



A Friend's Guide to Autism

An Autism Speaks Family Support Tool Kit





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Introduction

A Friend's Guide to Autism is a tool for friends of families affected by autism. The guide will provide you with an overview of autism, information about feelings your friend might be experiencing, tips to help you support both the child and family, stories of support and more.

Autism Speaks is committed to increasing understanding and acceptance of people with autism and their families and it is friends like you who help fuel this mission. Thank you for taking the time to learn more about what your friend is going through and how you can support his or her family.

If you are looking for additional information, the ***Autism Speaks Autism Response Team*** is here to help connect you with resources to meet your unique needs. They can be reached at

888-288-4762
(en Español 888-772-9050) or
FamilyServices@AutismSpeaks.org.

You can also find many more tool kits and resources at AutismSpeaks.org.

What is Autism?

Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication. We now know that there is not one autism but many subtypes, and each person with autism can have unique strengths and challenges. Most forms are caused by a combination of genetic and environmental influences, and many are accompanied by medical issues such as GI disorders, seizures and sleep disturbances.



Some facts about autism

- *The Centers for Disease Control and Prevention (CDC) estimates autism's prevalence as 1 in 59 children in the United States. This includes 1 in 37 boys and 1 in 151 girls.*
- *An estimated 50,000 teens with autism become adults – and lose school-based autism services – each year.*
- *Around one third of people with autism remain nonverbal.*
- *Around one third of people with autism have an intellectual disability.*
- *Nearly 1/2 of children with autism wander or bolt from safety.*
- *For most, autism is a lifelong condition.*

Note: *In 2013, the American Psychiatric Association merged four previously distinct diagnoses into one umbrella diagnosis of autism spectrum disorder(ASD). These included autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.*

What Does Autism Look Like?

Autism affects the way an individual perceives the world. Autism spectrum disorders are characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas. Taken together, they may result in relatively mild challenges for some-one less impacted by autism. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interfere with everyday life.

- "IF YOU'VE MET ONE PERSON WITH AUTISM - YOU'VE MET ONE PERSON WITH AUTISM."

Stephen Shore, Ed.D.

POSSIBLE SIGNS OF AUTISM

in babies and toddlers:

By 6 months, no social smiles or other warm, joyful expressions directed at people

By 6 months, limited or no eye contact

By 9 months, no sharing of vocal sounds, smiles or other nonverbal communication

By 12 months, no babbling

By 12 months, no use of gestures to communicate (e.g. pointing, reaching, waving etc.)

By 12 months, no response to name when called

By 16 months, no words

By 24 months, no meaningful, two-word phrases

Any loss of any previously acquired speech, babbling or social skills

at any age:

Avoids eye contact and prefers to be alone

Struggles with understanding other people's feelings

Remains nonverbal or has delayed language development

Repeats words or phrases over and over (echolalia)

Gets upset by minor changes in routine or surroundings

Has highly restricted interests

Performs repetitive behaviors such as flapping, rocking or spinning

Has unusual and often intense reactions to sounds, smells, tastes, textures, lights and/or colors



How Your Friend Might Be Feeling

Learning that your child has been diagnosed with autism is a powerful moment in a parent'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 including:

Shock: *"How can this be happening to my child?"*

Sadness or Grief: *"I have no energy."
"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 following the autism diagnosis.

What Causes Autism?

One of the most common questions asked after a diagnosis of autism, is what caused the disorder. We know that there's no one cause of autism. Research suggests that autism develops from a combination of genetic and nongenetic, or environmental, influences. These influences appear to increase the risk that a child will develop autism. However, it's important to keep in mind that increased risk is not the same as cause. For example, some gene changes associated with autism can also be found in people who don't have the disorder. Similarly, not everyone exposed to an environmental risk factor for autism will develop the disorder. In fact, most will not.

Most genetic and nongenetic influences that give rise to autism appear to affect crucial aspects of early brain development. Some appear to affect how brain nerve cells, or neurons, communicate with each other. Others appear to affect how entire regions of the brain communicate with each other. Research continues to explore these differences with an eye to developing treatments and supports that can improve quality of life.

What To Do When Your Friend's Child is Diagnosed with Autism



*This post is by Katie Read, an autism mom (x2) and Marriage and Family Therapist in Arizona. She can tell you, from experience, that diagnosis is a hard time, but it **gets better**.*

Having received the diagnosis twice, I have compiled the best advice from my personal experiences and around the internet to help you help your friends through the early days (without putting your foot in your mouth!). I get it. It's awkward and uncomfortable and no one knows how to respond. Here are some basics to get you started...

DO: **Call your friend.** Ask her how she's feeling. Let her know that she can vent or cry to you. We are all afraid of being downers to other people. Knowing someone can handle the hard stuff means everything.

Bring over a cup of coffee. Or a casserole. Or a bottle of wine. Or fourteen Cadbury bars. I'll always remember the friend who came by with Starbucks when she heard. The little things really do count the most at these hard times.

Keep inviting your friend to all things you would normally do together. Storytime on Tuesdays? Invite her. Playdate after school? Invite her. Your friend will decide if an outing is too much—but the worst thing is for her to feel isolated or rejected by the lack of an invitation.

Treat her child the same way you always have. If this is your nephew and you have always had free reign to correct his behavior, keep it up! We want our kids to have as typical a life experience as possible, which means typical experiences with every day people. Unless or until your friend asks you to treat their child differently, just keep up business as usual.

If you can offer to babysit, do it. You cannot imagine the to-do list that was just dumped on your friend's lap. Diagnosis means endless phone calls to insurance companies, state services, school districts, early intervention, speech, PT, OT, endless coordination of appointments, reams and reams of paperwork, and a whole reorganization of life as she knows it. And all of this has to be done while she is feeling grief, fear, and confusion—and still parenting and working and cooking and cleaning and living life. Even if you can supervise the kiddos downstairs while your friend starts her list of phone calls upstairs, it will help. A lot.

Do know that your friend is genuinely mourning a loss. I know it's taboo to say that early diagnosis is a time of mourning, but honestly, it is. Imagine going from typical parent dreams—that our kids will be athletes, valedictorians, successful spouses and parents—to simply wondering if they will ever live on their own, hold down a job, or even speak. There is grief there. Treat your friend as you would any person going through a tough time.

What To Do When Your Friend's Child is Diagnosed with Autism

DO NOT:

Don't use a bunch of platitudes to try to make her feel better. "It'll be all right, it's all good, everything happens for a reason, you're the best person to handle all of this." These things don't make us feel better. They might make you feel better to say, but they make us shut down the actual expression of our feelings, our fears, and our intense new stress.

Don't say, "I'm sorry." Honestly, this doesn't bother me personally. When people say, "I'm sorry," I assume that they mean they are sorry because it must be stressful and scary and hard—which it is. However, I know that many, many autism parents hear this differently and find it very offensive. Not worth the risk.

Don't avoid your friend, assuming they want space. If you give someone space without first asking if they want space, they basically feel rejected and isolated. Everyone wants the choice of space. No one wants space forced upon them. Invite your friend out as you normally would, and do not take it personally if she can't participate for a while.

Don't stop bringing your child around the child with autism. Your child will not be stunted by hanging out with an autistic child. In fact, your child will definitely have autistic peers in school, so might as well start their education (and your own practice of inclusion) now.

Don't humble-brag/compare/complain about your neurotypical kids. "I'm sure he'll start talking. It's just like how we never thought Billy would win gold at State, but then he did!"

No. It's not.

Don't assume there is some huge, glowing autism community that has scooped up your friend and given her a fabulous social life. There isn't. This disorder is wildly isolating for families. Plus, even when we meet other autism parents, the spectrum is so huge and our experiences so different that it's still often hard to connect. The lucky ones will find a few great people along this road, but in the early days, we really need our long-time buddies.

Now call your friend and get to Starbucks and put on your listening ears. She will remember it forever. I promise.

“In your lifetime, you will probably know more people and families affected by autism. You can choose to be part of the solution by helping support a friend, family member or neighbor. Take the time to learn not just about autism, but the individual child. Make the decision to accept children with disabilities and teach your children how they can help children with autism by being a friend too. Making the choice to support a family affected by autism is one of the greatest gifts you can give. It is also very likely that your act of kindness may turn out to be one of the greatest gifts you receive back as well.”

*Kymerly Grosso, author, blogger, autism mom
www.psychologytoday.com/blog/autism-in-real-life*

Supporting the Child with Autism

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

Find out about the interests of the child, 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.

If she is comfortable sharing, ask your friend if there are certain triggers that may upset her child or lead to meltdowns.

Keep your language as simple and concrete as possible, as people with autism are often very literal. But be sure to understand the difference between receptive and expressive language. Many children and adults with autism who may not be able to speak are fully capable of understanding what you are saying.

Figure out where your friend and her family are most comfortable. For some families, it is easier if you go to their houses. Some children with autism are more comfortable in their own homes. Some families may want to visit your home. If this is the case, you may want to ask your friend how you can make the visit the most comfortable for her child.

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 his or her diagnosis. The *Autism Speaks School Community Tool Kit* has a helpful section to help peers of children with autism learn to interact with and support their friends.



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. 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. 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 son’s father or any member family who lives close enough to help, but I have been so blessed to have my best friend Jaymie for the last four years be my sole support. She has been by my side every step of the way from when I started inquiring to my son’s 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 his GFCF diet. 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 the many hours of the therapy that he needed. That meant a stream of therapists in and out of our home. Also, it 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

**Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.**

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

AUTISMSPEAKS.ORG/ART



Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

To learn more about Autism Speaks, please visit AutismSpeaks.org.