

You, Your Family and Autism

How Will I Deal With the Diagnosis?

You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much, to want something so much and not quite get it.

Even though it is your child who has the autism diagnosis, it is important to acknowledge that autism “happens” to the whole family. It affects every member of the household. Autism can be difficult to deal with, both for the person diagnosed and for the family. It can lead to many changes in the family, both inside and outside the home. Luckily, with heightened awareness, there are many places to go for support and help. As you move forward with your child and your family as a whole, the staff at the Mayo Clinic has come up with the following advice to help you on your journey:

- **Learn about the disorder.** Just 15 years ago, many pediatricians hadn't heard of autism. Now, there are numerous books and websites dedicated to the disorder. Do some research so that you better understand your child's challenges and the range of services in your school district and state that may help.
- **Learn about your child.** The signs and symptoms of autism vary for each child, and young children have a hard time explaining their behaviors and challenges. But, with time and patience, you'll learn which situations and environments may cause problems for your child and which coping strategies work. Keeping a diary and looking for patterns may help.
- **Find a team of trusted professionals.** You'll need to make important decisions about your child's education and treatment. Find a team of teachers and therapists who can help evaluate the options in your area and explain the federal regulations regarding children with disabilities.
- **Help others help your child.** Most children with autism have no visible sign of disability, so you may need to alert coaches, relatives and other adults to your child's special needs. Otherwise, a well-meaning coach may spend time lecturing your child on “looking at him while he's talking” – something that can be very difficult for a child with autism.
- **Help your child turn his or her obsession into a passion.** The tendency to fixate on a particular narrow topic is one of the hallmarks of autism and it can be annoying to those who must listen to incessant talk about the topic every day. But a consuming interest can also connect a child with autism to schoolwork and social activities. In some cases, kids with autism can even turn their childhood fascination into a career or profession.



Caring for the Caregiver

Changing the course of the life of your child with autism can be a very rewarding experience. You are making an enormous difference in his or her life. To make it happen, you need to take care of yourself. Take a moment to answer these questions: *Where does your support and strength come from? How are you really doing? Do you need to cry? Complain? Scream? Would you like some help but don't know who to ask?*

Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself.

Parents often fail to evaluate their own sources of strength, coping skills or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax, cry or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is not helping you or your family. You may feel that your child needs you right now, more than ever. Your "to do" list may be what is driving you forward right now. You may feel completely overwhelmed and not know where to start. There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. Maintaining open and honest communication with your partner and family as well as discussing your fears and concerns will help you to deal with the many changes in your life. As some parents may tell you, you may be a better person for it. The love and hope that you have for your child make you stronger than you realize.

Here are some tips from parents who have experienced what you are going through:

Get going.

Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child and take care of yourself.

Ask for help.

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning? Can someone pick a few things up for you at the store or do a load of laundry? Or let other people know you are going through a difficult time and could use a hand?

Talk to someone.

Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.

Consider joining a support group.

It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources of information about what services are available in your area and who provides them. You may have to try more than one to find a group that feels right to you. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

You may also want to consider attending a recreational program for children with autism. This may be a good way to meet other parents just like you.

One study from Vanderbilt University, a part of the Autism Speaks Autism Treatment Network, found that mothers of children with autism benefit significantly from weekly stress-reduction classes led by other mothers. The classes reduced previously high levels of personal stress, anxiety and depression and improved the mom's interactions with their children.

“At my support group I met a group of women who were juggling the same things I was. It felt so good not to feel like I was from another planet!”

You may find a listing of support groups in the Autism Speaks Resource Guide at autismspeaks.org/resource-guide. Another avenue is through the local SEPTA (Special Education Parent Teacher Association) in your school district or online through the Autism Speaks Facebook page at facebook.com/autismspeaks.

My Autism Team, the social network for parents of kids with autism, is another great resource. On this site, parents of children with autism share their experiences, including their reviews of local service providers, to help inform the parents in their communities. Visit the site at myautismteam.com.

Try to take a break.

If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, getting out to a movie, going shopping or visiting a friend can make a world of difference. If you feel guilty about taking a break, try to remind yourself that this break will help you feel renewed for the things you need to do when you get back. Try to get some rest. If you are getting regular sleep, you will be better prepared to make good decisions, be more patient with your child and more able to deal with the stress in your life.

Consider keeping a journal.

Louise DeSalvo, in *Writing as a Way of Healing*, notes that studies have shown that: “Writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health, and positive behavioral changes.” Some parents have found a journal to be a helpful tool for keeping track of their child's progress, what is working and what isn't. Be mindful of the time you spend on the internet. The internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.

Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation.

As a parent, always remember to trust your gut.

There are many paths to take, treatment options and opinions. You know your child best. Work with your child's treatment team to find what works best for your child and your family.

Right now, while you are trying to make the most of every minute, keep an eye on the clock and frequently ask yourself these important questions:

Is what I'm reading right now very likely to be relevant to my child?

Is it new information?

Is it helpful?

Is it from a reliable source?

Sometimes, the time you spend on the internet will be incredibly valuable. Other times, it may be better for you and your child if you use that time to take care of yourself.

The internet will be one of the most important tools you have for learning what you need to know about autism and how



Becoming Resilient During Times of Adversity

by **Dr. Peter Faustino**, school psychologist, state delegate to the **National Association of School Psychologists (NASP)** and member of the **Autism Speaks Family Services Committee**

Resiliency, or finding ways to properly adapt to challenges or stress in your life, is a process, not a character trait. Research has revealed several key elements in fostering resilience and by considering the following, you will find you are not only helping your child but yourself and your entire family.

Connectedness: One of the strongest pillars in resilience is having positive relationships or feeling connected to others. While the diagnosis of autism may be extraordinary at first, it no longer is synonymous with being alone or having few places to turn for help. This tool kit is only one example of the ways in which Autism Speaks can lend support. Regional chapters of Autism Speaks all across the country can open up doors to other parents, families and communities who have experience with navigating the autism diagnosis. When relationships with friends, neighbors and family are based on mutual, reciprocal support and care, they can bolster resiliency.

Competence: Whenever a challenge presents itself, individuals can feel a loss of control over the situation and their lives. Competence or at this early stage learning about autism and then taking action on realistic goals will help you gain a sense of control.

Having trustworthy information and feeling more competent (not only about autism but in other aspects of your life) can be critical in maintaining a hopeful outlook.

Care: Eventually, your journey will lead to a place where you can balance negative emotions with positive ones. Taking care to avoid seeing an event as unbearable or unchangeable versus looking for opportunities and considering the event in a broader context can be an important factor to resilience. Positive attitudes such as encouraging yourself to try, being determined to persevere until success is attained, applying a problem solving approach to difficult situations and fostering feelings of determination or grit are critical. Care also refers to parents attending to their own mind and body, exercising regularly, as well paying attention to basic needs and feelings.

Resilience is the result of individuals being able to interact with their environments and the processes that either promote wellbeing or protect them against overwhelming influence of risk factors. In many cases, adversity can act as a spring board for growth and success, not only in our children, but in ourselves as well.

“Is Your Son On the Spectrum?”

**In her own words,
Alysia K. Butler, who has a recently diagnosed son, describes her
experience being part of the autism community.**

The question was slightly jarring to me. My son and I had just walked into a gymnastics class for kids with autism. We had received his diagnosis only three weeks before and we hadn't shared our news with anyone except for close friends and family. It was the first time we had been anywhere that was just for kids like mine and I wasn't really ready to talk to a total stranger about it.

“Yes,” I answered, trying to keep the conversation short.

“Hi and welcome! That's my son over there and my name is Sandy. How old is your son? Do you live in town? How long have you known your son was on the spectrum? What was his diagnosis?” I really didn't want to answer her. I wasn't even sure we belonged at this class and all I wanted to do was pay attention to my son to see how he was responding to the class. I watched the other kids as they came in – six boys and one girl – and my first instinct was that we were in the wrong place. One little boy was crying, another was spinning in circles and another one was running in all different directions. My son's not like that, I thought to myself. This isn't us.

And then I looked at my Henry. I watched him hold tightly to his one-on-one helper's hand as they walked on a low balance beam, but he wouldn't look her in the eye when she talked to him. I watched him try to run away to jump into the comfort of the sensory foam blocks and become so focused on that foam pit that he couldn't move on to anything else. I listened to him babble while he swayed back and forth on the rings and saw the terror in his face when the noise level got up too high. The tears welled up

in my eyes. We did belong here. This was the right place for him. We had found a safe place for him to exercise and develop his muscles in an environment that understood his special needs. For so long we had avoided the “regular” gym classes, music classes and playgroups because of his behavior. No one here was giving me the usual disapproving looks we get when we're out places and Henry starts to act up. I took a deep breath and turned to the mom.

“Hi! My son Henry was diagnosed with PDD-NOS a few weeks ago. We do live in town. In fact, I've seen your son at the preschool that my son attends. How long has your son attended classes here?”

It took everything I had to have that conversation, but it was such a relief. This other mom was reaching out to make a connection – to find someone else who struggles on a daily basis like she does – something I myself had been desperate to do for weeks and months. I was instantly welcomed into a community of people who “get it.” No one batted an eye when Henry buried himself under the foam blocks at the end of class so he didn't have to leave. I got comforting looks of understanding from all the parents and teachers when he had a major meltdown leaving the gym and big thumbs up from everyone when we finally got our shoes on and went out the door. These were moms and dads who shared my daily difficulties of just getting out of the house. Finally, we were somewhere that felt like we belonged.

“Will we see you next week?” asked the mom.

“Absolutely,” I replied.

How Will This Affect Our Family?

Even though it is your child who has the diagnosis, it is important to acknowledge that autism affects the whole family. This section of your tool kit may help you anticipate some of the emotions you and other people in your family will experience.



Telling Family Members

The following article, adapted from *Does My Child Have Autism?*, by Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the autism diagnosis.

Reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis.

“You know those behaviors we’ve been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn’t act the way he does because he’s spoiled or because he’s shy or because he doesn’t like us – he acts that way because he has autism. Autism explains why he doesn’t speak or use gestures and why he doesn’t seem to understand what we say. It explains why he’s not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys. I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early, and there are a lot of things we can do to help him. He’ll be starting some therapies soon, and I’ll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I’ll be glad to try my best to answer them. I know we’re all hoping for the best outcome possible.” After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop.

Telling Others

The following article from the book *Overcoming Autism*, by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, offers a suggestion for how to tell people, and explains why for some people, it can make life easier for you and your friends.

You should, you know. Tell people. You don't have to walk up to strangers on the street or anything, but confide in the people who love you. That was one thing we did right: we told our families and our friends right away. First we called them, and then we copied a good comprehensive article someone wrote about autism and annotated it with specifics about Andrew, and we mailed it out to everyone we knew. (You could do the same things with sections from this book, by the way.) None of our good friends pulled away from us because our kid had autism. Just the opposite – our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress on year after year. In all honesty, telling people what we were going through only made our lives easier. Before then, we worried that Andrew's occasionally aberrant behavior was off-putting. But once he had a formal diagnosis, everyone cut us a lot of slack, and instead of wondering what the hell was wrong with us as parents, most people we knew admitted to a newfound respect for us for dealing with so much. Real friends don't love you more for being successful or less for having problems. If anything, it works the opposite way – we're all so busy that sometimes we forget to stay in touch with friends when everything's fine for them, but we rush forward when they need us. Now is the time to take advantage of that. Talk your friends' ears off, complain, bitch and moan to them. You're dealing with a huge challenge, take advantage of every minor plus it has to offer.



Telling Peers

Talking with peers and other students is crucial to helping a child with autism become more comfortable in school or social settings. If peers are aware of their classmate with autism and understand the reasons behind his or her sometimes odd behavior, this will increase acceptance and limit bullying or taunting. It is important to explain autism to children in a way that they will best understand their friend or classmate. For example, talk about the fact that many of us have challenges. While one classmate might be unable to see and might need glasses as a result, this other child has trouble in social situations and needs support as a result. It may help to identify one or two peers who can serve as “buddies” to help your child feel more comfortable in school.

Stephen Shore developed a four-step process for disclosing autism, which he has found effective in a number of settings. In essence, it's a tool for placing a child's autism in context and helping others to understand that autism is not a “handicap,” but rather a collection of strengths and challenges. Through accommodations and support, people with autism can not only succeed but can even thrive.

Four Step Process for Disclosing Autism

by **Stephen Shore**

Start by delineating your child’s strengths and challenges. Use the word “challenges” instead of “weaknesses” because you can address challenges. If Joe’s been in class for a little while, a parent might say “Joey is very good at following the rules. When there’s a change in the schedule, though, you’ll see Joey get a little anxious.”

Try to find a strength that your child uses to accommodate for a challenge. For example, during lecture parts of class, your child might use a computer to take notes. A parent might say “Joey finds that writing by hand is very tough, so this is how he takes notes.”

Talk about other people’s characteristics to place your child in a broader context. A parent might say, “Joey has these strengths; other people have other strengths. We all try to build on our strengths to lead to productive lives.”

Lastly, bring out the label. Explain that autism is a set of traits, strengths and challenges, and that doctors and scientists have identified these characteristics as autism.



Explaining the Diagnosis to Your Child

According to experts, it is essential for parents to explain the diagnosis to their children. Oftentimes, this can help put children on a path to self-acceptance and can allow them the time to understand and ask questions. With no knowledge of their diagnosis, children with autism can often compare themselves to others and come to unfounded conclusions about themselves and their own well-being.

Children younger than eight years of age often do not think they are different from their peers, so the bigger picture of a developmental disorder may be too complex for them to understand. When talking to your child, remember to use age appropriate words and to think about it from his or her perspective, in order to improve the communication between the two of you. It can help to talk to your child about being an individual and explain that differences exist between all people. Using play, and sometimes books, can also aid in helping children with autism to better understand themselves and their diagnosis. Be sure to emphasize your child’s strengths as well as his or her areas of challenge. It is helpful to point out that everyone has areas of strength and weakness.

“Our son, age 9, was recently diagnosed with autism. He knows something is up but we’re not sure how to explain it to him. Advice?”

In the piece below, clinical psychologist Lauren Elder, PhD, answers one parent’s question about how to tell her son about his autism:

Sharing your child’s diagnosis with him is a difficult situation shared by many parents. Children need to understand what’s going on, but the discussion needs to be appropriate for their age and level of development. Your openness will help your child feel comfortable coming to you with questions.

I recommend a series of ongoing conversations rather than a one-time discussion. Here are some tips for starting the conversation and preparing some answers for questions that your son may ask:

Explain autism in terms of your child’s strengths and weaknesses.

You may want to focus on what he’s good at, and then discuss what’s difficult for him. You can explain that his diagnostic evaluation provided important information on how to use his strengths to meet his challenges. Focus on how everyone has strengths as well as weaknesses. Give some examples for yourself, his siblings and other people he knows.

Provide basic information about autism.

Depending on your son’s maturity and understanding, you may want to continue by talking about what autism means. You want to give your child a positive but realistic picture.

It may help your son to hear that autism is common and that there are many children like him. This can open a discussion about the strengths and challenges that many children with autism share. You might likewise discuss how individuals with autism tend to differ from other children.

For instance, you might explain that many children with autism are very good at remembering things. Some excel at building things or at math. Also explain that many children with autism have difficulty making friends and communicating with other people.

Don’t make everything about autism.

It’s important to emphasize that your son’s autism-related strengths and challenges are just part of who he is and why you love him. Be sure to point out some of those special qualities that have nothing to do with his autism. This will help your child understand that autism is something that he has, not the sum total of who he is.

Assure your child of support.

Explain to your son why he’s receiving the services he’s getting. For instance, you could tell him that he sees a speech therapist to help him communicate more clearly, or that he’s seeing a behavioral therapist to improve how he makes friends. Help him understand how you, his therapists and his teachers all want to help him. You can point out that we all need some help to become the best we can be. Some children need extra help learning to read. Some get very sad and need help in that department, etc.

Expect to repeat these conversations!

All children – and especially those with autism – need to hear some information multiple times. This doesn’t mean he doesn’t understand what you’ve told him. Rather, revisiting these topics can be an important part of his processing the information.

Find role models and peers.

It’s important for children with autism to spend time with typically developing peers. However, for children your son’s age and older, it can be a wonderful experience to spend time with other children on the autism spectrum. Consider enrolling your son in a play group or social skills group specifically for children with autism.

15 Tips for Your Family

As a result of her work with many families who deal so gracefully with the challenges of autism, family therapist Kathryn Smerling, Ph.D., offers five tips for parents, five for siblings and five for extended family members:

5 tips for parents

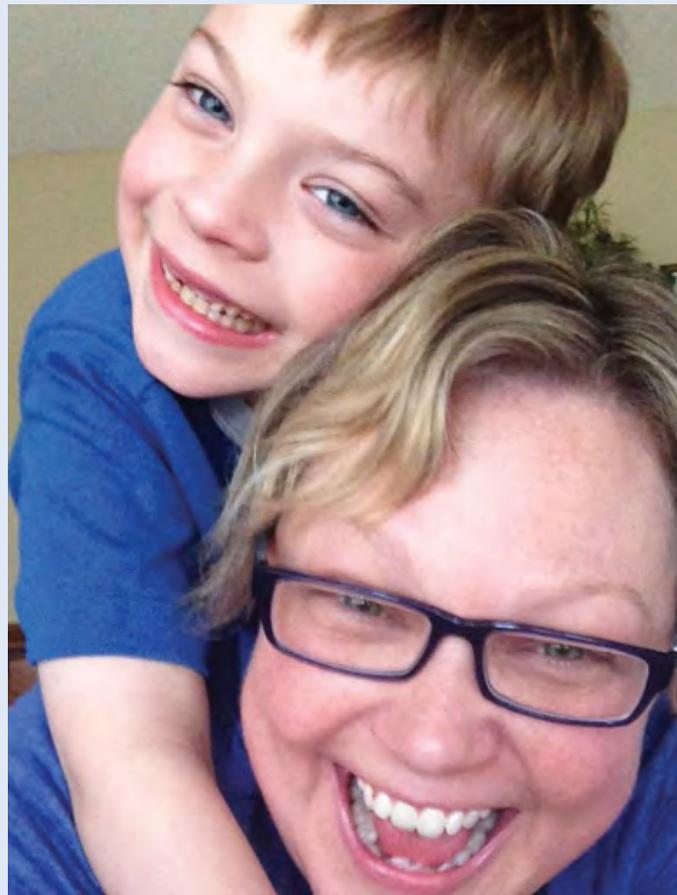
1. *Learn to be the best advocate you can be for your child. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.*

2. *Don't push your feelings away. Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's okay to feel conflicting emotions.*

3. *Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry. Try to have some semblance of an adult life. Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse and refrain from constantly talking about autism. Everyone in your family needs support and to be happy despite the circumstances.*

4. *Appreciate the small victories your child may achieve. Love your child and take great pride in each small accomplishment. Focus on what he or she can do instead of making comparisons with a typically developing child. Love your child for who he or she is.*

5. *Get involved with the autism community. Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything*



yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

"Learning more about my child's unique needs and abilities along with reaching out for support has enabled my husband and me to be better parents to our son and better partners for each other on this journey."

5 tips for brothers and sisters

1. Remember that you are not alone! Every family is confronted with life's challenges... and yes, autism is challenging...but, if you look closely, nearly everyone has something difficult to face in their families.

2. Be proud of your brother or sister. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic...they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister and sometimes you may not like him or her. It's okay to feel your feelings. And often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way he or she is!

3. While it is okay to be sad that you have a brother or sister affected by autism, it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.

4. Spend time with your parents alone. Doing things together as a family with and without your brother or sister strengthens your family bond. It's okay for you to want alone time. Having a family member with autism can often be very time-consuming and attention-grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.



“At first I felt lost and confused about my brother but now that my parents have helped to explain things to me, I can be a better big brother and help my

5. Find an activity you can do with your brother or sister. You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired he or she may be, doing something together creates a closeness. Your brother or sister will look forward to these shared activities and greet you with a special smile.

5 tips for grandparents and extended family members

1. Family members have a lot to offer. Each family member is able to offer the things he or she learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner or raising money for the special school that helps the child. Organize a lunch, a theatre benefit, a carnival or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.

2. Seek out your own support. If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support, so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face. Be open and honest about the disorder. The more you talk about the matter, the better you will feel. Your friends and family can become your support system...but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on, it will be easier. In the end, your experience with autism will end up teaching you and your family profound life lessons.

3. Put judgment aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options and are typically coming to well thought out conclusions. Try not to compare children. (This goes for typically developing kids as well.) Children with autism can be brought up to achieve their personal best.

4. Learn more about autism. It affects people of all social and economic statuses. There is promising research, with many possibilities for the future. Share that sense of hope with your family, while educating yourself about the best ways to help manage this disorder.



5. Carve out special time for each child. You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different, but all of the children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for 15 minutes. If you go to the same park every week, chances are over time that activity will become easier and easier...it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate the effort that you are making.

There are also specialized tool kits for specific people in your life. To access them visit: autismspeaks.org/family-services/tool-kits/family-support-tool-kits.

“Talking to other grandparents helped me to feel part of a bigger community and to learn more about my granddaughter. I am now able to help my family the best I can and spend quality time with each of my grandchildren.”