



A Friend's Guide to Autism

Autism Speaks Family Support Tool Kit



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This tool kit is specifically designed for friends of families affected by autism. Thank you for taking the time to look for information and resources to help support your friend and their child affected by autism.

This tool kit will serve as a guide to help you learn:

- More about autism
- How your friend may be feeling if this is a new diagnosis
- Supporting your friend
- How you and your family can interact with and support the child with autism



In this kit, the umbrella term “Autism” refers to the Pervasive Developmental Disorders, also known as Autism Spectrum Disorders, including Autism, PDD, PDD-NOS, and Asperger Syndrome.

For simplicity, we have also used the generic pronoun “she” when referring to a friend.

ABOUT AUTISM

What Is Autism?

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders.

People with autism have symptoms or difficulty in three areas:

1. Social interaction
2. Language as used for social communication
3. Repetitive interests or behaviors.

How common is Autism?

Today, it is estimated that one in every 88 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is not established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 54 boys is diagnosed with autism.

What causes autism?

The simple answer is we don't know. The vast majority of cases of autism are idiopathic, which means the cause is unknown.

The more complex answer is that just as there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when combined with exposure to as yet undetermined environmental factors. Timing of exposure during the child's development (before, during, or after birth) may also play a role in the development or final presentation of the disorder.

What does autism look like?

While all children with autism have problems in three main areas, appearance and severity of symptoms is different in each child. No two children with autism are exactly alike.

These are what the core symptoms might look like:

<p>SOCIAL</p>	<ul style="list-style-type: none"> • Less eye contact, use of gestures or facial expression • Difficulty understanding the emotions and feelings of others • Difficulty playing with same age children • Problems making and keeping friends • Less sharing of interests with others.
<p>COMMUNICATION</p>	<ul style="list-style-type: none"> • Lack of speech • Slow to learn speech • Unusual speech (repeats things, speech sounds unusual) • Difficulty making conversation • Less imitation and pretend play
<p>REPETITIVE BEHAVIOR</p>	<ul style="list-style-type: none"> • Repeating activities or movements (rocks, spins, flaps hands, flicks fingers) • Uncommon, strong, limited interests (often talks about the same topic or plays with same item, knows a great amount of information on topic) • Plays with parts of toy rather than the toy as a whole (i.e. spins wheels of toy car)

Source: National Institute of Mental Health (NIMH). For more information on autism visit: www.nimh.nih.gov

IT'S IMPORTANT TO REMEMBER - "IF YOU'VE MET ONE PERSON WITH AUTISM - YOU'VE MET ONE PERSON WITH AUTISM."

STEPHEN SHORE, Ed.D

HOW YOUR FRIEND MAY BE FEELING IF THIS IS A NEW DIAGNOSIS

Learning that your child has been diagnosed with autism is a powerful moment in one's life. The joy from the birth of a child and the hope for his or her future is all of the sudden confronted by many unknowns. Your friend may experience a range of emotions that includes:

Shock: *"I can't remember how I drove home after hearing the diagnosis for the first time." "How can this be happening to my child?"*

Sadness or Grief: *"I have no energy; I can't do the things I normally do for my family. "I find myself crying a lot. "I feel overwhelmed by sadness."*

Anger: *"We didn't deserve this." I am so angry this is happening."*

Denial: *"He will grow out of this." "I can fix it." "The doctors are wrong."*

Loneliness: *"I have never felt so alone."*

Acceptance *"I feel we can get through this and be okay."*

It is important to know that your friend may be experiencing many of these feelings, and she may have different feelings about the diagnosis at different points in time. This is not something she can control. Her life will no longer be the way she thought it would be, so she may need some extra support and understanding during these different stages of emotions

THIS IS THE SAME FRIEND YOU HAD BEFORE HER CHILD'S DIAGNOSIS. SHE JUST HAS A DIFFERENT FOCUS FOR HER CHILD, AND SHE NEEDS FRIENDS TO SUPPORT HER AND NOT LET HER LOSE THE PERSON SHE WAS BEFORE THE DIAGNOSIS.

WHAT CAN YOU DO TO HELP DURING THIS TIME?

Let her know that you are there for her. You may want to ask how her child is doing and then let her take the lead. If she wants to talk about the diagnosis and her feelings, be a good listener. Some parents may not want to discuss the diagnosis (at least not yet), and for these friends it is important that you maintain your contact with them. Invite her to go for a walk or a cup of coffee. Try to keep the conversation away from your child's achievements and successes. At this particular time it may be difficult for your friend to share in your joy.

Ask your friend if there are any websites or books that she thinks would be helpful as you learn more about autism. She will appreciate that you are looking to support her and her child.

Do not share the diagnosis with others. Even with the best of intentions, each family is different when it comes to telling people about their child's diagnosis. They will tell people when they feel comfortable doing so.

Some families affected by autism have found that initially it was easier to maintain friendships through phone calls, texts or emails.

Offer to watch your friend's child with autism (if you are comfortable doing so), or to watch the typical siblings so your friend can get even a brief break from the chaos of her life.

Offer to help out with errands. Sometimes it can be hard to take a child with autism out on a variety of errands. If you're going to the grocery store or dry cleaner, perhaps you can find out if your friend needs anything.

Let your friend know that you can be her "go-to friend" if she needs someone to pick up or drive the typical sibling to activities or events, etc.



HOW CAN YOU SUPPORT YOUR FRIEND?



10 Things You Can do to Help a Family Affected by Autism

When a child is first diagnosed with autism, parents often scramble to find appropriate autism services, doctors, schools and therapists. What we don't always anticipate is that relationships with friends, family and neighbors often change. Some will stand by our side, doing what they can to help and embrace our child no matter the diagnosis. However, some people will either sit quietly on the sidelines or abandon the relationship altogether.

So what happens when you find out that your friend, family member or neighbor has a child who has been diagnosed with autism? How can you help your friend? How can you help their child? There are many ways you can assist a friend from talking to offering a playdate. Here are 10 things you can do to help a family whose child has been diagnosed with autism:

1. Being There

It sounds easy enough, but parents of children with autism need someone to listen and ask how they are doing. As a friend, you may not understand all the autism jargon, but moms and dads who have kids with autism often want to talk about their kids.

What can happen, however, is that the diagnosis of autism pushes us and our kids into isolation. It isn't like we want to be isolated, but we are sometimes so busy with autism related activities and therapy, it does not leave much time for anything else. Offering to come over for a cup of coffee or to get together just to talk can be one of the best ways to help your friend get out of his/her autism bubble and combat the isolation.

2. Discussing Autism

To talk about autism or to not to talk about autism?...That is the question. The answer is "It depends." Most parents who have kids on the spectrum are more than willing to talk about autism. But there are parents who do not want to disclose the diagnosis, talk about autism at all or how it affects their child. Some parents may be in denial about the diagnosis and will not even want to say the "A" word let alone discuss the topic.

So if you are a friend, what do you do? Let your friend bring up the topic of autism, and do ask how the child is doing. Even if a friend does not use the "A" word, he/she will appreciate you asking how their child is doing in general... without ever discussing autism. If your friend is open about the diagnosis, showing interest in their child and the topic of autism is certainly appropriate. Because we never take progress for granted, parents who have kids with special needs are proud of their children's smallest accomplishments. To know that friends care about our kids makes sharing these times all the more special.

3. What Does a Child With Autism Look Like?

Seems like a strange question. But I know that there have been times when a person has met my son and then makes a comment such as, "He doesn't seem like he has autism." or "He doesn't look like he has autism." The interesting thing is that there is no "look" to autism. Yes, some of our kids may have similar behavioral or social characteristics, but they are all very different. So this is why if someone tells me they have experience in autism, that doesn't mean they will know or understand my child.

If you do know, watch or teach another child with autism, it is best not to compare what you know to the child you are meeting. Also, I would refrain from telling your friend about how

**"OUR MOST DIFFICULT TASK AS A FRIEND IS TO OFFER UNDERSTANDING
WHEN WE DON'T UNDERSTAND." ROBERT BRAULT**

HOW CAN YOU AND YOUR FAMILY INTERACT WITH AND SUPPORT THE CHILD WITH AUTISM?

Your friend will appreciate that you want to interact and support her child with autism. Here are some suggestions:

Find out about the interests of the child with autism, and ask him or her about them. Children with autism will be more willing to interact to the best of their ability if you ask them about something that is important to them

For some families, it is easier if you go to their house. Some children with autism are more comfortable in their own homes. But do not assume that this is the case for all families. As we mentioned before, each person with autism is different. You may want to ask your friend what is best for her child and her family. Some families may want to be invited to your home. Spending time in a friend's home can combat some of the feelings of isolation. If this is the case, you may want to ask the family how can you make the visit most comfortable for the child with autism.

It's important that you provide your children with information about how to best interact with the child with autism. Keep in mind that not all families tell their child about their diagnosis. You may want provide your own children with tips and information regarding this. Please see the Resource Section for tips on how to be a friend to a child with autism.

The following is a list from Ellen Notbohm titled Ten Things that Every Child with Autism Wishes you Knew:

Here are ten things every child with autism wishes you knew:

I am first and foremost a child. I have autism. I am not primarily “autistic.” My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about. As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me: My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today’s special. Music whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload! My sense of smell may be highly sensitive. The fish at the meat counter isn’t quite fresh, the guy standing next to us hasn’t showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they’re mopping up pickles on aisle 3 with ammonia....I can’t sort it all out. I am dangerously nauseated. Because I am visually oriented (see more on this below), this may be my first sense to become over-stimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There’s glare from windows, too many items for me to be able to focus (I may compensate with “tunnel vision”), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can’t even tell where my body is in space.

Please remember to distinguish between won’t (I choose not to) and can’t (I am not able to). Receptive and expressive language and vocabulary can be major challenges for me. It isn’t that I don’t listen to instructions. It’s that I can’t understand you. When you call to me from across the room, this is what I hear: “*&^%\$#@, Billy. #\$\$%^*&^%\$&*.....” Instead, come speak directly to me in plain words: “Please put your book in your desk, Billy. It’s time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

I am a concrete thinker. This means I interpret language very literally. It’s very confusing for me when you say, “Hold your horses, cowboy!” when what you really mean is “Please stop

running.” Don’t tell me something is a “piece of cake” when there is no dessert in sight and what you really mean is “this will be easy for you to do.” When you say “Jamie really burned up the track,” I see a kid playing with matches. Please just tell me “Jamie ran very fast.” Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

Please be patient with my limited vocabulary. It’s hard for me to tell you what I need when I don’t know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong. Or, there’s a flip side to this: I may sound like a “little professor” or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called “echolalia.” I don’t necessarily understand the context or the terminology I’m using. I just know that it gets me off the hook for coming up with a reply.

Because language is so difficult for me, I am very visually oriented. Please show me how to do something rather than just tell me. And please be prepared to show me many times. Lots of consistent repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, and helps me manage my time and meet your expectations. I won’t lose the need for a visual schedule as I get older, but my “level of representation” may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

Please focus and build on what I can do rather than what I can’t do. Like any other human, I can’t learn in an environment where I’m constantly made to feel that I’m not good enough and that I need “fixing.” Trying anything new when I am almost sure to be met with criticism, however “constructive,” becomes something to be avoided. Look for my strengths and you will find them. There is more than one “right” way to do most things.

Please help me with social interactions. It may look like I don’t want to play with the other kids on the playground, but sometimes it’s just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I’m delighted to be included. I do best in structured play activities that have a clear beginning and end. I don’t know how to “read” facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it’s not that I think it’s funny. It’s that I don’t know the proper response. Teach me to say “Are you OK?”

Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums, or whatever you want to call them, are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log, noting times, settings, people, activities. A pattern may emerge. Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment. Parents, keep in

mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders, and gastrointestinal problems can all have profound effects on behavior.

Love me unconditionally. Banish thoughts like, “If he would just.....” and “Why can’t she.....” You did not fulfill every last expectation your parents had for you and you wouldn’t like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it. And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I’m not good at eye contact or conversation, but have you noticed that I don’t lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won’t be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh. They had autism too. The answer to Alzheimer’s, the enigma of extraterrestrial life -- what future achievements from today’s children with autism, children like me, lie ahead? All that I might become won’t happen without you as my foundation. Be my advocate, be my friend, and we’ll see just how far I can go.

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STORIES OF SUPPORT

So many friends, so many stories, but one friend in particular stands out, my friend Shani. My son Ryan is 10 years old and was diagnosed with PDD NOS when he was 6. Ryan is a brilliant boy with an amazingly sweet heart, which is evident for those who take the time to get to know him. That is what stands out about my friend Shani, she always takes time for Ryan. Regardless of the times he has ignored her, rebuffed her or yelled at her for getting the wrong type of pizza, for serving him orange juice with pulp or for not putting enough Goldfish crackers in his bowl, Shani “gets” Ryan because she tries. It is easy for people to overlook Ryan. When he fails to say hello, fails to acknowledge your presence, or just completely ignores your question, it is easy for people just to walk away or give up. Not Shani, she engages Ryan one way or another. She has never treated Ryan any differently than she would any other child. Sure, she may let him get away with his “bossy” tone of voice more so than the next kid, but she will not hesitate to say, “Ryan you have to ask me nicely if you want a snack”. She loves him and sets boundaries for him just like she would any other child visiting her home.

Shani’s love and patience for Ryan is not only evidenced to his mama bear who is so protective of him, but to Ryan himself. Ryan only allows a few people “in”, so while on vacation with Shani and her family, when I witnessed him lean his head on her shoulder, I knew she had cracked the Ryan code. There was no secret password, no special trick, no gifts or rewards, just her time, her patience and her sincerity, which kids like Ryan can pick up a lot more readily than one would assume of a child with ASD.

As for the gift of friendship to Mama bear, I can’t even recall the number of times I have picked up the phone in tears feeling like I have failed Ryan once again and she tells me how lucky he is to have me as his mother. Her compassion and understanding shines through for a friend who needs to be reassured that I’m doing my best, despite the many bumps along the way. Motherhood is so rewarding and fulfilling, but even the best of us have our ugly moments. Parenting a child with ASD seems to make the ugly moments more guilt filled. That is why each and every one of our friends is so important, but it is the friend who sees through the stubbornness, rigidity and quirkiness of my son to find a sweet, beautiful little boy that is so deserving of my acknowledgment today. Shani will never understand the depth of my gratitude, respect and love I have for all that she is to me, to Ryan and to the rest of my family.

Kathy, mom of Ryan

My name is Jessica and I have a beautiful, amazing, sweet, smart, perfect 2 year old son named Cashius who is autistic. I may not have a lot of support from my sons father due to his own issues. Or any family that lives close enough to help. I have been so blessed to have my best friend Jaymie for the last four years be my soul support! She has been by my side every step of the way from when I started inquiring to my sons doctors "shouldn't he be talking by now" or when my family said "oh he is a boy they are just late talkers". She was there telling me go with MY feelings. She takes my son to therapies and being involved in countless sessions teaching her own three kids how to work with him. Taking time off of work to go to an ABA conference to better her skills to help Cashius. She let's me have my own meltdowns and is always there to help me up after I'm done. She is always thinking of new ideas for Cashius' meals because of the GFCF diet. When I'm just getting the nuggets and waffles over and over she finds new and exciting things for Cashius to try. Last night we were talking about how the NFL is wearing pink and I said I think it's cool. She just shook her head and said it really pisses me off. And immediately I knew she was upset that autism doesn't have that much support and awareness as breast cancer. Lol... Only someone who truly loves someone on the spectrum can understand that feeling. Not only does she make me feel so lucky to have found someone who is so loving and supportive and just amazing. But the person who is the luckiest is Cashius to have her in his life!

Jessica, mom of Cashius

When my son Matthew was diagnosed with autism, we were lucky enough to get him many hours of the therapy that he needed. That meant a stream of therapists in and out of our home. Also, meant that my older son Danny needed to play quietly so that he didn't distract his brother. My good friend Ellen also has a son Danny's age, and they are good friends. Ellen stopped by to drop something off, just as I was explaining to Danny why he couldn't have a friend over while Matthew's therapists were here. Ellen called me later that night, and asked if Danny could have a standing play date at her house every Thursday while Matthew's therapists were here. I could have cried, I was so worried about Danny and my friend Ellen knew just what we needed!

Jeanine, mom of Matthew

RESOURCES

[Autism Speaks](#)

[How to be a Friend to Someone with Autism](#)

by Peter Faustino

[The Autism Acceptance Book](#)

by Ellen Sabin

For questions, please feel free to contact the Autism Speaks Autism Response Team at 888 – AUTISM2 or familyservices@autismspeaks.org.

Visit [Walk Now for Autism Speaks](#) to get involved in a walk in your area.