

## Supporting Siblings: Tips for Parents and Caregivers

Sibling relationships are often complex and multifaceted, and this is especially so when autism spectrum disorder (ASD) is involved. In addition to joyful typical sibling interaction, at young ages, siblings of those with ASD may experience a range of challenges before they've developed the skills to understand or cope with those challenges. Often siblings will go on to develop increased tolerance for differences as well as higher levels of empathy and altruism based on their experience. At the same time, due to the complexity, unpredictability, and specialized needs associated with autism, siblings may be at greater risk of poor psychological adjustment. As siblings transition to adulthood, they may be asked to take on the decision-making, oversight, and financial responsibility of caregiving.



Individuals with a diagnosis of ASD may present with a wide range of strengths, challenges, and co-occurring conditions. In addition, siblings may also present with their own individual strengths and needs, and the family's culture and values are also important to consider. In other words, supporting siblings is not a prescriptive or a "one size fits all" approach. The following is a list of suggestions, tips, and considerations, yet it is important to emphasize that these recommendations are not exhaustive or applicable for each unique family structure.

### *Supporting siblings throughout childhood:*

1. **Provide language to describe what ASD is.** Your child may be questioned by peers, family members, and others in the community about ASD. Provide them with accurate and appropriate terms or scripts to be able to answer questions or respond to misinformation.
2. **Introduce information about ASD at a developmentally appropriate level.** With younger children, the conversation may begin with discussing how brains all work differently and understanding individual strengths and weaknesses. Be sure to communicate that we don't know what causes autism and that no one can "catch it" from another person. With an older child, the conversation may begin with a discussion around the symptoms of ASD and understanding how those symptoms impact day to day life.
3. **Discussion of ASD should be ongoing.** Remind your child they can come to you at any time with questions, concerns, or for reassurance. Help them label the emotions they may be experiencing without judgement. Some days they may experience negative emotions and/or thoughts about their sibling with ASD and that is ok. Allowing for an open, accepting conversation reduces feelings of shame they may experience if they have negative thoughts about their sibling.

4. **Praise them for sharing their feelings and acknowledge understanding of what they are feeling.** Encourage them to discuss how they may be feeling and recognize those feelings could change by the day, the hour, or the moment. It is common for siblings to experience intense emotions at times, ranging from sympathy to guilt or anger. Normalize and validate feelings, recognizing no feelings are wrong. However, your non-ASD child may need help learning ways to cope with negative emotions when they do come up.
5. **Have direct conversations about needs and fairness.** Siblings may have a difficult time understanding why the family member with ASD receives so much more attention, care, time, etc. Whenever possible, try to foster a culture of fairness. However, in many families with ASD, needs will be drastically uneven, and equality may be difficult to achieve in the day to day. If it feels comfortable and appropriate to do so, a conversation about the difference between equity and equality may be helpful as it relates to specific accommodations in your family. Nevertheless, an open, developmentally appropriate conversation about your intentions and actions as a parent will be more beneficial than allowing your child to come up with their own narrative. Simply reminding your child (out loud and often) that they are loved and cared about will go a long way.
6. **Carve out dedicated “special time” as consistently as possible.** Make a point of having “special time” when your non-ASD child can receive one-on-one attention. This can be difficult as there are only so many hours in the day, but even 10-20 minutes reading together, playing a game, or cooking a meal together can communicate to the sibling that they are also a priority and an important part of the family. This doesn’t have to be a special outing or a long duration of time. Fewer, high-quality interactions will pack a bigger punch than more frequent/longer interactions that may be more distracted or stressful. Try to structure these special times into the day or week so they occur as consistently as possible.
7. **Foster inclusive activities.** Find ways to encourage your children to connect with one another, whether that be through a game that can be played at home or in a more structured, deliberate way, such as a club or group in the community. Your non-ASD child will likely be your child with autism’s biggest advocate and role model. And your child with autism may give your non-ASD child a tremendous amount of meaning and sense of empathy. In a lot of cases, the relationship between your children can be very “typical.” It is important to not make quick assumptions about preferences or accessibility.
8. **Recognize not everything has to be done as a family.** It’s ok not to do activities together all the time. Verbally acknowledge to your child what your rationale is when making these types of decisions, reminding them that it is important to be reasonable with expectations and to set everyone up for success. Validate your child’s feelings if they express that something feels unfair and create an actionable and realistic plan, together.
9. **Invite input from the sibling when planning special occasions.** If your non-ASD child is old enough to do so, include them in the planning of holidays, trips, and other special

occasions. These events may look different than those of their peers, and thus, different from their perceived expectations. Proactively and collaboratively problem solving through challenges can be helpful logistically and can help to make the sibling feel that their input matters.

10. **If applicable, make sure that sibling safety is always supported and prioritized.** If your child with autism can become aggressive or engage in unsafe behavior, it is important to take steps to ensure your non-ASD child's safety and to explicitly teach them how to engage and respond safely.
11. **Acknowledge your limits as a parent and the benefits of a third-party.** If sibling dynamics and needs are feeling particularly challenging, it may be beneficial to seek professional help. This may be in the form of individual or group therapy, a support group, family therapy, or another specialized service available in your community.

*Some notes on supporting and preparing older adolescent and adult siblings:*

1. **Start to involve the adolescent/adult sibling in the autistic individual's care.** This may mean bringing your non-ASD child to medical appointments, day program visits, therapies, evaluations, inviting them to observe meal planning activities, etc. This will build familiarity with what may be involved as a guardian/support and will assist in decision-making down the road.
2. **Talk about what may be expected from them later in life and invite feedback.** Speak directly to your non-ASD child about what level of support their sibling may need from them and what that may look like. Invite some time for reflection and then a follow-up conversation eliciting feedback may be helpful.
3. **Plan early and thoroughly.** If some level of support transfer may be needed in adulthood from the parental figure to the non-ASD sibling, plan as early and as comprehensively as possible.
4. **Connect with other same-aged families.** It may be helpful to engage with other aging caregivers and their adult children to learn about what may be working, what isn't, and what their experience has taught them.
5. **Seek out professional assistance.** Whether it be for guardianship guidance, financial planning, housing, etc. there are medical, psychological, educational, legal, financial, and community-based experts (and government agencies) that may be available to help. The Lurie Center for Autism offers [several workshops for aging caregivers](#) that may be helpful.



**Resources:**

**Books:**

- *All About My Brother* by Sarah Peralta
- *Autism: Living with My Brother Tiger* by Linda Lee, Forward by Dr. Margaret Bauman
- *Autism through a Sister's Eyes* by Eve B Band
- *The Boy Who Went Away* by Eli Gottlieb
- *It Isn't Fair! Siblings of Children with Disabilities* by Stanley D. Klein & Maxwell J. Schleifer
- *Billy's Sister: Life When Your Sibling has a Disability* by Jessica Leving, Ian Robertson, & Wiem Sfar

***For teen/adult siblings:***

- *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities* by Don Meyer & Emily Holl

**Additional Resources:**

- [Organization of Autism Research \(OAR\) - Sibling Support Guides](#) (including a parent guide, a teen guide, and a colorful workbook for elementary-aged children:
- Boston Medical Center's online [Sibling Resource Packet](#) which includes a short story for younger siblings (5-8 yrs old), an interactive comic for tweens/teens (10-14 yrs old), and young adult Q&A discussion and stories/blogs (15-18 yrs old)

**Groups & Organizations:**

- [The Sibling Leadership Network](#)
- [The Sibling Support Project](#)
- [Siblings with a Mission](#)
- [The ARC](#)
- [The Sibling Transformation Project](#)
- [The Center for Siblings](#)

## About the Authors



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