



A Sibling's Guide to Autism

Autism Speaks Family Support Tool Kit



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OTHER GUIDES IN THE AUTISM SPEAKS FAMILY SUPPORT TOOL KITS SERIES:

A Parent's Guide to Autism

A Grandparent's Guide to Autism

A Friend's Guide to Autism

THANK YOU TO THE MEMBERS OF THE COMMUNITY WHO REVIEWED THIS TOOL KIT AND SHARED RESOURCES FOR THIS PROJECT:

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Dear Parents:

A Sibling's Guide to Autism was created for siblings who have a brother or sister diagnosed with autism.

We know that some parents of children with autism can be under tremendous stress and it may seem like there is never enough time to do everything that needs to be done.

We hope this guide will be helpful in opening a dialogue with your other children as they are adjusting to life with a sibling on the autism spectrum. The intention is to create an opportunity for siblings to focus on their feelings, reactions to their sibling's diagnosis and get information about autism.

If you feel your other child is having an unusually difficult time adjusting to their sibling with autism, please do not hesitate to consult a professional. Finding a professional that you can talk and share your concerns with will help you achieve a positive outcome for your family.

Sincerely,
Family Services
Autism Speaks

***Highlights for Parents:**

The guide has been designed for children ages 6-12, the information can be adapted as needed to other age and education levels.

The guide is written in an interactive format so parents and siblings can set aside some quiet time to read the guide together.

Please remember there are no right or wrong answers to questions in this guide. It's important to be a good listener, and acknowledge your child's feelings.

We welcome any feedback or suggestions for improvement. Please email us at: familysupportkits@autismspeaks.org

LEARN ABOUT AUTISM

What is Autism

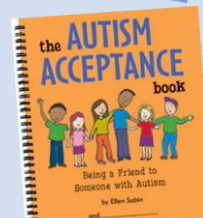
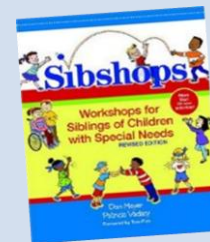
Autism is a complex brain disorder that affects the way a person's brain works. It is one of a group of disorders called "Autism Spectrum Disorder," also referred to as "ASD." A spectrum disorder can include many symptoms.

Even though there are many people with autism, each person is very different in terms of his or her challenges, abilities, and personality. Some people with autism may require a lot of help, while others need less assistance at home, school, and in the community.

Often people with autism have difficulties in three areas:

- **Talking or expressing their thoughts**
It can be hard for a person with autism to express their thoughts and to understand what others are saying. They can also find it difficult to use language and some people with autism may not be able to talk at all. Some kids with autism have unusual ways of learning, paying attention, or reacting to different feelings.
- **Learning how to play with others**
People with autism may be easily frustrated in social situations, making it difficult to develop and maintain friendships. They have a harder time learning how to play and interact with others.

Children's Books on autism and sibling relationships and other resources are available at [Autism Speaks Resource Library](#)



- **Unusual Behavior**

Some people with autism act or behave in unusual ways. 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.

People with autism may also have some strong abilities. Each person is different so the abilities are unique to that person, but they may include:

- A favorite subject that they know a lot about
- May be really good at art, music or math
- Can be very loyal and honest
- Can have a really good memory
- May have the ability to take things apart or put things back together quickly
- Can be really good at puzzles
- Works hard to learn new things

Just as you have some things that are hard for you and some things that are easier, so does your brother or sister with autism.

It is important for you and your family to understand your brother or sister's unique challenges and special abilities, so he or she feels accepted and supported.

QUESTIONS ABOUT AUTISM

What causes autism?

No one is certain what causes autism, but it's likely that there are many contributors such as your genes you inherited from your parents, and interactions with the environment. Just as there are many different types of autism, there are also a variety of factors that contribute to the development of the disorder.

Researchers are working hard to figure out what causes autism so they can better identify what kinds of therapies are most effective in treating it.



Can I get autism from my sibling?

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

How many people have autism in the world?

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 information. A recent study found that 1 out of 88 people in the United States have autism. For some reason, boys seem to have autism more often than girls. The rate of autism in boys is 1 in 54 and for girls it is 1 in 252.



YOUR BROTHER OR SISTER HAS AUTISM

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.

It's okay to have feelings about having a brother or sister with autism, but it doesn't help to keep those feelings to yourself. Remember your mom and dad may be having similar feelings, and it's important to share with them what's going on with you.

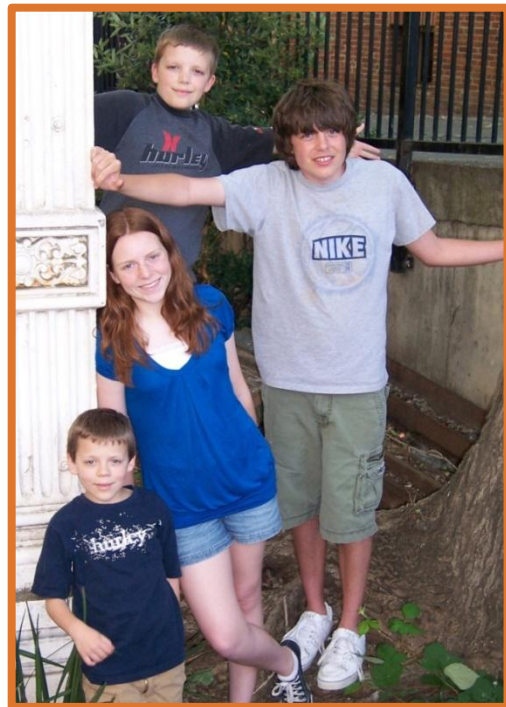
It is very important to remember that your brother or sister is just like any other child, except he or she has autism. This is a time for you and your family to learn as much as you can about autism. Your support is very important and will help your brother or sister to improve and be the best he or she can be.

At times, you will need to talk about

how all of this affects you. 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 and 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? 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?

Since your sibling was diagnosed with autism what's different for you?

1. _____
2. _____
3. _____
4. _____

Do you have questions that no one has been able to answer yet?

1. _____
2. _____
3. _____
4. _____

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 suddenly 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 is important for you to know the best ways to interact with your sibling.

Things to ask your parents about before you start to play with your brother or sister:

1. _____
2. _____
3. _____

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.

Celebrate Yourself!

Siblings of people with autism are more likely:

To accept differences among people.

To be a loyal friend and stick it out during good and bad times.

To learn how to tolerate different situations, and be smarter and more mature than other kids their age.

To feel proud for their sibling with autism, especially when they see how hard they work to overcome a challenge.

Finding an activity you can do with your brother or sister will allow you to have fun and enjoy each other's company.

Some activities you may enjoy doing with your brother or sister:

1. Playing a board game or working on a puzzle.
2. Playing an interactive video game.
3. Playing a physical game, like tag or jumping on a trampoline.

What activities can you and your sibling do together?

1. _____
2. _____
3. _____

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!



YOU ARE NOT ALONE – 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 it 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 cause family conflicts.

Sibshops-The Sibling Support Group is a sibling support groups that can help sibling friendships and relate to other peers who have a sibling with autism. To find a local sibshop in your community visit: www.siblingsupport.org

Sibshop offers moderated listserv for Siblings and Parents:

Sibkid listserv
www.siblingsupport.org/connect/index.html

Sibparent listserv
www.siblingsupport.org/connect/sibparent-a-listserv-just-for-parents



Feelings I may need help with:

1. _____
2. _____
3. _____

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.

What is special about you?

1. _____
2. _____
3. _____

What special activities do you most enjoy?

1. _____
2. _____
3. _____

RESOURCES

The Autism Acceptance Book: Being a Friend to Someone With Autism
By Ellen Sabin

My Brother Charlie
By Holly Robinson Peete and Ryan Elizabeth Peete

The Other Kid – an interactive workbook available In English and Spanish
By Lorraine Donlon
www.theotherkid.com

Siblings: The Autism Spectrum through our eyes
By Jane Johnson and Anne Van Rensselaer

Sibshops: Workshops for Siblings of Children with Special Needs
By Donald J. Meyer and Patricia F. Vadasy

Sometimes My Brother: Helping Kids Understand Autism Through a Sibling's Eyes
By Angie Healy



SIBLING'S STORIES

My younger brother, Hunter, was diagnosed with autism when he was 3 years old. Since then it seems that our family has grown so accustomed to how he reacts to certain situations that it's hard to think back to when my family was first starting to cope with his autism. Today, my brother is 19; he lives in his own home with support services.

I will never forget the struggles and added stress our family would go through in order to slip Hunter through some "close to normal" niche like attending the movies on a Saturday night or eating dinner in a family restaurant. Sometimes these excursions would go without a major incident, but all too often they would not. This, however, would never dampen the flame of my mother's love and willingness to help her sons to the best of her ability.

Yes, there are many difficult things about having a member of a family diagnosed with autism, but I will say, it has brought me many different perspectives of how a family can work through hard times and still be a family. I also learned many things about myself, watching my brother get all the attention wasn't easy for me. I still struggle with ways to get my fair share of attention in our family!

I love my brother for who he is, and it will remain that way for as long as I can keep it. My heart goes out to the families involved with autism, may you find a way to be thankful and enjoy your family.

-Sean, brother of a young man with autism

The right word to explain how I feel about my brother is bittersweet. I feel both happy and sad to have an autistic brother.

Sometimes it makes me feel happy, because I learn how to take care of a special needs child and what some people have to deal with. I think that because I have an autistic brother, it's easier for me to deal with people who are different. Another good thing about Austin's autism is that it means that I fight with him a lot less than I probably would if he weren't autistic.

Sometimes I feel really mad, because it seems my brother is always messing things up for me. I feel so mad about my brother sometimes that I just wish he weren't autistic. That's why I'm creating this charity. That way, I can help other people and myself with their autistic brothers or sisters.

Sometimes it's really tough for me to deal with Austin. He doesn't listen to me, hurts me, embarrasses me in front of other people, ruins things that I'm working on, and just frustrates me. For example, last year we went to a July Fourth party at my dad's friend's house – and Austin jumped in the pool with all his clothes on! He laughed so hard! Everyone was staring at him.

I also feel kind of proud, because I know my brother better than anyone else does. I am so close to him. When it's his birthday, I can get him something I know he will like, because I know him so well. My mom and my dad know a lot about my brother, but probably not as much as I do. So you can understand how I feel proud.

-Julia, sister to a brother with autism



ABOUT AUTISM SPEAKS

Autism Speaks is the world's largest autism science and advocacy organization. Since its inception in 2005, Autism Speaks has made enormous strides, committing over \$160 million to research and developing innovative new resources for families. The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. In addition to funding research, Autism Speaks has created resources and programs including the Autism Speaks Autism Treatment Network, Autism Speaks Autism Genetic Resource Exchange and several other scientific and clinical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2, which Autism Speaks celebrates through its Light It Up Blue initiative. Also, Autism Speaks' award-winning "Learn the Signs" campaign with the Ad Council has received over \$272 million in donated media. Autism Speaks' family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit and a community grant program. Autism Speaks has played a critical role in securing federal legislation to advance the government's response to autism, and has successfully advocated for insurance reform to cover behavioral treatments in 27 states thus far, with bills pending in an additional 12 states. Each year *Walk Now for Autism Speaks* events are held in more than 80 cities across North America. To learn more about Autism Speaks, please visit www.autismspeaks.org.

ABOUT THE CO-FOUNDERS

Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Senior Advisor at Lee Equity Partners and Chairman and CEO of the Palm Beach Civic Association. He served as Vice Chairman of General Electric; and as the Chief Executive Officer of NBC and NBC Universal for more than twenty years. He also serves on the boards of the Polo Ralph Lauren Corporation, Mission Product, LLC, EMI Group Global Ltd and the New York Presbyterian Hospital. Suzanne Wright is a Trustee Emeritus of Sarah Lawrence College, her alma mater. Suzanne has received numerous awards, the Women of Distinction Award from Palm Beach Atlantic University, the CHILD Magazine Children's Champions Award, Luella Bennack Volunteer Award, Spirit of Achievement award by the Albert Einstein College of Medicine's National Women's Division and The Women of Vision Award from the Weizmann Institute of Science. In 2008, the Wrights were named to the Time 100 Heroes and Pioneers category, a list of the most influential people in the world, for their commitment to global autism advocacy. They have also received the first ever Double Helix Award for Corporate Leadership, the NYU Child Advocacy Award, the Castle Connolly National Health Leadership Award and the American Ireland Fund Humanitarian Award. In the past couple of years the Wrights have received honorary doctorate degrees from St. John's University, St. Joseph's University and UMass Medical School – they delivered respective commencement addresses at the first two of these schools. The Wrights are the first married couple to be bestowed such an honor in St. John's history.