



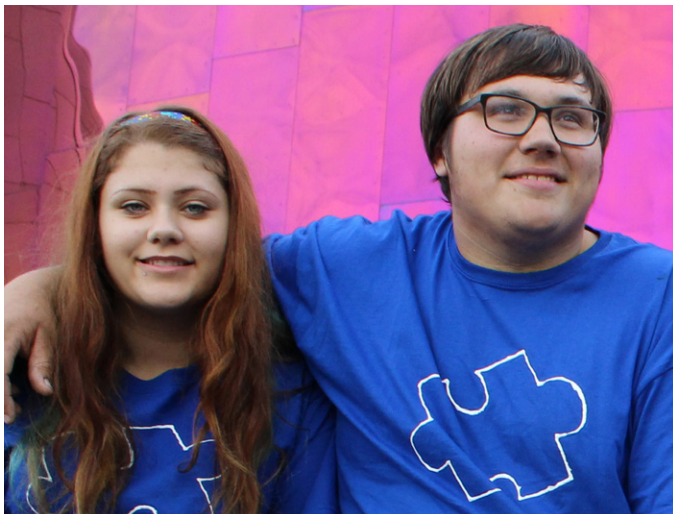
A Sibling's Guide to Autism

An Autism Speaks Family Support Tool Kit

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About Autism

Autism is something that affects the way a person's brain works. Most people with autism have a hard time communicating with others, and some might have unusual behaviors because their brain is wired differently from yours. People with autism also have many unique strengths and differences.

Even though there are many people with autism, each person with autism has very different challenges, special abilities and personalities. Some people with autism may require a lot of help, while others might not need very much at all. There are some who might not be able to talk at all, and others who might talk a lot.

Introduction

You are probably reading this guide because your brother or sister has been diagnosed with autism. You have come to the right place! You are likely experiencing lots of different feelings right now – you might be worried, scared, surprised, confused, sad or even mad. It is normal for you to have a mix of emotions because your life is now going to be a little different. This guide is for siblings like you to understand a little bit more about autism and learn what you can do to help your brother or sister and take care of yourself. You will also read some great stories from autism siblings just like you!

It is very important to remember that your brother or sister is just like any other boy or girl, except he or she has autism. Try to always keep in mind that he or she is still the same brother or sister you know and love, your family just has learned something new about him or her. Now that your brother or sister has been diagnosed, your family can start getting him or her the help he or she needs to address challenges he or she might face. This is a time for you and your family to learn as much as you can about autism. Your support is very important and will help your brother or sister to improve and be the best he or she can be!



What Does Autism Look Like?

Often people with autism have difficulties in three areas:

Talking or expressing their thoughts:

It can be hard for people with autism to say what they are thinking and to understand what other people are saying. Some kids with autism have unusual ways of learning, paying attention or showing different feelings. They can also become very upset when there is a change in their routine

Learning how to play with others:

People with autism may be easily frustrated in social situations, making it difficult to develop and maintain friendships. It is probably easy for you to play with your friends, but because it is sometimes hard for them to communicate, kids with autism can have a hard time playing with other kids. It doesn't mean they don't want to play – they just need a little help.

Unusual behaviors:

Some people with autism act or behave in ways that might seem a little strange to you. For example, they may suddenly make sounds and move their bodies in unexpected ways. They may make less eye contact and don't always like to be touched. You shouldn't be afraid of these behaviors – they are usually just ways that people with autism try to communicate their thoughts and feelings, since they can't always do that the way you can.

People with autism may have a hard time telling their parents or others what they want or need. They may seem like they are not listening or refusing to play with other kids. It is important for you and your family to understand your brother or sister's unique behaviors, so he or she feels accepted and supported.



Below are other behaviors people with autism may have:

Rocking back and forth

Making funny sounds

Making loud noises

Hitting or biting themselves or others

Running away from others

Playing with toys differently

Becoming fixated or obsessed with something ordinary in their environment



While your brother or sister may face some challenges like those listed above, many people with autism, including your brother or sister, also have unique strengths and abilities. Some of these include:

Expert knowledge on a particular favorite subject or skill in a favorite area

Strong memory skills

Excellent attention to detail

Strong ability to follow rules and routines

Very loyal to and honest with the people they love

Unique sense of humor

Non-judgmental of others

What Causes Autism?

The short answer is we do not know. Research shows that there are certain genes (which you inherited from your parents) and interactions with the environment that make a person more likely to have autism. Just as there are many different types of autism, there are also a variety of factors that contribute to the development of autism.

Researchers are working hard to figure out what causes autism so they can better identify what kinds of treatments will be the most helpful.

CELEBRATE YOURSELF!

Siblings of people with autism are more likely to:

- accept differences among people.*
- be a loyal friend and stick it out during good and bad times.*
- learn how to tolerate different situations better.*
- be more mature than other kids their age.*
- feel proud of their sibling with autism, especially when they see how hard they work to overcome a challenge.*

Can I Get Autism From My Sibling?

Autism is not contagious. You cannot catch autism like a cold or the flu. You don't have to worry about getting autism from your sibling or others you know who have autism.

How Many People in the World Have Autism?

We are not sure how many people in the world have autism. More countries are starting to document the number of people with autism more accurately. The United States has some of the best documentation.

A recent study found that 1 out of 59 people in the United States have autism, including 1 in 37 boys.

Learning About the Diagnosis

Learning that your brother or sister has autism can be a very difficult experience. You may have noticed behaviors that upset you and hearing the word "autism" might be confusing for you.

During this time, your life and that of your family may feel different than they were before this happened. You may be worried about how this will affect the future. Sometimes you may worry about how your family will cope.

At times, you will need to talk about how all of this makes you feel. So don't hesitate to seek out a family member, teacher or friend with whom you can be open and honest about your questions and feelings.



Some things you may be having trouble with:

Understanding why your brother or sister acts in what seems to you to be strange ways.

Feeling like your brother or sister gets more time and attention from your parents than you do.

Feeling embarrassed about your brother or sister's behaviors when you are with friends or out in the community, like at a store where other people may stare at you or react negatively.

Not knowing how to play with your brother and sister.

Some questions you may have:

Will I get to spend alone time with my mom or dad? Do they still care about me?

How much time do I have to play with my brother or sister? What can we do that he or she will like?

How can I explain my brother or sister's behavior to my friends?

Why doesn't my brother or sister have to do chores and other things around the house like I have to do?

It is important to know that you can ask your parents any of these questions. They won't be mad; they will be happy to see that you are interested in supporting your brother or sister.

How You Can Help

Your relationship with your brother or sister is very important. So it makes sense that you will want to spend time together and for you both to feel comfortable and safe when you are playing.

There may be times that your brother or sister does something abruptly or in an unusual way that can cause you to feel frustrated and upset. Ask your parents about activities that you and your brother or sister can do together. It may take a little time and a lot of patience to learn how to play with your brother or sister, but it will be worth it in the end. As you spend time with your sibling, it is likely you will get to know him or her better and you will start to appreciate the differences between the two of you.

Many siblings like you have said that it can be hard to get close to a sibling with autism. Sometimes your sibling's behaviors may make it seem like he or she is not interested, or you may have difficulty getting his or her attention.

Finding an activity you can do with your brother or sister will allow you to have fun and enjoy being together. See if he or she has a favorite game you might be able to play together. Your brother or sister is still your sibling, so it's important to have a good relationship. Together as a family, you can figure out ways to make sure everyone is happy 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.

How to Ask for Help

Sometimes kids who have a brother or sister with autism can feel lonely. A good way to deal with this feeling is to connect with others who can understand what you are going through. Talking to your family or to a good friend can help. There are also special support groups for young people like you where you can talk to other kids about what is like to have a brother or sister with autism. This type of support group is called a "peer support group." When young people participate in such a group, they often find new ways of dealing with situations and almost always feel less alone.

Having a family member with autism can often be time consuming for everyone in the family, and very often siblings feel that their brother or sister becomes the focus of everyone's attention. It is easy to feel like your parents have little time or energy left to focus on you.

Your parents and others you trust can help you work through some of the feelings you are having. Some common feelings are anger, resentment, sadness and frustration. Most likely, your reactions and feelings are perfectly normal and it does help to talk about them rather than to feel like you have to keep the feelings inside or to express them in ways that may not be very constructive.

Because you have a sibling with special needs who may take up a lot of time and energy from your parents, it is important to know about yourself and what is special about you. You need to feel important too.



Five Tips for Brothers and Sisters

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 siblings, that originally appeared in the Autism Speaks 100 Day Kit:

- 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.

- 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.

Five Things Siblings of Someone with Autism Want You to Know

*Being a sibling to someone with autism is a unique experience that can be difficult for other people to understand. In the essay below, Marissa Hacker, whose twin brother Matthew has autism, shares from her perspective what siblings like you may want other people to know. Marissa started **Fantastic Friends**, an organization that teaches people with autism the value of friendship, like Matthew. It might be helpful to write your own list, or share some of these with people in your life you think might want to learn more about what you are going through.*

This is what I want people to know about having a sibling who is on the autism spectrum...

1) My sibling is my best friend and knows EVERYTHING about me.

That's right, folks. You may not think they are listening, but OH BOY, are they listening! I was chatting with my mom the other day about how I felt emotional about certain things that I have been through. Supposedly, my brother was in the other room taking a nap. Right after these words left my lips, a very concerned Matthew dashed into our living room pouring out the words, "Marissa, why are you unstable and have you been unstable your whole life?" Yea, that's my brother for you! He knows everything and anything about me.

So next time you tell us something, you better believe that our siblings will know and find out (somehow) too!

2) Treat our siblings like you treat everyone else.

This is so extremely important! It doesn't matter if our siblings stim, rock back and forth, script from movies, etc.! That is just how they are. Accept it, y'all.

This is a sibling hot button. Please talk to our siblings just like you talk to us, and don't baby our siblings, either. If my brother wants to talk about Disney movies, heck, you better tell him your favorite Little Mermaid character. Go with it :)

3) We have our own identity.

"I LOVE and adore your brother. He is so cute and funny and amazing and smart and charming!" "I saw the picture of you and your brother on Facebook, you guys are SO CUTE!" "You're such an amazing sister! I bet your brother can't live without you."



Thank you, thank you, seriously everyone, thank you! You're compliments really do mean a lot to us and make us feel like the superhero siblings that we are destined to be. However, it is important to remember that siblings lead their own lives and have their own personal identity. As much as we adore our special needs brothers and sisters, we also like to just have "us" talk. Once in a while, talk to us about things we like, such as activities we are into, our favorite movies and of course, other fun things that make our world go round.

Make us feel like we have our own personal identity, in addition to having the "super sibling" identity.

4) Accept and understand my sibling, don't judge.

We all want our siblings to feel loved, accepted and included. As a sibling, it can be INCREDIBLY frustrating when people don't understand or don't try to understand how my sibling feels.

The quote is so true: "Don't judge unless you have walked a mile in his shoes." If our siblings are having a bad day, such as having a meltdown or acting unusually, please don't judge the person, their sibling or their parents for the behavior. Please people. You don't live with autism 24/7 and you see my sibling on a very limited basis. You have no clue how my sibling behaves in other settings. Plus, we all have bad days. Who am I to take a life analysis on you and your bad days?

So please don't judge, jump to conclusions or blame family members for behavior. We are here to celebrate all of our siblings and their incredible talents and uniqueness.

5) Siblings have a sharp "hurt" radar.

Since birth, I have always protected my brother. I am his big (well, older by 1 minute) twin sister and I will ALWAYS protect him. In school, people were mean to Matthew and used to make fun of him. When I would find out, I would ask him who did it, and the next day I would immediately confront them in a nice way.

Together we will always stand up for our special needs siblings and try to make the world more accepting and understanding place for them.



Words from Autism Siblings Like You

“When my parents came home from the doctor that day, they were silent, which was quite unusual for both of them. My sister was two years old at the time she was diagnosed, I was ten years old and my other brothers, five and six. I was the only one who could understand out of the four that something was not right. I was sat down, and given the news that my sister had something called autism. My initial response was to cry, I was an emotional child, but then I began to ask questions. What is autism? What does that mean for my sister? My parents had little information, as did most people over a decade ago, so I took to the internet and began to research what this was. I found an organization that supported those with autism and began my launch into becoming an ambassador in my community for autism. I learned and researched all that I could possibly learn about the spectrum at that age. Following my time and research, I wanted to help. I approached my elementary school teacher and asked that if I were to create a puzzle piece ribbon pin, could I sell them along with gum and candy to fundraise for a local autism awareness walk? I was nervous that the answer would be no, and that my hopes of helping my sister would be destroyed. However, not only was I able to go ahead with my fundraiser, I was put in charge of leading an assembly and going to some of the classrooms to teach the other students about what I learned about autism! I was so shocked and nervous and grateful all at the same time. Through the fundraiser and walk and other random donations, I was able to raise over \$500 for autism as a fourth grade student. It was quite the experience.”

Austin

“When I was little, the doctors said my brother Pat would never speak. I wondered if my brother would ever be able to talk to me and tell me how he felt and why he cried and screamed. I wondered why we couldn't leave the house without tears, even to go to the grocery store or why my mom was tying his shoes at ten years old. I didn't understand why he didn't respond when we screamed 'Patrick!' over and over the day my mom asked me to watch him for two minutes and he wandered away. I wondered how many other six-year-olds had lost their brother before and if they understood the guilt.

Then he proved everyone wrong and he spoke. I wondered if he would ever be able to tie his shoes, and when he learned how to tie his shoes, I wondered if he would ever be able to ride a bike. Pat now rides his bike all over the place all by himself. He volunteers at homeless shelters, the library and the hospital. He has made strides that could inspire anyone on their darkest days.

While there are a lot of things I don't know, I do know that there is nothing Pat can't do...He will face challenges we will never face but he can do anything. And if he lives with me for the rest of my life, I will be the luckiest big sister in the whole world to have every day blessed by the honesty, innocence and joy that someone with autism brings.”

Natalie

“My younger brother Derek is the best thing that ever happened to me. He showed me how to appreciate the little things, to have an open heart and open mind, and above all, he allowed me to be the best person I could be. Through him, I can see the world differently, and can never let that go. Throughout the years I've struggled with feelings of guilt, and an unwillingness to let go of the things outside my control. Why couldn't it be harder for me and easier for him? Why can't I make it better, why can't I make it fair? While I know these feelings won't go away completely, I know that I'm a better person because of this amazing kid, and we are better because of each other. Despite the hardships he continually overcomes, he is truly the happiest person I know.”

Kristyn

“My brother Tyler was diagnosed with ASD when he was five. Like many older siblings, especially early on, I didn’t understand why my brother behaved differently. I didn’t understand why he hated crowds, would scream and yell at the drop of a hat, and didn’t act like my friends’ little brothers; and my treatment of him showed it. But, after 16 years of living with Tyler and nearly 10 years working and volunteering as a counselor and mentor to other children with ASD, the most important thing I’ve discovered is this: Tyler has done more for me and for this family than we could ever hope to do for him. Understanding Tyler took a long time. It took a lot of effort and self-inventory on my part and even today, I make mistakes. But this process has given me an inner strength, a quiet dignity and commitment to responsibility that I would not have found without him. He taught me the true meaning of compassion, to take peace and solace in the little gifts bestowed upon us each and every day. The man I am today, I owe to Tyler.”

Zak



**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

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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.