



ORGANIZATION FOR
AUTISM RESEARCH

Life as an autism sibling:

**a guide
for teens**



When your brother or sister has autism, you have a different kind of sibling relationship. While it can be enjoyable and rewarding, you may also experience challenges and feelings that are tough to deal with.


Two young adult siblings created this resource after connecting with dozens of teens about the ups and downs of growing up with a brother or sister with autism. The advice provided in this

guide is based on their questions, concerns, and insight. The tips and stories featured are written by teens who have kindly shared their very real experiences.

You might find that you can relate to some of what's written. What's most important to remember is that there are others out there who understand what it's like to be in your shoes.

Explaining autism

I'm worried about people meeting my brother and asking me questions about his "weird" behaviors. How do I explain them in a way that people can actually understand?

 Our friends, classmates, or strangers probably won't have very much experience with autism, and might not know how to react to someone who has it. You can help people feel more comfortable around your brother or sister by explaining a little about autism.

People that ask about your sibling will probably want an explanation of his or her particular behaviors; it's what they're going to notice first. Does he rock back and forth when a room becomes too noisy? Does she repeat movie quotes because it makes her happy? You will probably understand your sibling's behaviors better than most – so tell people what you know.

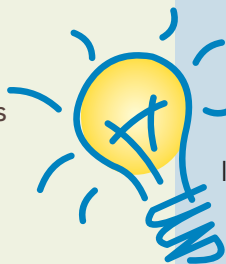
Not everyone realizes that autism is different from one person to another. Depending on what they've learned before, they might think all people with autism are "really good at math," or "never like to be touched." While these may be true in some cases, try letting them know that each person with autism has unique strengths and challenges.

Keep explanations of your sibling's autism short and sweet. Some people may also ask questions that seem rude or way too personal; remember that you don't have to tell anyone anything that makes you feel uncomfortable.

Autism basics: help friends understand autism by breaking it down for them. Some things you could mention are:

- ✓ The full clinical term is Autism Spectrum Disorder (ASD). ASD affects a person's brain development, which leads to a number of challenges in areas such as: behavior, communication, and forming social relationships.
- ✓ "Spectrum" describes the range of abilities and difficulties someone with autism has. It helps account for all the different types of autism out there.
- ✓ There are more than 2 million people diagnosed with autism in the U.S. alone. (Autism Speaks, 2014 – <http://bit.ly/OARSibs22>).

People with autism express how they're feeling in a different way. This might be something worth mentioning to others. You could describe how your sibling communicates his or her feelings by explaining why he or she sometimes behaves in an "unusual" way. Maybe you have a brother who starts flapping his hands and laughing when you're about to take a car ride. This would suggest that hand-flapping is the way he shows excitement.



Dealing with a different "normal"

When I see friends messing around with their brothers and sisters, it makes me realize that I'll never have those kinds of moments with my sibling. It hurts to know that nothing is ever going to be normal.

You and your sibling with autism might not have a typical relationship. It's not unusual to feel a sense of loss, particularly when you see your friends doing things with their brothers and sisters. Sometimes you may feel like you're the only one without that normal sibling experience, and wish your brother or sister didn't have autism. You're not the only one who feels this way.

The relationship you have with your sibling can still be enjoyable, and it will get stronger if you show signs that you care about your brother or sister. For example, if your sibling has achieved something, give them a high-five or tell them what a great job they've done. If your sibling is really into something (like films or the weather), try expressing some interest and having a conversation about it. Your brother or sister may not be able to respond in the same way that your friends' siblings do, but your gesture will be appreciated.

Additionally, consider common interests you share with your sibling and put them into action. Even if you can't think of examples right away, there are likely to be some. Maybe you both enjoy the same kind of music, so you two can spend time together listening to your favorite singers or bands. It might also be good to do something with your sibling that he or she really enjoys. Perhaps going for walks is one of their favorite things - why not offer to accompany him or her on one? These sorts of activities might not be the kind your friends enjoy with their siblings, but that doesn't mean they're not just as worthwhile.



Try finding things both you and your sibling like to do together.

This may seem tough if you're really into sports when your sibling is really into animals, but common ground might be closer than you think. Maybe going to a local forest or nature reserve to check out wildlife would satisfy your need to be active, AND your brother or sister's desire to be amongst animals. Get creative - you might be surprised at what you can come up with.

Remember: If you ever feel guilty for having more opportunities than your sibling, keep in mind that **you should enjoy your life, too.** Even though your sibling may not be able to do all the same things as you, it doesn't mean that they can't be happy.

We asked teens:

How do you and your sibling maintain a good relationship?

"We get along best when we're talking about our parents. We don't have any other siblings, and really connect on the fact that we're the only two people in the world who know what it's like to have our parents as parents... it's those times that make me feel like she and I are close and no one else could ever understand our relationship!"

Parents, time, and expectations

I feel like my parents barely notice me because they're so busy with my sibling. It's not like I want constant attention, but I wish they'd try keeping up with what's important to me.

Your sibling with autism can demand a lot of your parents' time and attention. As a result, you may have more responsibility and independence, which can be great. Sometimes, however, you might just want a bit of recognition. It can hurt if your parents don't seem to notice when you've achieved something important to you, such as being selected for a role in the school play or making a sports team.

Your parents might be busy with your sibling, but they still want to know how you're doing. Find a good time to approach them and talk about how you're feeling, even if it may be tough to do. You'll almost always feel better for it afterwards, and your parents might surprise you with how much they actually do notice.

If there's a special event you want your parents to attend, try talking to them about it in advance. It will give them extra time to plan. This is also good to do if you just want to spend some time alone with one of them. If you really want to go prom dress shopping with your mom, pick a time with her to do so. If you want to go to a ballgame with your dad, find a good weekend and suggest it to him.

Talking to parents about how you're feeling can be tough.

Here are some tips that might help you get through some of those discussions:



- 1 Know what you're going to say.** Having a plan keeps you from getting sidetracked during a discussion. It helps to write it out on paper, even if you're the only one who's going to read it.
- 2 Think about the outcomes.** Try to imagine what your parents might say back to you. That way, you can be ready to answer questions and respond to their feelings, too.
- 3 Remain calm.** It's easy for emotional discussions to get a little heated. If everyone keeps a level head, it will be easier to say what needs to be said.
- 4 Be honest.** If you can be straightforward about how you feel, you're going to get more out of a discussion. Be clear, and then listen to what your parents have to say. You'll understand each other better and be able to come up with a solution.

We asked teens:

How would you talk to your parents about issues you're having with your sibling?

"My suggestions are to take a few deep breaths... think about what you are going to say and how you are going to say it. Try not to be mean about your sibling."

"Make time to talk with your parents. Explain that there is something on your mind or that you have questions, and then set a time to spend focused solely on the conversation – no TV on, no Facebook, no dish washing, etc."

"Keep the conversation real, but keep it positive. Try not to blame your parents."

When you need some space

Sometimes your brother or sister with autism can stress you out. It's important that you have strategies when times start to get difficult; see the box on the left for examples. It's also worth ensuring that you've established your "stress-free" personal space; the box on the right suggests ways on how to do so.



Whether you're dealing with tension at home or simply mad at your brother or sister, **having a go-to plan when times get tough might make things easier for you.** Try these strategies:

- ✓ **Talk to a friend.** If possible, try meeting at their house or a public place.
- ✓ **Connect with other teens** that have siblings with disabilities. They probably understand what you're going through better than most. Check out the resource box on the last page for information on where to find other siblings like yourself.
- ✓ **Take a break.** Get lost in something you enjoy, like music or writing, even if it's just for 15 minutes.
- ✓ **Exercise.** Being active can be a great outlet for frustration and leaves you feeling calm. Run, work out, play basketball... whatever helps you de-stress.



It can be frustrating when your sibling messes with your stuff, gets into your room without permission, or breaks something you own. Don't assume your brother or sister knows that they're out of line. Instead, **establish your boundaries** by:

- ✓ **Being clear.** Tell your sibling very clearly which spaces and things are yours. Don't assume they already know.
- ✓ **Repeating yourself.** You may need to explain boundaries several times to get your sibling to understand what you mean. Calmly explain it as many times as necessary, without shouting or getting angry.
- ✓ **Going on the defensive.** If your sibling is still overstepping boundaries, talk to your parents. Maybe you can install a lock on your door, or find a safe place for things you don't want accessible to your sibling.

A Sib's Perspective:

"When I was a kid, I thought my parents loved my older brother more than me. They made every effort to try and accommodate him. If I didn't want to eat what was being served for dinner, my parents would tell me to finish my food. When my brother didn't want something, they would cook up a whole new meal for him. When I was struggling in school, my parents would question my work ethic. When my brother was struggling, my parents would blame his school. My parents told me about my brother's autism when I turned eight years old, and they also signed me up for a support group specifically for siblings of people with developmental disabilities. It was a place where I felt like I could talk to people about how I was feeling, and they would understand (from experience) where I was coming from. With time, things got easier for me, and my experience with my brother has made me a more understanding and compassionate person."

Meltdowns

It feels like whenever my family and I are out in public, my brother will have a full-blown meltdown. People always stare so I get really embarrassed, but I also worry about how angry he gets. What can I do about this?

Meltdowns can have many possible triggers, but they usually occur when people with autism are really frustrated. To relieve that stress, they might do things that look like the temper tantrums you associate with young children. However, when you see someone older behaving in that kind of way, it's a whole different story. Some family trips may get cut short because your brother or sister becomes overwhelmed and can't handle a particular situation. You might have to avoid other activities altogether. Most siblings can't help feeling embarrassed or frustrated when outings don't go the way that they should.

These challenges and feelings may be hard to come to terms with, but instead of focusing on negative experiences, try picturing times when things have gone right. Maybe your sibling likes going to see musicals or taking trips to theme parks. A small number of bad experiences tend to stick out, but you likely have had some great times together. And there are many more to come!

If you want to help make outings go more smoothly, try discussing a game plan with your parents. Maybe you can make sure your sibling's environment is safe if he or she has a meltdown, or reassure onlookers that your sibling's behavior is just their way of expressing frustration.

We asked teens:

How do you cope when your sibling embarrasses you?

"My brother embarrasses me whenever he comes with my mom to drop me off or pick me up at camps, parties or other places he's never been before. I deal with them by just walking away and trying to forget the mean looks he gets from people."

"Whenever my brother has a meltdown, or even just does something unusual, I think about how I'd feel if I saw someone's brother doing that. It helps me realize that people aren't staring to be mean; most are genuinely concerned about whether your sibling's okay. That's nothing to be embarrassed about."

5 ways to deal with embarrassment:

- **Remember that everyone gets embarrassed.** Most people's siblings embarrass them, whether they have autism or not. You are not alone in feeling this way.
- **Surround yourself with good people.** Real friends will make you feel better, rather than embarrassed about your sibling – even during meltdowns.
- **Take a different perspective.** Most embarrassing incidents with your sibling won't seem as bad a week later. Even in the heat of the moment, ask yourself if it's really that big of a deal.
- **Make it a funny story.** Some autism-related stories your family tells may have once been embarrassing incidents. Over time, however, you'll learn to smile about them.
- **Let it go.** Embarrassing moments are temporary; your sibling is not. They might behave a little strangely, but they're still your sibling, so hold your head high.



A note about meltdowns...

Some people with autism can act out aggressively when they are in pain or bothered. It's just because they have difficulty expressing themselves. However, that doesn't mean it's acceptable for them to hurt you, another family member, or make anyone feel unsafe. If you're worried about your sibling's behavior, talk to your parents or an adult you trust - especially if the behaviors are becoming uncontrollable.

Looking ahead

I'm about to finish high school, which has made me start thinking about the future. I won't be around as much anymore, which might be really hard for my sibling. But it also makes me wonder: what about when my parents can't take care of her anymore? What is my role going to be? I want to help out as much as I can, but there are things I want to do on my own, too.

Finishing high school marks a step into adulthood, and can spark thoughts about your future - including how your sibling with autism will fit into it. In the short term, you may worry about how he or she is going to react to you not being around as much and vice versa. In the long term, many siblings find themselves torn between wanting to care for their brother or sister with autism when their parents become unable to, and wanting more independence in the future.

Want some more advice on planning for the future?

There are sites that help adult siblings of people with disabilities work through tough issues. One example is: <http://bit.ly/OARSibs20>

Other autism resources to check out:

- 1 SibTeen.** A Facebook group just for teenagers who have siblings with disabilities to talk, swap stories, and exchange advice.
Link: <http://bit.ly/OARSibs21>
- 2 Sibshops for teens.** A support group that offers fun and relaxing breaks for siblings of kids with disabilities. Check if there's one in your area:
Link: <http://bit.ly/OARSibs18>
- 3 Organization for Autism Research (OAR).** Have more questions about autism? Check out OAR's site for autism information and other helpful resources.
Link: <http://bit.ly/OARSibs23>

If you're thinking about moving away from home (to travel, attend college, start a new job, etc.), you may want to make keeping in touch with your sibling part of your routine. A phone call or video chat every so often is likely to help your sibling (and you) adjust to the change, making the distance between the two of you easier to deal with.

When thinking about your future role in your brother or sister's life, there are a lot of things for everyone in your family to consider. Every situation is different, partly depending on whether your sibling will live independently or require some form of lifelong support. More importantly, it's a case of how much responsibility you would like to take on for your brother or sister. Many teenagers that want to break away from their families feel guilty for not being more involved. However, it is essential to acknowledge that your life is your own; you don't have to be responsible for your sibling, and no one should expect you to be.

It's important to have an honest conversation with your parents about the future if you're feeling worried, even though it may be hard. Together, you can create a plan, whether it involves you or other support services, so everyone feels comfortable with what to expect in the years to come.

Remember:

Being a sibling of someone that has autism isn't always easy. Sometimes you'll face challenges that take a lot of effort to overcome. One of the best things you can do is **give yourself some credit**. You're not in an easy situation, but you're doing a great job. Take a deep breath, and make sure you've got someone to talk to when things get rough.



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