Your son or daughter knows they're different. Your typical child knows their sibling is different. Give them information on their level. The more they understand it, the more they'll be able to adjust positively. Our children are younger versions of ourselves. They need information, they need support, they need to meet other brothers and sisters. All of this is extremely beneficial. So I hope I've covered that to some extent now.

Nancy: Well, there is one question and I wonder if that would be your answer, you just said was all those different things. Macy in Roxboro, North Carolina asks, "How do I deal with my oldest typical child that acts out for attention due to feeling left out because of the attention my autistic son gets?" And probably would be all those things you said, just time on with his parents.

Robert: Yeah. I want to show now a slide that actually my daughter wrote this when she was 11.

Nancy: I got it.

Robert: Is that up? Okay. I mean I think, "My brother always hogs my dad." This is my

daughter when she was 11. "Whenever we go canoeing: Dad hogger. When we go hiking: dad hogger. Every time he's around and I try to go near my dad: dad hogger." So I mean when I showed it, it seems a click. This is what the experience is like. Our children with autism really do hog our attention. They can't help it. It's not their fault. But our other children often feel marginalized, neglected, ignored, and what we want to do is give them attention in the ways that they need it. The acting out as a way to get attention is something a child can learn in a family that has a child with autism. So we want to notice their accomplishments, notice their contributions, just notice them as much as possible and that will minimize this problem of having to have a problem to get noticed. It's understandable. It's to some extent often unavoidable. But we can counteract it by trying to pay special attention to each of our children.

Nancy: In my circle of friends, we discussed some parents say it's okay, some parents wouldn't do it enough now in the back but do you see if it's okay for a parent or a family to consider for this special child that would not enjoy the festival for instance and to go out and take the typical kid?

Robert: Well, I think the choice is very family to make. Some families kind of split up in order to do it. You know, but sometimes, it depends what works. You know, sometimes you need an extra person to go along to help with you know, your child on the spectrum. I think there's a lot of possible ways to work this out. Obviously when I look for things where the family can be together as a whole, but I would say also like look for things that are fun and look for things that meet needs that aren't being met. So I can certainly understand people not wanting to do that, but it really depends on your situation on what you're comfortable with and what would work in your own family. So that's the way I look at it.

Nancy: And there are kid groups which often, can sibling groups join..

Robert: Right. There's kind of popping up everywhere. So this book, *Sibshops* I'm showing the cover in a minute, which is available everywhere. If in your area there's nothing going on for siblings, this is something you can ask from a local school district or agency. And *Sibshops* is a program developed by Don Myer and there's also a whole network of training for this and there's a website—siblingsupport.org is the website and there's information there for and by siblings of all ages. *Siblingsupport.org*.

Nancy: Very nice.

Robert: So are there some questions of relationship?

Nancy: There were. The one from Brenda Lee in Slidell asks, "How to be more than roommates as husband and wife? I keep hearing about this on TV shows and Facebook. How can we see it's prevented I guess than becoming roommates and what to do if it's already occurring?"

Robert: Wow. Well people don't get married to be roommates but it does happen. We get absorbed and it happens in plenty of families and plenty of marriages not just when there's a child with autism but what can happen is there's so much emphasis on taking care of the child that the marriage and the relationship suffers. So I'm going to show everyone a few slides about that. See if this one comes up.

One of the first books I read about autism was called *A Place for Noah* and Josh Greenfeld who wrote the book said it this way. "There is a strain on any marriage whenever a baby is sick. And we always have a sick baby." You know when your baby is little, as if the baby is having digestive problems or feverish or having a cold, we're checking on this, we're watching, we're a little bit on edge. And autism can leave us on edge kind of indefinitely. So in order not to become roommates, we have to find ways to connect to how this is going on just like we're looking for ways to connect with our kids or looking for ways to connect with our partner sometimes.

A really good book about married life in general that I would recommend is called *Grown-Up Marriage* that is by Judith Viorst. She puts it this way and I think this is why we're coming up momentarily. "Although marriage is for grown-ups, very few of us are grown-up when we marry...But marriage which can be the most vexatious of human relationships can also be the engine of our growth."

So while we're dealing with autism, can we find a few minutes to spend with each other? While we're raising any child, how do we do it? And a lot of people have been worried about the divorce rate and for years, it's been a myth in the public, kind of an urban myth as well as in the autism community that the

divorce rate was 80%. Recent research has confirmed that the divorce rate in families that have a child with autism is comparable to the national average. However, the stress and the distress is much greater in general. So, however, the opposite is also true that couples report great love in coming together as a result of having a child with autism—learning to work together, learning everything we can learn about ourselves and just, in the sense, not to be, had a cliché about it, about the meaning of life and what's really important. A lot of people are becoming closer.

Why does it feel like being roommates? I'm just putting up a slide. This one talks about how children add to the family but subtracts from a marriage. And moms are often preoccupied. It is normal—preoccupied with taking care of our kids—that's a normal and natural process. But with autism, it lasts longer than the typical kids. So this starts to take the strain on the marriage on not having much time together.

And then in terms of, when you talk about roommates, let's talk about the bedroom a little. For men, a man may need sex to feel close. But on the other hand, a woman often needs the closeness to feel romantic and sexual. And so this is the dilemma for many couples and it might be more true for couples who have a child with autism who are more tired, more stressed, more absorbed in day to day things and not having much time for each other.

So what do we do about it? I want to talk a little about that. I think, here are some tips that I think might start to warm up a relationship. This slide is called Tips for Couples. I think we all want to be appreciated and I think for men, it's often hard to listen to problems without trying to fix it. So I suggest for women to tell him to just listen, that that's all you need. And I think you have a better listening partner. And for men and women, tell each other what's going well. I urge men to tell her what she's doing well. Tell her how you appreciate her as a mom for your kids and likewise for women. Tell your partner what he's doing well. Tell him how he is being a good father and role model.

And men are pretty good at taking breaks better than women anyway. So guys, give your wife a break, give your partner a break. And for women, while it's hard to talk to men about what we can't fix or change, tell your partner what he can do for you and often you'll get a good response that way.

And then look for the times, you might not be able to have a date night but look for the romance in everyday life. Look for a hug. Look for a time you can talk for 10 minutes about something other than your kids or other than autism. Look for a time to take a walk around the block or just little things that you would do with a friend. Relationships start out with friendship and it's friendship that maintains them.

So there are just some little ideas about how to avoid being roommates. And a lot of it is looking for each other, finding each other and finding the ways to spend time with each other. You might not be able to get a baby sitter but there are moments you can steal just for the two of you and that's what's going to bring a little romance back, a little excitement and connection about being together. When you love someone, you want to be with them so that's what we want to look for.

Nancy: Dr. Naseef, this question calls right in line here with what you're talking about. Maybe you'd have some more information for her. It's Denise in Canada. She asks, "As a mom, I find myself completely roughted on a daily basis. Our marriage has suffered tremendously. Every ounce of energy seems to go to our child. Sleeping in his own bed is an issue for us that it can take anywhere from 20 minutes to an hour to get him to sleep. Then I ever so quietly tiptoe to bed like a zombie, and an hour later, he is in our bed. That leaves us with no time together as a couple. It's not that I'm not interested in making love with my husband, it's been I'm so sleepy and tired and he hates the children as much as he is. Any suggestions?"

Robert: Well the sleep problems are really common with autism and you know, it might, I mean one idea is to consult with a professional who is skilled in this area and it can help develop a plan to help with sleep. Although this is one of like the major problems with autism is kids that can't sleep through the night and they are always coming in your room and it could be like the typical kids who do it when they're little but it goes on a lot longer with autism.

So you know, one idea is to get some help for the sleep problem, sometimes medication is helpful and necessary, but certainly, there might be some behavior modification if possible. But there's really no easy answer. And this question really, I think will resonate with a lot of people. It's not that a mom in your situation isn't interested in sex and romance, but the strain of life just doesn't

make it too appealing. So you might look for other ways to be together and I'm not talking about just physically or sexually but look for other ways to be together. Look for ways to show him that you do want to be with him and it might be possible, you know, at some point to have a baby sitter or to go out or to go away for a weekend together. That you know, there are different possibilities but I would certainly urge you to get some help with the sleep problem. The earlier in life that you can work on this and hopefully get your child to sleep in their own room at least for a part of the night, the better it will be. The older your child gets, the harder it is to break that pattern.

Nancy: I can concur that and we've done that.

Robert: And have you succeeded?

Nancy: Yeah, the sleep issues have been very much remedied. I can say that I'm having more energy or I won't get the end of the night than I ever have before but we are making a concerted effort together to make ourselves the priority again. We had fallen to the back burner and Sam is 13. I don't know how much long but we can sit on the back burner and shimmer as we. So making our relationship the priority has really given us a forefront for us lately. And I think it has made a huge difference in our stress levels and how we deal with him. You know, if we're getting along, then we're much better at coping with him, you know as he's 13.

Robert: So how do you make time for each other? How is that working in your situation?

Nancy: One thing we do is while he's at school, we meet for lunch. We don't have to get a sitter, we don't have to pay a sitter, we just go meet for lunch, and that just gives us you know, 45 minutes of undivided time with each other once a week. We did go to retreat recently and talked about everything from what made us fall in love with each other to what we're you thinking yesterday. So we did what we did. Now, it was a very good time for us and we can marry 20 years to go back and talk about, wow, really, what was it? What was it I like about you back then?

Robert: Right.

Nancy: It's really healthy for our relationship.

Robert: And I bet it's still there, isn't it?

Nancy: It is, I remember. And it made me come home and get out the old home video. And to see us as a young couple again, that was really fun and it has made me want to spend more time with him because I remember now, I do like this guy. We can hardly have our whole sentence of conversation together but I do like him. So I think just making an effort that's made him totally different.

Robert: Right. And I think that might make a difference for this woman, just finding the place to make an effort or the way to do it. And hopefully, her husband too can respond to that.

Nancy: Yeah, I know that a big strike in marriages is when one part of the marriage isn't fully invested in diagnosis. This is a question from Mary from Louisiana. It's right on the hedge. She says, "I have a husband and 2 kids, high functioning, not otherwise specified. The 2 kids are high functioning autism." Her husband's in denial. The marriage with the roommate may be due to the child being on the spectrum. She says yes, but also how do you get past a husband that's in denial and grandparents that are in denial?

Robert: Well, you know, everyone is different but I think one of the things that really helps them most is these times spent with your child. Like often, when I see dads who are really connected both with their spouses and with their kids, they spend a lot of time with the kids, so any way you can make that happen is going to break through. Did she mention how old the kids are?

Nancy: No, she did not.

Robert: So I mean it's hard to accept. It's hard for everyone to accept, and sometimes the best way although I don't mean this in a flip way is to just accept where the people in our lives are that autism is painful and difficult to understand and to accept, to be willing to live with. That's what I mean by acceptance—to be willing to be there. But I think the more exposure people has, the more time they're around a child who's different. The denial kind of melts away. It's easy to say, you know, nothing's wrong with him or nothing's wrong with her. They're just normal. They're just having a problem. This will go away. It's easy to say that. It is painful to face the realities that this condition is ongoing and it

ebbs and flows, but it's ongoing. But I think time is really one of the healing factors here.

Nancy: I did want to mention to our callers that if you would like to ask Dr. Naseef live question, you can press *2 and that will raise your hand and I will unmute you and you can ask your questions. So it's *2 to raise your hand if you have a question you'd like to ask.

I'm going to go back to our submitted questions through the website and see... there's a lot of questions here speaking about aggression, aggression towards siblings, how to deal with aggression. A lot like towards siblings, how do I get my typical child to be safe when my other child is acting out?

Robert: Well, this is one of the most difficult and trembling things. I think again, it's hard to just solve this problem without knowing the situation. But I think it might be important to get a professional person involved. Let me talk about some of the principles here that might help people to figure it out. I think it's really helpful to learn about the principles of positive behavioral support. And when we look at behavior this way, we want to observe when is the problem happening, what's going on in the situation, is the child trying to get something, trying to get away from something, are they responding to something sensory, something in the environment—but just what is going on. And likewise, observe when everything is feeling smoothly and there isn't a problem. We can often learn clues for how to solve a problem by seeing what's not happening.

So there's a few concepts, but when you're immersed in this, it's hard to be objective and children with autism, and particularly when there is more of a language impairment, are much more physical than they might be otherwise. And one of the things that's often helpful to realize, to know, is that as your child develops more of the communication system, whether that's verbal, whether that's picture exchange, whether that's signs, that the more your child learns to communicate, generally the less of this kind of problem behavior we see where the child is becoming physical. But certainly, I get somebody, a behaviorally oriented therapist who understands the situation to help you.

Nancy: Very good advice. I'm going to go ahead and take a live call.

Robert: Okay.

Nancy: There's a slight delay so I will unmute them. Hi caller, can you please state your first name?

Julie: Julie.

Nancy: Hi Julie. What's your question?

Julie: How do you deal with feelings of jealousy towards, you know, seeing anybody actually, other family members, extended family members who have normal kids, friend's kids, and you know, that don't have these problems?

Robert: Well, I think these feelings are natural. That's the first thing, that you're not a bad person. You're a normal person to have them. It's almost impossible to not compare, to not notice. So your first step is to accept that you're noticing this. And to me it implies that there's some pain in the situation. There's a longing for a typical child and that's normal and that's natural. And letting that feeling be actually may help it to pass and in time, you may be able to enjoy these other kids as opposed to find your mind comparing your situation to theirs. But I certainly found early on in my son's life the same thing. It was very painful to be around people with typical kids whether they are my nieces and nephews or friend's kids or neighbor's kids. The pain is just there all the time. I think what you're feeling is a reflection of your pain. And I would just, you know, want to support you on that and let you know that other parents are feeling the same thing in this situation and it ebbs and flows and the times passes but to some extent, you know, it will never be that far away.

Nancy: Thank you, Julie. I hope that helps.

Julie: Yes, thank you.

Nancy: Dr. Naseef, I know that you've gone through it and I know that a lot my friends have gone through it but did you experience the stages of grief when your child was diagnosed?

Robert: Oh sure. I mean that was beside myself for a long time, and really a long time.

Nancy: And your child is an adult now so...

Robert: Right.

Nancy: Did it ebb and flow?

Robert: Did it what?

Nancy: Did it ebb and flow? Did it come and go?

Robert: Oh yeah. Oh yeah for sure. And definitely worse in the beginning and less over time. You know, but I can't tell you that it doesn't come back because it does. I mean sometimes I'll see particularly a dad you know or the son of almost any age and doing something I can't do with my son and it will come back for a moment. You know, I feel a sense of longing or loss. But compared to when he was little, that passes. You know I just notice it. But at the beginning, it was very intense.

Nancy: How about when you see other family member or other friend's kids meeting milestones like driving, getting married, having kids?

Robert: Well, that can be hard to enjoy. I mean I certainly experienced that but you know, as time went on, I've been able to enjoy the accomplishments and the lifecycle events of other people's kids and it's great, but that was very hard to enjoy for a long time. So but I think what helps is to know that isn't crazy, that isn't neurotic, that it's a normal response to a difficult situation and that you can have these feelings and that they pass, you know. They ebb and flow, but you can make peace with this. It's not a defect in you that you feel it, that you might be jealous, that you might have trouble enjoying a situation which is easy for other people because their kids don't have the same challenges and hard for you. So developing some compassion for our own selves, for our own struggle is really helpful in this, as opposed to trying not to feel it. Trying not to feel it is like quicksand where we get stuck in it.

Nancy: I'm sorry. Do you see that men or fathers tend to grieve differently than the mothers?

Robert: Well, it's more on the inside of the guy. It's verbalized. The same feeling and phases seem to be there, but it's more inner. And for men, it's harder to admit this kind of feeling than it generally is for women.

So I just put up a slide of a woman sinking in quicksand and I always, I like to ask what will help her. What happens if she keeps kicking and screaming and trying to get out of there? The quicksand will suck her in. What helps her get out is actually to stop kicking and let herself float to the top. Trying to escape our feelings is like quicksand.

And there maybe a little more we can talk about here. I'm going to put up another slide. This was called The Rule of the Mind. It should come up there momentarily. When we try not to think about something, and whether that's a thought, a feeling, an urge, a sensation, it often actually you know gets us stuck on that. So let's try these little experiments just for 10 to 15 seconds. How many times have you thought jelly doughnuts in the past week or about chocolate?

Nancy: Practically every day.

Robert: Now use all your mental powers not to think about chocolates just for about 15 seconds. Let's see what happens. And you can be my subject, Nancy. Just 10 seconds.

Nancy: I've heard you failed.

Robert: That's 15. So what happened as you tried?

Nancy: My mind kept going back to chocolate.

Robert: And this is a simple experiment that's been done in laboratories, that actually trying to stop thoughts is counterproductive, it makes us think them more. What is more helpful with our difficult thoughts and feelings, whether that's jealousy or sadness or anger is to just notice them and let them be and be honest with ourselves and be honest to whoever we can be open with. And then it tends to like float to the top and float away. But trying not to think it keeps us stuck there. So we need some strength inside ourselves to face these difficult things and support from others and we move through it. And the moving through it involves and is helped by learning to enjoy our children again, by forming a relationship that is based on who our children actually are, not who we originally wanted them to be. You know, there's a parallel in our marriage too and

forming a relationship with the person we're really with and not who we wish them to be, but who they're really with, who we're really with. And when we're working on that relationship with our child, some of these difficult feelings pass, some of these difficult behaviors even less so. As we're learning to connect with the autism in place and as part of how we calibrate our connection, understanding how it affects us.

Nancy: For our listeners on the phone, if you would like to ask live questions, please press *2, and that way your hand is raised. You can ask about anything, chocolate, pretty much anything.

Robert: Even chocolates.

Nancy: Even chocolates. Going forward to your asking about taking care of yourself, when you are grieving, how do you take care of yourself as well as take care of your child when you're still on that grieving process?

Robert: Well, I don't notice a fulltime thing, but I would say kindness towards ourselves is one of the way of taking care of ourselves. Looking for ways to take little breaks for things we enjoy maybe meeting a friend for coffee or tea or snack or lunch, taking a walk, just little things, realizing that we need time for ourselves. Are there little things you do in that way, Nancy, that you might want to share?

Nancy: Yeah. We've just joined the YMCA for instance and I have arranged for a parent of another special needs child to swim with my child while we're there. While he's swimming, I go do yoga or get on the elliptical machine or do something. I'm still in the building, I'm still available but I'm doing my own thing. And some days, I'm able to break away and go do my own thing and some days, I'm not but the days that I am able to, wow, that's me tired. And it's a little good mental break. Personally, I've joined you know, several groups. There's one here locally called Special Moms and we are Moms of all different kinds of special kids and we get together once a month and we don't necessarily even talk about our kids, we just go bowling or get a bite to eat or something and we just spend time together just to get a break.

Robert: Take a break from talking about kids.

Nancy: Take a break from talking about it but it's all, if you have meltdown because you

didn't get a strike, we all know why. It's not it solely.

Robert: Great. And the other thing I find in a way you just said about the gym is you're looking for these opportunities to just fill some time for yourself but you're available as you're needed but you're really going to grab this time for you.

Nancy: Exactly. Exactly. And trying to find things that my son likes to do like walk the track. We're walking the track together and he's swimming out, the basketball hoops and all that kind of stuff. I'm still able to get a break because he's happy and you know, he's engaged, he's happy, he's content for the moment. I'm taking this moment.

Robert: Wow.

Nancy: I'll grab it here and there where I can.

Robert: Sure. Makes all the sense in the world.

Nancy: Books on tapes or e-books, they're my best friend because you can go somewhere in the book mentally but I'm still sitting in the car waiting for therapy to start. Mentally, I'm a million miles away.

Robert: And just getting some for yourself.

Nancy: Uh-uhm. Filling some time. And we have a question here from a caller.

Robert: Sure.

Nancy: Hi welcome to the program. Your first name?

Mary: I'm Mary.

Nancy: Hi Mary, welcome. Did you have a question?

Mary: Hello. You know, I'm going to be honest, I've got so much on my mind and I'm kind of losing track. I'm the one who called who wrote about my kids. I have an 11-year-old, who's my youngest who was diagnosed with PDD at 3-1/2 and then she's become more obviously, but then my boy is 13 and my husband is also, I

don't know if you saw that message, he is high functioning and a very successful man but he doesn't have a communication skills because of other things that I dealt with. I just don't know until I ended up with him but we've been together 21 years and I just sorted it out to nail it down this last year so I didn't realize this existed until after I had my youngest boy also does fell somewhere on it.

Robert: So you got a family of spectrum.

Mary: I've got an eldest who's not and she's 15 but she and I connect and do all these for each other but we're both just kind of sorting out that daddy is and kids, my middle one looked ADHD for a while to many people and so it's been quite a period of adjustment even more recently in the last few years sorting it out more. So I guess I was wondering about one thing. You know my youngest has, they both are obsessed with stories. They love manga and video stuff and they play together because of it which is good. The boy was a talkative one with ADHD kind of thing even though he would stay on his obsessions and was kind of hyper and play with the younger one because they were finding way to bond that way and he didn't know what to do with her. First, I allowed it so they do have a relationship and they support each other that way by being friends, but at the same time, they are obsessed in these little stories they make up and pretend and she will go off and do it by herself. As parents sometimes, it's almost schizo you know, she is kind of talking back and forth and recently, she told me she has thoughts she doesn't want invade her mind and coming in. And I just wondered have you heard of that as being an early symptom of that?

Robert: It's really kind of hard to answer this question. But you know, I think you need a professional until I sit down with you and your daughter and sort this out. I mean this isn't really something I could talk about without knowing the situation and talk it myself. But there might be something going on with her. There's a lot going on in your family. I mean you're in a very challenging situation.

Mary: Thank you.

Robert: Sure. And I wish I could be more helpful but this is too complicated for this medium.

Mary: Thank you.

Robert: Sure.

Nancy: Thank you Mary. That's hard. I can't imagine what it's like to have one of the parents to be on the spectrum as well.

Robert: Well sometimes that's interesting thing to talk about. Maybe we can chat for a few minutes about it. Sometimes that could actually be a little bit of a benefit if the person on the spectrum and sometimes it's mom, sometimes it's the dad can be really good interpreter and understand her of what's going on with the child. If they understand their diagnosis and you know, and are tuned in to the whole situation. So I mean that's...

Nancy: I haven't thought of it that way.

Robert: It's quite—but if somebody is not comfortable with the diagnosis, is in denial of it, undiagnosed, that can really be hard. So there's a lot of advantages that could happen but it really requires everybody dealing with the diagnosis and being comfortable and understanding themselves. There is a parent on the spectrum or with some of the same characteristics, it's really more common than I think we even can imagine sometimes.

Nancy: Really?

Robert: Yeah. Coming up more and more and more that after a child is diagnosed off and one of the parents is diagnosed or the parent, you know, identifies because they have some of the characters existing.

Nancy: Sounds very interesting.

Robert: I want to tell people while we're online, if you want to check out my website, for our psychology practice, *alternativechoices.com*, you'll see our Facebook feeds into there. We have a blog as well and we're always posting things that people write in and the therapists that work with us write in. Like today, if you go to our web page, there is a blog on sensory perspectives by Kate Altman and you can write from our website, see all the recent postings on Facebook. You don't have to be a Facebook member but if you get a Facebook ID, you can become a fan and you get to see from our site. But visit our website, you'll see our blog and our Facebook.

Nancy: We can friend you from Facebook?

Robert: Yeah. Actually it's called fan for an organization.

Nancy: Fan. There you go.

Robert: And like right now, I just looked at it and you don't know about this, but there's just a new blog that is from the Art Therapy World which is art therapist talking about their work with art therapy and children with autism and all kinds of images there that children with autism have made. So that's actually something that was just posted today.

Nancy: Very nice. I'll check it out. While we're talking about the internet, Hugo from Texas asked if I could share some more information about the Special Moms group and I'll quickly just let folks know that this was just a group started by a mom of a special needs child here in our local town. She just started the Yahoo Group and people that she would meet at therapy or friends that she knew, she would just invite them to join and I think the group may have 300 some people in it now.

Robert: Wow.

Nancy: You can post questions through the group, you know if you need some advice or if you have something to sell or something autism-related to sell or, you know, this will always communicate back and forth if you have a group. And then like I said, we get together once a month for breakfast, lunch and dinner. So if you can make dinner but not breakfast, you know, there's an opportunity there. And we have a couple of ladies that organize it now. But we all take turns hosting. So we get together typically at Christmastime and they have the sheet laid out for the whole year and you just pick which month you want to host.

Robert: Wow.

Nancy: It can be anything from bowling to, I actually hosted one recently where I took my group of friends to our local art studio that has classes for special needs and they have a little gift shop where they sell the items and so we got together and we just made an art project and they shopped at gift shop and got to learn more

about that program. So some of these are really fun times to get the other kids on therapy. It's kind of fun. So we always try to think of different new creative things to do because that's getting together to eat, which is always a bonus. But that's a little bit about the Special Moms group and anyone can start a group like that.

Someone has posted a question, Dr. Naseef, asking what is your website again and can you repeat the name on Facebook?

Robert: Sure. *Alternativechoices.com*. So if you go to *alternativechoices.com*, Facebook feeds in and you'll see right there and you can either just view the current postings or you can go, you can click and go to Facebook and I'll give you our Facebook, well on Facebook, we're *alternativechoices* also but if you put *alternativechoices* in the Facebook search engine, you'll come up with us. So I mean hopefully that answers it.

Nancy: And I think on your website, there is also like a listing of books that you...

Robert: Yeah.

Nancy: Publications people can pick up.

Robert: Right. And there's articles I wrote and the articles I wrote are still on your website, Nancy, from the conference that I cover? Did I lose you? Nancy? Hello.

Nancy: I'm back.

Robert: Oh okay.

Nancy: Are you still talking? I lost power.

Robert: Oh no. I thought it was me and I was starting to call you on your cell. So anyway, we're all back.

Nancy: Sorry about that everyone. I lost power and I'm back now. We did have a question from Carol of Houston. Carol asks, "I have trouble finding peace with not doing enough. How do you advice feeling the guilt of what—"

Robert: I'm losing you again, Nancy. Hello. Well let me talk a little about Carol's question on guilt and I hope this is coming through. I think moms more than dads experience a lot of guilt in this situation and it's hard to know when you're doing enough. I do think one way to look at this is that guilt is normal particularly when we have a child and the child is so different and guilt ordinarily is helping us look at our responsibilities in life. But sometimes, that feeling of being guilty that I'm not doing enough, we want to look at that more closely and see what we're actually doing and how much we're responsible for it. And I used earlier the idea of quicksand that may be nothing's enough because that may really be a true thought but it might not be your thought if nothing's enough. It might be that you're facing a difficult situation, you're facing a disorder that's lifelong, that ebbs and flows but doesn't go away. Some acceptance of the lifelong nature of autism may help you let go because to some extent, just remember this about responsibility, that is a normal feeling but successive guilt can keep us from living fully and you might want to again connect with other parents, other moms, the guilt feelings are all over the place and just talking to other people in similar situations, you may find a great relief. It takes some courage to admit, hey I feel guilty, hey, I'm not probably doing enough, but I think you'll benefit from sharing that feeling. And looking at what you are doing and giving yourself some credit.

Are you back, Nancy?

Nancy: Yes, when you're speaking about guilt. I have some guilt about my phone's battery but I'm back.

Robert: Are you responsible for it?

Nancy: I'm not responsible for anything. Dora from New York, New York asks, speaking of guilt, "How do you discipline a child when you know that it's the diagnosis?"

Robert: Well, if the behavior we're seeing is part of the diagnosis, then it's not a question of discipline in the sense of punishment. One way I think of the word "discipline" is look at the root and in the root, if you look at the word discipline, we can also see "disciple." And it's the way I would say to think about it is that we're responsible to lead our children, to teach them particularly when we know that a given situation, that a behavior is part of the diagnosis that just doesn't make

sense to be, in a sense punishing it, but it does make sense that we're trying to teach skills to deal with the situation. But you know, this is really a sticking point for people. And I think you'll feel pressure from other people that you know, maybe they're saying your child just isn't disciplined and that's why they're acting the way they are. But if you know it's part of the diagnosis and you're dealing with the diagnosis and you're getting them help and you're helping, then the consequence of discipline doesn't exactly fit. But we do want to deal with the behavior and help our children learn and develop as fully as possible within who they are. But they need our acceptance to do that, they need our love. They need us to understand them and to feel understood. So I hope that helps a little bit. I certainly understand the question.

Nancy: Yeah. I do to. Carmen in Canada asks, "Do you ever come to peace with your child having autism and where are you with it right now?"

Robert: Wow. I think unless people do come to some peace with this, or an awful lot. And I think I am, most days, most times. Of course, when there is a problem, it kind of stirs up a lot of old stuff, you know.

Nancy: Yeah.

Robert: And that's just to be expected but there's just less and less of that and more peace. And you know, I know he's made me a different person. I thought I would change him and in the end, he just changed me, changed the way I think about life, changed the way I think about parenthood, just really changed who I am in a good way. So that brings me peace. But it's not an easy journey. It's just not. I don't think anyone would just choose this just for the heck of it.

Nancy: No, no, I agree. Not something anyone would wish but when you do come to peace with it, it's a blessing at times, not always.

Robert: Not always, right. I mean I think that's real life, Nancy, I like the way you put it. I mean it's not a blessing 24/7. It's really not but there's a lot of silver linings and it's normal to like wanted to cure it and wanted to go away and the fact that's like our protest, like wanting it to go away is a protest about the relationship that we've lost, that typical relationship, and a protest against the difficulties of this.

Nancy: We have a question from, well, several people have asked this, but this is from Lorie and she kind of sums it up. She's from California. She says, "How is your son doing now?" She has a 26-year-old son with high functioning autism but still living with her and she wants to know how your son is doing now.

Robert: Well my son has a severe, you know, pretty classic case of autism. He lives in a group home. So you know, it's a different situation and I don't, I'm not involved in his day to day care. I see him regularly. In some ways, I think her situation can be more difficult than mine in that her son's at home and you know, I don't know the details but that's me nor my situation. But there is a whole range of outcome to this all. I mean some are living in home and working, some are living at home and not working, some of those with autism live on their own, some married and have their own families. There's everything from very severely disabled to mentally gifted and living in many ways a normal life, you know, with autism.

Nancy: Stephen Shore is one of those people.

Robert: Oh absolutely, one of my best friends.

Nancy: He's amazing. Again, if anyone's calling in on their phone and they would like to ask a question to Dr. Naseef, all they have to do is press *2 and that will let me know that you've raised your hand and you have a question that you like to ask. We still have questions coming in about any advice for grandparents.

Robert: Well, this is a great topic. I think for grandparents, often the issue is—how do I help my child? I'm worried about my baby who's now in a situation that's very challenging. And I think you know, just in a simple way, that what's most helpful is to just be a good grandparent, just embrace the situation, ask what you can do to help, and just be there, and support your son or daughter. I met a lot of great grandparents in this. There's 2 books I would want to recommend written by a grandpop I know, by Dan Gottlieb. One book is called *Letters to Sam*. Sam is his grandson who has Asperger's and it's a collection of letters to Sam about different situations. Another book and you can look for this on Amazon, it's called *The Wisdom of Sam*, which is about situations in Sam's life and things that Sam says. And if you want to see a YouTube of this grandpop and his grandson, go to [youtube.com](https://www.youtube.com) and click in Wisdom of Sam and you'll just see a really beautiful like a 2 or 3 minute YouTube. Sam has autism and his grandpop has

quadriplegia and is in a wheelchair. They're both different, they're very close, and they're wonderful books that speak to everyone in general and to grandparents.

Nancy: I read that book, the *Letters to Sam* book. I have a Sam so it was, just as if it was my Sam and I have to tell you, after I read it, I went out and bought every topic they had and gave to everybody I knew.

Robert: Oh wow.

Nancy: It was a must-have reading and it's a marvelous book and especially coming from his grandfather. It is a recommended reading for all grandparents. Speaking of grandparents and relatives especially going into the holidays here, being around extended family who is not around the child as much, Jean from Elgin asks, "What to say to relatives who are showing their dislike for how the family is handling the child who is screaming?"

Robert: Wow.

Nancy: How do you handle the relatives?

Robert: Well it's exasperating. Of course, it's difficult for everyone. It's difficult for mom, dad and the other kids and the relatives understand it less. So it might not be so much as how you handle the relatives as so let's just go back in time to when we have this experience. What did we think when the kid was just screaming? Were we kind and compassionate or did we wonder the same thing? Did we wonder like what the hell is going on and why doesn't this stop and why don't these parents like make the kids stop? It's a really tough situation and I think it's disturbing to everyone. So you know, we can give people information but we can't change how they think but over time, I found an awful lot of these changes as people understand it, as they're around the child more. But I think for everyone, it's just difficult to be around the screaming kid. We all want it to go away and if you allow yourself to look at it that way, you might feel like sort of less judgment and less annoyance with your relatives but I certainly understand the situation and hope that it gets better for you. I hope that helps.

Nancy: Great advice. Personally, I don't let it get to me because I understand that they don't get it.

Robert: So you accept that they don't get it? You accept where they are?

Nancy: And they may never get it and that's okay.

Robert: Did some of them get it? Have some of them gotten it over time?

Nancy: Well yeah. But just when I think someone's got it, they say something really off the wall that tells me, okay, I see that you truly don't get it. Like someone says that he just needs spanking.

Robert: Alright. That's like the worst of all. I mean it could be worse.

Nancy: Yeah. So it's one of those situations where I'm not going to waste my time trying to explain autism to you. I'm just going to do what I need to do. And hopefully I only see these people once a year.

Robert: Right, right, right.

Nancy: If they're interested in learning more, you know, they can go out and learn more about autism on their own. So often, my child looks so typical out in public for instance, the strangers that when he does melt down, I get to learn it.

Robert: Yeah sure, hard to understand.

Nancy: And I grown that thick skin where I don't get embarrassed anymore except I had recently an episode where my son was just lying on his back in the middle of Panera Bread screaming obscenities.

Robert: Oh gosh.

Nancy: I'm at the counter and thinking, somebody needs to consult your child. Who's kid is that? And I felt myself turn beet red wanting to leave the situation and we did, we ended up just leaving, but—

Robert: Which is sometimes the best situation.

Nancy: I didn't get my Panera so it wasn't ideal.

Robert: Oh no, that's so good.

Nancy: Yeah. I really needed that. But yeah, I mean sometimes you just have to drop it and go. There's nothing you can do about it. My kids, my teenagers, my typical teenagers also have learned to just ignore it and move on but at first, they would leave me stranded in a situation and they would be to the door of the store and me carrying the meltdown to the door. They act like they knew who I was. So that's how they cope which is perfectly fine with me. I don't know what I would do if I was in their situation either. You know, what do siblings do? How do they cope with the embarrassments of being in public with their siblings and the siblings melting down?

Robert: And that can be harder for them than for us.

Nancy: Absolutely.

Robert: How do you see that?

Nancy: How do I see that?

Robert: The difficulty for a sibling going a meltdown?

Nancy: Well, you know, the entire store is looking at you and my kids would make a beeline away from the situation as quickly as possible. And I didn't take it personally. I mean if I was in their situation, I would have done the same thing. I just gotten the heck out of dodge.

Robert: Right. There's a feeling of not wanting to be seen when you're embarrassed that I want to hide, I don't want to be seen. So just that you could recognize and support your kids in that is kind of make their life better. It doesn't make it less embarrassing but it lets them know you understand, you care. But—

Nancy: And I will often dress Sam in a t-shirt or something that has the word autism in it. He has one that says, "Staring will not cure my autism."

Robert: Oh wow. I love that one.

Nancy: And he wears them in public when we go out. And then if he does have a meltdown, it's a little more obvious why. I'm not just a bad parent. We're not just doing wrong thing. There's a real reason. So that helps.

Robert: Yeah, yeah. That's wonderful.

Nancy: Talking about siblings, Mike from New Jersey asks, "My children yell and scream when people enter the house or if we go somewhere. What can I do at Christmas when the relatives come over? My boys spend the day in their room or under the table."

Robert: Well it might be a little too stimulating for them. I think we have to look for situations that will work. Although it's painful and that's a time that the grief comes up around the holiday when you just want everybody to be together. But it might not be the best thing for your kids. So you might want to have them spend the short time with everybody and then let them have some time alone doing something else or someone spends time with them separate from the whole gathering. Now, it's not ideal but it might make everything go smoother and it might lend a feeling of acceptance and peace to the situation. It's when we expect something to be different from the way it is that we suffer the most. When we can face the problem and look at the choices we have for dealing with it, that's when we do better. That's when things go smoother and that's when there's a little more peace.

Nancy: And along the same line, Collie says, "How do you handle the relatives that do not think there's anything wrong with your child? How do you help them to understand why you avoid some big functions, big parties, that the son will not handle well and will be overwhelming for him?"

Robert: Well she's coping with it. She is picking the situations that work and not punishing herself or her child by getting into the ones that don't work. Now, it's like you said earlier. I mean some people may never get it, some will get it. I found over a period of time that a lot of people arrived at their own way of understanding the situation and that there was more acceptance. But you know, I think this is what to some extent we have to make peace with that we can't change all this. We can't change other people's reactions. We can just speak our truth and live our truth. Accepting autism doesn't mean liking it. The situation you're describing is not something to be liked but I think there's ways

to make a little peace with it.

Nancy: When we would go to family functions, I found that the kids, the cousins, and so forth accepted my explanation as to why Sam screams instead of talks better than the adults.

Robert: Yeah, yeah. Well, and the other thing that I think it might be going on in the back of the people's heads is there's a genetic connection with this and there might be some worry about whether it will happen to them or some guilt about is there a problem in our genes. There's often a lot that's not being said that people might not have the words or the courage to say what they're really thinking. So it's really a sticky and sometimes dark situation, but I think we just try to pick the best situations we can for our kids and our families and just do the best we can. We can account for other people's consciousness and evolution but over time, some people change and some people don't. We find out who our real friends are. We find out who is really with us and is supporting our journey.

Nancy: Yeah. It does help to divide and conquer if you have a spouse that's on the same page and you both can attend the event together and drive separately and then when that threshold has been reached, the one parent has just already agreed, okay, I'm leaving the party early, you know you can say. And we see parents doing that.

Robert: And that works.

Nancy: Yeah. I just recently had a great time in a relative's wedding. Even though we took Sam, she lasted through the meal and he was done. And my husband had already said when he's done, I'm done. And I got one dance from the dance floor with Sam and then they took off. And I had a ball. I had a ball and no guilt. It works out wonderfully if you have someone that can share that with you.

Robert: That's wonderful.

Nancy: So it's not an everyday thing but sometimes it works.

Robert: You have to let go of wanting to do this like everybody else and just find a way

that worked for you and your family.

Nancy: Yeah.

Robert: And it's just your acceptance and it took your husband's acceptance to make it work. And you had a good time and your son probably did too. He didn't have to stay so long that he melted down or that he became miserable.

Nancy: Yeah. Just accepting him for who he is and his threshold has been monumental for our family. I don't want him to have to stay for 6 hours if his threshold is too. It just makes everybody miserable.

Robert: Right. You want to leave in an hour and 59. Well, everybody is still happy.

Nancy: Exactly. And everyone commented on how well behaved he was and how much fun it looked like he was having and if he had stayed another 15 minutes, they would have seen the other side. So when he's done, he's done.

Robert: Right. Wow, Sam is really doing great.

Nancy: Exactly. That's what we heard. That's what we heard. He is doing so much better. I'm like I think maybe we're the one that are learning.

Robert: Right, right. And yeah, sometimes it's like we're learning to be with each other. You're learning to be with him within the limits of what works and there's a lot of happiness that can be found that way and a lot of misery when we don't find it, when we try to keep making it into a situation that isn't.

Nancy: Yeah. And a lot of people questions about how do we get our child to sit at the holiday table, or maybe he doesn't sit at the holiday table, maybe he can't yet.

Robert: Right, right. Maybe he will.

Nancy: Yeah.

Robert: Maybe he really will but if we let go, if he can't do it and he let go of it now, we're going to have a better holiday.

Nancy: That's great advice. Ellen from Idaho Falls asks, "How much should you expect the siblings of an autistic child as far as helping out with the child?" She says that she has 6 children and a very busy household? So how much do you think siblings should be responsible?

Robert: It varies. Now when the child who has autism is the younger child or the youngest child, the kids pitch in and want to help, because older kids always want to help with little kids. Now, it's mostly always. But when the child with autism is older or bigger, that becomes hard to do. It's kind of counterintuitive. So you know, I met a woman from Chicago, this was several years back and she had, I don't know, 7 or 8 kids, but the youngest one had autism and I said, "How do you manage that?" And she said, "Well we call the meeting and we said to our children, your little brother has autism and he was the youngest." And she said, "He is the runt of the litter. I want you all to pull together and help." And it worked because he was the baby. But it wouldn't work so easy if he was the oldest one because if he's the oldest or one of the oldest, the expectations are different. The little ones want to look up to him. But they can't.

So every situation is different. I think regardless of, I gave an example in terms of this birth litter which we don't know here in this situation, but most kids want to help, but to expect them to do too much could be a burden for them. So you know, it's really challenging when you have a large family and I came from a large family myself. So, it's quite natural for you to feel overwhelmed. But I think you may get more involvement from the siblings by expecting less. Now that makes sounds counterintuitive but I think they may pitch in more if you're not like requiring it. And I hope that makes a little sense. Again, one of the things that's hard to get into without knowing a little more.

Nancy: Do you think it's helpful to educate the siblings on like you said before, you know, educating them about the disability but also about things you can do behaviorally to help them or sensory issues or...

Robert: Oh yeah. I think all of that plays a part. I think you know, just like we love our children, they love their brother and sister but it can be pretty mysterious as to what's going on. So I would keep giving them information at their level, helping them providing opportunities for them to meet other siblings, that's often really helpful to them, just this parents meeting other parents can be just so very helpful. And in the long run, this child with autism can contribute to everybody

so we can all learn, we can all become better people in the process.

Nancy: I definitely think my teenagers have become better people just because they are more understanding of disabilities or abilities and also when we see that child melting down in the mall, we have that knowing look like that might be autism. You know, that might not be bad parenting; however, that might be something more. And you know, a little more compassion.

Robert: Wow, that's great.

Nancy: That's helpful for our typical kids too.

Robert: It makes us all better people in that way. Again, not that we volunteer for this, but in the end, we may all be better people and our typical kids as well.

Nancy: Sure. Now, did you have any slides or any information that we haven't covered yet that you'd like to?

Robert: I have a lot and some that I like to. So I will do that. And I want to mention again for anyone listening to go to our website, *alternativechoices.com*, and I notice that just while we were talking, 10 more people friended us or fanned us on Facebook, so I thank you. You know, keep tuning into that. We post things several times a week and we invite you to join the conversation there that will be ongoing and we have people from around the country and either other countries checking in there.

So I do have some more slide that I'd like to show you and talk a little bit about as a way maybe of summing up a little.

Nancy: Yeah, you have about 3 or 4 minutes.

Robert: Okay, here we go. Often the question comes up of what does acceptance mean? How do I come at a peace with this? And I think for some people, it feels like acceptance means giving up, but I don't think it means that at all. It doesn't mean wanting or liking autism. It doesn't mean changing your opinion about how hard it is. It doesn't mean being resigned to a miserable life and it doesn't mean giving up on life or possibilities. What does it mean? I think acceptance means opening up to what we're really thinking and feeling and being willing to

be there. Accept our own thought, feelings, sensations, and being willing to be right there in our lives and it's then that we can look at what can we change and what remains the same. And that's the meaning we see in the serenity prayer.

So having my son and this slide that comes up shows him more recently. We're riding this like big three-wheeler because he can't ride a two-wheeler, and this is right outside the group home where he lives in Pennsylvania. When we accept our own feelings and our own selves and understand autism, it can be like falling in love with your child all over again, and I think some of that came out in the stories you shared, Nancy. And in accepting these feelings and finding the way to relate and the way to make things work, our mind clears up and we can enjoy life, not that it's easy but it can be a good life even though it's a hard life.

And somebody asked me like what's it like? Well, in some way— and am I at peace with it? Well, yes I'm at peace with it, but in some ways, I never stop playing to hear the sound of his voice. My son is nonverbal. I'm showing you a slide of him when he was a little, and you could see him like clicking his fingers. And you know, my head can go back there and flash. I imagine other people's can as well.

The slide I'm showing now shows my book, *Special Children, Challenged Parents*, and as I mentioned earlier, this was something I wrote in a letter to Tariq. "I tried so hard to change you, and in the end, it was you who changed me. Instead of becoming the son I wanted you to be, you helped me become the man I need to be." So that's really been my journey with my son.

So I don't know, in the serenity prayer, and these concepts exist like pretty much in every faith tradition and I just want to like kind of end on that note. It starts with, "God, give us the grace to accept with serenity the things which cannot be changed, the courage to change the things that should be changed, and the wisdom to discern the one from the other." So it's not a matter of giving up. It's a matter of looking for what can be changed, accepting that responsibility so if we're working on changing what's changeable and we're making peace with autism, then we can let go of guilt. We just have to work on the changeable and discern one from the other. And if we're doing that, if we're finding the things that work, if we're finding the ways to enjoy our family and enjoy our child with autism, then what's clearly going to happen is we're going to find some peace and we're going to find some enjoyment in life the way it actually is.

So that's what I wish for everyone tonight. It's been really good to be here. I thank you for the opportunity, Nancy.

Nancy: I thank you for being here and sharing so much great information with us. Every time I talk with you, I learn something new.

Robert: It's always good to know.

Nancy: I'm going to go and hug my kid now.

Robert: Okay, perfect. I think I'll go hug mine too.

Nancy: I think we should. And I also want to share with our participants that if you want a transcript of this event, please join the Spectrum Gold Club by clicking the button on your screen. We will send you a copy of the webinar audio and transcript plus we will send you 29 other webinars when you join. Also tell us what you think. Call us at 877-211-0212 extension 1 and leave a short comment or testimonial. That number again is 877-211-0212 and I want to thank everyone for attending and being part of this great webinar. And thank you again, Dr. Naseef, for sharing your wonderful lesson with us.

Robert: Thank you Nancy. Certainly, I look forward to work with you in the future.

Nancy: You too. Have a wonderful evening.

Robert: Okay, bye-bye.

Nancy: Bye-bye.

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