



ENGAGING FATHERS

Robert Naseef, Ph.D.

When a child is diagnosed with autism, the reaction of parents can range across a wide spectrum of emotions, including worry, stress, sadness, relief, and more. Typically, mothers take the initiative and get on every wait list possible, set up school Individualized Education Plan (IEP) meetings and start making visual schedules to follow at home. What role do fathers play after a child is diagnosed? Are their thoughts and feelings the same as their partner's?

I am a psychologist and specialize in helping families of children with special needs. After my own son was diagnosed with autism, I saw a real need to connect with and support fathers who are raising autistic children. I have been organizing father support groups for over 20 years, and have come to learn a great deal about amazing fathers around the world who are raising children on the spectrum.

What's it Like for You?

Here are some of the questions I pose to fathers who are raising a child with autism. What's it like for you? Can you recall all the details of your child's diagnosis, and relate how your child is doing at school? Do you know all the things your partner is doing to support your child? While such information is valuable, it's also important for fathers to acknowledge and express what it is like for them to raise an autistic child. No response to these questions would be considered "wrong." Fathers can say whatever is on their mind and in their heart. If you are a father, how would you answer the question, "What's it like for you?"

In my experience, I have found some common themes that emerge when men are asked this question. The following are some of the most common responses.

STRESS

Fathers are living with a great deal of stress. While they are willing to admit to the stress in their lives, they have difficulty admitting that it weighs them down into a depressive state.

WORRY

They worry about the future, as well as where their children will live when they grow up, and who will take care of them.

DIFFICULTY CONNECTING

They often admit that they are having difficulty connecting with their child.

SHOCK

Fathers are often shocked and in disbelief after an autism diagnosis. This can lead them to offend their partner or child, which in turn creates deep feelings of guilt.

FEAR

They want to do what is right for their family. They want to provide support and assistance, but they are afraid of doing or saying the wrong thing.

BROKEN HEART

Fathers' hearts are broken because many of the things they envisioned doing with their child will not become a reality.

ANGER

Fathers sometimes admit to being harsh and angry with their child, but find that the disciplining techniques used by their parents do not work with their child.

These are difficult conversations. It is hard to be frank and genuine, and to put your deepest thoughts and feelings into words. In one support group I conducted, one man admitted to being depressed and then burst into tears. The emotion in the room was palpable. While others did not admit to being depressed themselves, they came and stood around this man and sought to comfort him.

Feeling some grief and sadness is normal, but getting stuck in that mindset is not healthy for the parent or the child. Autistic author Jim Sinclair offered the following advice to parents:

This grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person.

You didn't lose a child to autism. You lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you.¹

Engaging in the Journey

I have seen many fathers take time to process and understand the autism diagnosis. Even though they don't have the words to express what is happening and may not know how to help, we do need fathers who are actively involved. Fathers need to take action and be engaged in this journey so that they can be an important figure in their child's life. Here is my advice on how fathers can be included in the journey.



CONNECT WITH YOUR CHILD

Focus your attention on connecting with your child, even though you may not know how to do this. One man I know said that when he hugs his son, he doesn't get a hug back. Another said that his son literally pushes him away when he gets too close. The idealized image of a father and son playing baseball together doesn't always come to fruition. How can fathers connect? The first step is to start where your child is comfortable. If your child is lining up cars, get on the floor and line them up with him. If your child is pacing around the room, pace with him and see what happens. Play video games with him, build things together, or take things apart together. Play with action figures together, or go for car rides together. Determine what your child is interested in, and build on that interest. This will help you find a way into your child's world. At first, you may need to do something that doesn't interest you. In time, however, you will find things you enjoy doing together. As your child becomes comfortable with you entering his world, he will start to feel understood and will soon be more open to your interests and activities.



LEARN ABOUT AUTISM

Learn and read about autism. Find articles and books on anything related to autism. Find out what specific challenges your child has, and read about them. The more you understand about autism, the more involved and effective you will be at home. As part of your learning journey, become involved in your child's school meetings, therapy sessions, and doctor's appointments. Do not rely on your partner to always be the one who reports on what was discussed at these meetings. The more involved you are in the appointments and management, the more you will understand your child. The more you continue to learn, the more you can contribute at each meeting.



FIND BALANCE

Fathers need to recognize and admit to some of their painful thoughts and feelings. Be honest. These feelings are normal and natural. When we are forthright about our dark feelings, we can also be open to the good things we are experiencing. Light comes into our hearts and lives when we are open to all of our emotions. Once you can recognize all aspects of emotions, you can make a conscious decision to not let the difficulties be a dominant force in your life. Make connecting, communicating, and being together as a family a dominant theme. At times, we are all distracted by thoughts and feelings of how difficult this journey is. If we have the goal of focusing our attention on the positive experiences and accomplishments, we will be better able to manage the rough patches.



BE ENERGETIC AND POSITIVE

Fathers need to be energetic and positive around their children. While our children may have challenges that other children do not, the focus cannot always be on the difficulties. Be positive and fun, and go on adventures. Be excited about the things that make your child smile. Tell jokes, and use funny voices when you read books with your children. They will lean on your energy and positivity.



CONNECT WITH OTHERS

Connect with other fathers at your child's school or clinic. Find other fathers with whom you can share your feelings and successes. You are part of a select group of men who are raising children with autism. It's both hard and wonderful, and the things your children are teaching you are unique. Tell other fathers how you are connecting with your child, and watch to see how they are connecting with their children. Learn from them, and confide in them. You will see that they can help you become a more engaged father.



APPRECIATE AND LISTEN TO YOUR PARTNER

Couples and partnerships raising a child with autism can be under a great deal of stress. It's important to work together and to find ways to communicate effectively. Begin opening these lines of communication by giving credit where credit is due. Tell your partner that you recognize everything that he or she is doing, and that you appreciate it. The sooner in the process you do this, the better your relationship with your partner will be. Everyone wants to feel appreciated for what they do. Expressing this appreciation will open the lines of communication and empathy. When your partner responds, listen carefully. Your partner may need help with something, or may just be looking for a listening ear. Appreciating and listening to your partner's feelings and concerns will help you work together better and provide the support your child needs.

My son has autism. When he was diagnosed in the 1980s, I felt all alone. I didn't know anyone else who had a child with autism. My son stopped speaking when he was 18 months old and never spoke again. Today, he lives in a group home. He doesn't speak, read or write, but he is happy. It's a life I couldn't have imagined when he was born. As I learned more about autism and started connecting with my son, I developed a deep relationship with him. He has transformed me and, in doing so, has brought light and love into my life.

There is so much that you can learn from your child. You really will become a better person. You'll be less selfish, and will learn how to manage difficult tasks. You will become patient and understanding. Your child will teach you to look inside yourself and find your true values. Raising a child with autism takes you on a journey in which you become wiser, more compassionate and more loving. That relationship, and all it entails, will transform you into a better human being.

Reference

1. Sinclair, Jim. (1993). Don't Mourn For Us. *Autism Network International Newsletter, Our Voice*, 1:3



Robert Naseef, Ph.D. has a distinct voice as a psychologist and father of an adult son with autism. He has spoken nationally and internationally, training professionals in treating autism and other developmental disorders and supporting families. He has a special interest in the psychology of men and fatherhood. His 2013 book, ***Autism in the Family: Caring and Coping Together*** integrates advances in research and treatment with clinical experience to help families navigate the emotional landscape and the practical roadmap through the lifespan. He has appeared on radio and television. He is the co-editor with Cindy N. Ariel of ***Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*** (2006). Dr. Naseef gave a TEDx talk entitled "How autism teaches us about being human" which you can see on YouTube. He serves on the Leadership Council of the AJ Drexel Autism Institute. Visit him at www.alternativechoices.com; you can access his social media at <https://linktr.ee/RNaseef>

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