

## **BROTHERS AND SISTERS: COPING WITH SIBLING ISSUES**

**We have other children besides our son with an ASD. How do we explain the diagnosis to them so that they can accept their brother's condition?**

If there are siblings in the family, they need to be told about their brother's or sister's ASDs in an appropriate way. Don't be afraid to tell them, but also keep in mind that they may be overwhelmed. Often parents don't give siblings information about ASDs because they're trying to protect them. But this kind of thinking can backfire, and siblings can become frustrated, impatient, and nonaccepting of their brother or sister who cannot play with them, seems to ignore them, or throws horrific tantrums. Also, if siblings are not told the truth about ASDs, they tend to develop their own misconceptions. One child believed that he caused his brother's condition because he secretly hated him when he was born. Another child was afraid to be in the same room with his sister because he thought her condition was contagious, and he might catch it. One little boy kept trying to force a baseball cap onto his brother's head "to keep his brains from falling out any more."

How do you talk to siblings about ASDs?

First of all, be aware of your own feelings about the disorder; you're a role model for your children, and they'll be sensitive to your reactions. Are you

feeling upset or angry or having trouble accepting the diagnosis? If so, this may be reflected in the way that you talk to your other children, either in your tone of voice, your mannerisms, or in the words that you use to explain the differences of your child with an ASD. If you are still struggling to sort out your own feelings, keep negative feelings in check when you tell siblings about ASDs. Your overall goal is to encourage a bonding relationship among siblings. With that in mind, explain your child's ASD in a way that is compassionate and clear. Siblings may not know how they are supposed to feel when they hear the news of a brother or sister's diagnosis and are likely to follow your lead. Help your children feel comfortable with the diagnosis.

When explaining an ASD to siblings, make sure to take into account their age and comprehension level. Because a two- or three-year-old sibling will not understand the phrase *autism spectrum disorder* or even the word *autism*, it's not necessary that you offer an explanation. But he or she can be taught how to play with a brother or sister in ways that won't cause unnecessary upset. For example, a two-year-old can learn to clap her hands rather than pull her brother's hair to get his attention and learn to roll a ball to her brother to interact with him. In fact, siblings of any age can learn appropriate ways to act and interact with a brother or sister with an ASD.

A four-year-old sibling is likely to ask many "why" questions when you explain that a brother or sister has an ASD. "Why can't my brother speak?" "Why won't he play?" "Why does he flap his hands?" Simple answers are required here. "Your brother hasn't learned how to speak or play," or "He flaps his hands when he feels upset." Make sure the sibling understands that certain inappropriate behaviors are unintentional. "I know you're upset that your brother knocked over your tower of blocks. He didn't mean it." Then help the sibling rebuild the tower.

With siblings who are five to seven years old, you can use appropriate, simple terms to explain ASDs. In *Siblings of Children with Autism: A Guide for Families*, Sandra Harris and Beth Glasberg describe a creative solution for explaining ASDs to this age group. You can create a book with your child and illustrate it with photos. In their example, seven-year-old Joe wrote a book about his brother Jack, who has an ASD.

Joe and Jack are brothers. Joe likes to play, but Jack doesn't know how to play. Jack has autism. That makes Joe sad because he wants to play ball with Jack. Mommy says maybe Jack can learn to play with Joe. Dad will teach Jack how to play ball with Joe. This is a true story. The End.<sup>1</sup>

You can also read some of the wonderful children's books on ASDs that are available for this age group. Because children this age may not be ready to tell you how they are feeling, you can initiate conversations about emotional situations. For example, a sibling may be fearful when your child with an ASD throws a tantrum. You can reassure the sibling by saying, "It's okay to be afraid, but I will protect you and keep you safe."

Siblings ages eight to twelve can understand that ASDs are a problem in the brain, and that's why their brother or sister can't play, talk, or relate to them. You can model the behaviors that you want them to emulate when dealing with their siblings with ASDs. Siblings will look to their parents to see how they should react in situations that make them feel helpless or as if they have no control. For example, if the child with an ASD throws a block at a sibling, should the sibling yell at him? Demonstrate to the sibling that yelling is not the best solution and that a stern "No" is what may be required. Then explain that the behavior was not intentional and explore any feelings the sibling may have. Always let siblings know that they can come to you for help. It's crucial that children know their parents will support and protect them. At this age, they may have to field questions from their peers about ASDs. Therefore, let them know that they can come to you with any questions. Siblings this age should be encouraged to not only show compassion toward their brother or sister, but also to pursue their own interests outside of the home.

If the siblings are teenagers, you can explain ASDs in more detail and how it affects their brother or sister on different levels—socially and behaviorally. But remember that even if they understand the disorder on an intellectual level, they'll still need your support in dealing with feelings surrounding the diagnosis. Don't be discouraged if your once loving and attentive child has morphed into a teen who ignores his brother with an ASD and acts aloof, preferring to hang out with his friends. This is a typical developmental stage during which peer pressure may take precedence over family matters. Encourage your teen's independence, but at the same time, discourage a total rejection of the child with an ASD. Offer your teen coping strategies. If another teen makes fun of the fact that he has a brother with an ASD, teach him how to respond so that he can maintain his self-esteem. "My brother has an ASD—that's why he can't talk. But he's a computer whiz. You wouldn't believe what he can do." On some days, teens may feel embarrassed by a sibling with an ASD, especially when there are public displays of inappropriate behaviors, such as flapping or grunting at the mall. On other days, teens may feel pride in taking responsibil-

ity for their sibling with an ASD. Whatever feelings emerge, it's important for you to acknowledge and discuss them. Don't let an embarrassed teen feel ashamed about feelings of guilt or anger. Acknowledge these feelings and come up with ways to deal with them. Sharing your own feelings can also encourage your child to communicate and feel less alone.

Although parents may feel anxious about sharing the diagnosis of ASDs with siblings of any age, ironically, children and teens can often be much more accepting of the diagnosis than adults simply because they don't have any preconceived notions or biases about ASDs. By taking the mystery out of ASDs, siblings have the potential to be understanding, accepting, and supportive of their brothers or sisters with ASDs—and of all people with disabilities.

Here's what one mother says about explaining her son's diagnosis of an ASD to his brother.

I am the mother of a child on the autistic spectrum—a beautiful, funny, and mysterious eight-year-old named Max. When asked by friends or by other parents to try to explain what autism is, I often think about the way I try to describe Max's disorder to his younger brother, Tyler. I tell them, "When a person is autistic, it means that something in their brain is different than in other people's." To Tyler, age five, I explain that his brother Max's brain works differently from ours, so that it's hard for him to communicate what he's thinking or feeling. "That's why Max doesn't really want to play with other kids—except you—because he has his own very special ways of doing things, and it upsets him when they get disrupted."

Then Tyler points out: "But mom, Max taught himself Italian on the computer and is the smartest boy in his class—so how can he be autistic?"

I try my best to explain to Tyler that while every person is different in his or her own way, a person with autism has a uniquely different way of seeing and experiencing the world. Of course, I can't even begin to explain to him why Max is completely fascinated by the letters of the alphabet, or why he loves to count the numbers hidden on lampposts (numbers that most people never even notice), or why he needs to play the same song over and over and over again, or why Max knows the capital of every state or could read by the time he was barely eighteen months old, or how he achieves prodigious feats of memory that we now take for granted.

Tyler already knows I don't have those answers. Yet, even at five, Tyler already instinctively puts out his hand to make sure his older brother doesn't run across the street and grabs onto Max's shirt at the museum so he won't sprint off or get lost. He feels the need to look out for Max any way he can. He's even taken to making wishes in wishing wells for him.

Tyler's reaching out to his brother is just one of the ways that the mystery of autism has grabbed our family, the way it grabs all families it touches. To live with a child with autism is an often painful, but always inspiring journey that has forced us to hold together with love and commitment. It is a disorder that brings profound perspective and, yes, even a deep sense of joy. And that, perhaps, is the greatest mystery of all.

### **Our son's siblings know that he has an ASD, but we still haven't told our son that he has an ASD. Should we tell him?**

In the beginning while you're trying to sort out your own feelings about the diagnosis, it's not necessary for you to tell your child about her condition. In fact, in most cases, your child will be too young to understand.

How to explain ASDs to your child depends on your child's age and her level of understanding. Children with ASDs who have average or above average intellectual ability can be told about their conditions, but in a way that they can understand and with sensitivity to their feelings.

Telling your child about her ASD is a personal decision. If you do decide to talk to your child about it, do it earlier rather than later. It's better that your child hears about ASDs from you rather than from her siblings or from other family members or friends. School-age children with ASDs often begin to develop an awareness that they are different, and self-esteem issues can arise if you're not honest with them about their diagnosis.

Some parents report that telling their children about their conditions made it easier for them to accept themselves. Understanding the reason why they had trouble in certain situations, like paying attention in noisy classrooms or finding buddies on field trips, helped these children feel more empowered. Giving them a reason for their challenges actually enhanced their self-esteem.

If you don't feel comfortable telling your child that she has an ASD, that's okay, but you may want to explore the reasons for your decision. Is it because of your own discomfort with the diagnosis? Is it a desire to protect your child? If so, from what? Some parents seem to perpetuate the stigma of ASDs by not

telling their children. While parents may have good intentions in keeping the diagnosis a secret, they need to realize that other people will know, and there's nothing worse than a teenager finding out from someone else that she has an ASD.

Here's what some parents had to say.

We didn't have a formal conversation with our daughter to tell her she had autism. We just never hid it. We talked about autism around the house from when she was young so that she and her brother and sister would know about it. It was always a part of our lives, and we wanted them all to accept it and not to be ashamed. Why hide the truth?

Our son is pretty severely autistic, and I'm not sure if he would understand it even if we told him. I guess I like to fantasize about telling him. Just having that conversation would be great.

I'm an adult with Asperger's, and I have a son who has the same diagnosis. I wish my parents had told me about my diagnosis when I was younger, so I wouldn't have had to wonder why I felt so different from the other kids. I told my seven-year-old son recently, and he was okay with hearing it. I used some books to help me tell him.

### **I've explained my son's diagnosis of an ASD to his siblings, and his sisters are okay, but his brother is not. He used to be so well behaved, and now he's acting out. What can I do?**

Siblings who act out may be experiencing feelings of jealousy, resentment, or being left out because your child with an ASD requires more attention or receives special treatment. While there is no denying that your child with an ASD does require more attention, be careful about how you choose to deal with the sibling. Your typical son may tell you he's angry that you're not paying enough attention to him. Instead of giving into feelings of guilt and immediately jumping to the defensive, you can apologize, tell him how much you love and value him, and show empathy. "I'm sorry that I haven't spent as much time with you. You have every right to be angry with me. I'd feel the same way if I were in your shoes." Then ask questions and work together to figure out ways to reconnect and make him feel more special. Let him know you appreciate that he shared his feelings.

Sometimes, siblings may be acting out because they are afraid. You can come up with strategies for protecting a sibling from potentially hurtful situations—both emotional and physical—such as finding a hiding place for a child’s special treasures, so they will not be destroyed, building a tower in a private place, or removing a sibling from the room if the sibling with an ASD is having a physical and emotional outburst.

If you don’t encourage your children to express their feelings, their repressed feelings may manifest in other ways. Children may develop physical ailments, such as stomachaches or ulcers; emotional difficulties that result in depression; or behavioral problems, such as acting out in school. Also, siblings who may appear okay on the outside may not be okay on the inside. One mother had no idea how much her typical twelve-year-old daughter, a straight-A student, was affected by her brother having an ASD until she brought home C’s on her report card. Her daughter explained that she’d been struggling with her schoolwork but had felt guilty about asking her parents for help. Children will often hold in their feelings to protect their parents because they can see how difficult it is for the parents to support a child with an ASD. It’s important for you as a parent to let them know that you are there to protect them, not the reverse.

Siblings may also act out because they feel unduly burdened with the responsibility of being caretakers to their brothers or sisters with ASDs. Parents are often tempted to delegate caretaking responsibilities as soon as the sibling is old enough to take some of the pressure off them. Be careful. The child with an ASD is already demanding much of your attention, and siblings may have mounting resentment if they feel that they need to focus all their attention on their brother or sister as well. This can have a negative impact on the child’s development, as well as strain sibling relationships.

Responsibilities must be divided up in a fair way. Household chores can include the child with an ASD, who can help by setting the table or feeding the dog. A sibling should not be required to be a disciplinarian. With the exception of mild reprimands, it is the parents who are responsible for discipline. Siblings should not have to be full-time babysitters either, although some child care responsibilities are appropriate, in much the same way that an older sibling would take care of a younger typical sibling.

You can make a difference in encouraging and guiding sibling relationships. Research indicates that the majority of siblings learn to handle and adapt to the experience of growing up with siblings with ASDs without negative effects. In fact, they often feel more positive about themselves and their situations.

## **Sometimes our daughter's siblings feel embarrassed by her behaviors, like when she's stimming in public. What can I do to help?**

Sometimes siblings may feel uncomfortable or embarrassed when a child with an ASD stims in their presence in public. It's important to acknowledge their feelings of embarrassment and teach them strategies to deal with difficult behaviors, both on an emotional and practical level. Be a role model. Demonstrate how to express feelings appropriately. Show siblings what to say and what to do when their brothers or sisters with ASDs are engaged in self-stimulatory behaviors.

On a practical level, be aware of how you are behaving toward your child with an ASD when she is stimming. If you yell at her, you can bet that a sibling will do the same thing when the situation arises again. If you stress out, a sibling will probably react the same way. Also, your stress may further exacerbate the stimming behavior. You hold a tremendous amount of power. Make sure you are demonstrating appropriate behavior.

On an emotional level, you can model how to express feelings. It's okay for you to admit, "Your sister's behavior sometimes makes me feel anxious." In fact, it's healthy for siblings to know that you're human, too, and sharing your feelings can help relieve any guilt or shame they may have about their own reactions. It's important to teach siblings to differentiate between having feelings and acting on them. Siblings have every right to feel frustrated but do not have the right to act on their frustrations by yelling at or hitting the child with an ASD.

## **How do I help my daughter form a relationship with her brother with an ASD? She's tried to interact with him, but he's just not responding. I don't want her to give up, but I know she's discouraged. Is there anything I can do to help?**

Just as parents dream of what it would be like if their child didn't have an ASD, siblings dream of having a typical brother or sister. Siblings generally want to bond with their brothers or sisters with ASDs but may not know how. Don't let them become discouraged when their efforts to play are ignored. You can teach them simple interactive skills. Find out what games or exercises the child is doing in treatment sessions and teach the sibling how to play them. For example, a young sibling can be taught how to roll a ball to her brother, blow bubbles,

and help assemble a puzzle. An older sibling can be taught how to play games, as well as how to give praise (“Good job throwing the ball!”) and give simple instructions (“Go get your cup”).

Siblings can also be included in a child’s therapy session as peer models who demonstrate play skills or social skills. Being involved in this way can make them feel special and important. Some siblings feel jealous that their brothers or sisters with ASDs are getting all the attention by going to therapy and are therefore happy to take part in the process.

Teaching siblings how to interact with their siblings with ASDs can make a big difference; it encourages the bonding process as well as boosts their self-esteem. One study compared before and after videos of siblings interacting with brothers and sisters with ASDs. The after videos, where the siblings had been taught certain play skills, showed that they were generally happier and played with their brothers or sisters more often and for longer periods of time.

**I know it’s difficult for our daughter to handle having a brother with an ASD all the time. I realize that so much of my time is devoted to him. How can I show his siblings how much I love them?**

Your child with an ASD should be made to feel like a part of your family, not the center of it. No child, typical or with an ASD, benefits from *all* of his parents’ attention.

Parents need to spend special, individual time with each of their children. While you may find it difficult to cram one more thing into your already busy schedule, this is crucial for your other children’s development and self-esteem.

Carve out an evening or weekend day to focus on the sibling, rather than on your child with an ASD. Watch TV together, go to a movie, or play a game of cards. Just being together and sharing something between the two of you can go a long way in letting the child know how much you care.

Don’t feel compelled to do everything as a family. Sometimes, it’s okay to attend a sibling’s soccer game or dance recital without bringing your child with an ASD, who may not only have trouble sitting through these events but also take the focus away from his sibling.

## How can I maintain a sense of “normalcy” in our family for all of our children?

Here are a few simple tips.

- *Provide consistency.* Your child with an ASD and your other children need you to establish and stick to a routine—even if it’s a new routine as a result of your child’s diagnosis. Routines can provide comfort and a sense of normalcy for everyone.
- *Set realistic expectations for your children, your spouse, and yourself.* If you set goals that are beyond everyone’s reach, you set everyone up for failure. Rather than piling on more and more responsibilities, adjust priorities. For example, it may be more important that an older sister is helping her brother with an ASD have breakfast rather than keeping her room neat. You may also want to lessen her current load of responsibilities for a while if you sense that she is having a difficult time adjusting to her brother’s diagnosis.
- *Be patient and show compassion.* The diagnosis can be rough on everyone and, even though your own distress may cause you to feel impatient or short-tempered, it’s important that you don’t take your frustrations out on your children.
- *Demonstrate love and respect to all of your children.* Siblings can often feel left out and may need extra hugs and some special attention.
- *Focus on positives.* Minimize the focus on misbehaviors and comment on positive aspects of all your children.
- *Say thank you.* Thank your children for taking care of their brothers or sisters with ASDs and for making the necessary adjustments and accommodations in their own lives to help support their siblings with ASDs.

## SOME THOUGHTS FROM SIBLINGS

Here are some letters from the siblings of children with ASDs with whose families I consult. This first letter was written by an eleven-year-old boy about his five-year-old sister with an ASD.

We mostly include my younger sister in everything like going out to dinner and going to family stuff. But once we went to Florida for a long weekend without her. She stayed home with Grandma. I guess once in a while we go to the movies without her. I think that's normal. My friend Pete told me his sister doesn't always go with him when he goes out with his parents and his sister doesn't have autism.

The following is a joint letter from the brother and sister of an eleven-year-old boy with an ASD who recently went into a respite facility.

We kids have a little bit of trouble having an autistic sibling. The autistic child gets more attention than the others just because he needs more help. Our names are Diane and Scott, and we have an autistic brother that no longer lives with us. Scott and I were not doing as well as we could have in school when my brother was here. This was because our parents were always chasing after our brother in the neighbors' yards, getting him ready, cleaning up the food he threw on the floor, and a lot of other things. So we were never able to study. This gave us no time for what we had to do. For example, studying for tests, or playing games, or going somewhere. We love our brother very much and were sad he left, but it has also made him and my family happier. Now he gets to go swimming daily, and he's lost quite a few pounds, and he is with people his level and people like him. Now our parents are able to help us study for tests, play games, and also they can attend our sports games. Life is different here, but we still are a happy family, no matter how close or how far, we still love each other.

This letter was written by a seven-year-old girl about her nine-year-old brother.

Dear Santa,

Today I'm not writing about myself, I'm writing about someone else. I would like to ask you to please help my brother Michael. My brother has prob-

lems. He is autistic. He can't talk, so we can't understand him. When he wants something and we can't understand him, he starts to cry. If my family could hear him speak one word, it would be a miracle. If you do anything to help him speak, my family, friends and Michael would be very happy. So please, he needs your help. Thank you. And let him have a happy Christmas . . .

Sincerely yours,

Darcy

P.S. Merry Christmas . . .

Siblings deal with their own special issues surrounding ASDs, and it's important that their emotional needs are met so that they don't feel isolated. There are wonderful support groups that exist for siblings, both live and online. You can also be proactive by setting up a support group at your child's school. One mother spoke with the school psychologist who organized weekly meetings for siblings of children with special needs. It became a great way for her daughter to connect with other children who were dealing with similar issues so she could feel less alone. The school psychologist led the group in games and discussions. The group provided a safe space for the kids to vent their frustrations and talk about private issues that they didn't feel comfortable sharing with their parents. "It's like a private club," one sibling said. "It's been a great way to make new friends and talk to other kids who understand what I go through." You can contact your local ASA chapter for locations of sibling support groups near you in the United States or find your local international organization in Appendix E. You can also check Appendix F for online sibling support groups.

# **KEEPING IT PERSONAL: COPING WITH YOUR FRIENDS, YOUR MARRIAGE, AND YOUR SELF**

## **How do I maintain my friendships when my friends have typical children and my child has an ASD?**

The nature of your friendships may change after your child is diagnosed. Part of this is a result of time constraints. Much of your time is devoted to your child, with little left over to nurture friendships. Additionally, you may feel that your friends who have typical children really can't relate to your situation and that you can't relate to theirs.

After Jake was diagnosed, I had trouble trying to muster up feelings of joy upon hearing about a friend's daughter who sang in the school play or a friend's son who excelled at baseball, while my own son couldn't even speak let alone hold a baseball bat. I confided in my closest friends about how I was feeling, but even then I felt somewhat disconnected. They were compassionate and caring, yet I got the sense that they didn't really understand what I was going through. And so, I

pulled away. I kept isolated. I understood my feelings, even if no one else did, and so I rationalized that I could work out my feelings by myself. But my strategy didn't work out the way I planned. I sank into a depression. I became more anxious. It took me months to realize that this was not the best strategy, and it wasn't a realization that I came to on my own. I had friends who did not give up on me, who kept coming after me even after I rejected their efforts to help. And I had a really good therapist who encouraged me to maintain my friendships.

Through my consulting work with families of newly diagnosed children, I've been able to collect stories from other parents about how their friendships were affected.

We've maintained our friendships. My husband and I have always said that we wouldn't let our son's condition define us, so we actually don't purposely seek out other parents of autistic children. Initially, right after the diagnosis, I had a hard time being out with my friends. If they complained about their children, I resented that. How dare they complain about these trivial things their children were doing? Their children could speak, couldn't they? They had a perfectly normal life ahead of them, didn't they? I wanted to scream that out to them, but didn't want to come off as being self-righteous and indignant. This was an initial reaction, and it was based on hurt. I am so fortunate to have my best friend from when I was three years old as a support. I don't know what I'd do without her—we've been through a lot of tears together and I truly feel I'm not alone. I would have felt differently if I didn't have her.

It's amazing how many new friendships we've formed as a result of autism. It's like a whole new community. At first I found it difficult to share what we were going through with my old friends who had typical children, so we really relied on the friendships we made in the support groups. Now we're more comfortable speaking with and spending time with our friends who have typical children. It's like we have two sets of friends, and they're all special.

My friends were surprised about the diagnosis but have been my saving grace. They bring their kids over for play dates and give our son special attention.

My friends constantly remind me that typical kids do crazy stuff too. They tell me stories about how their kids have tantrums and have screaming fits in the mall. When my son bit his teacher once and I was nearly in tears, one of my friends told me about the time that her kid bit the teacher. I know it isn't exactly the same, but I love that my friends want to share their experiences with me, so I won't feel so bad. They support me as a parent and as a person, and they see my son for who he is—a kid with quirks who also has his strengths. One night my friends came to get me for a “reverse intervention.” They said I wasn't having fun anymore and so they took me to a bar where we sat and drank cosmos and laughed and cried. I don't know what I'd do without them.

Here's my advice. You don't have to maintain all of your friendships after your child is diagnosed, but you should maintain some, make new ones, or at least have one friend in whom you can confide. It's so important to your well-being. Parents often find that by virtue of being part of the community of ASDs, they make new friends. There are wonderful support groups available for parents of children with ASDs. In addition to providing emotional support, these new friends, having walked in your shoes, may offer valuable practical advice on treatments, resources, service providers, and conferences in your area.

### **My marriage was fine before our son was diagnosed, but now it seems to be under stress. All of our focus is on our son with an ASD. What can I do to keep my marriage together?**

An ASD has an impact on every aspect of a family's life, especially a marriage. An ASD can either be the glue that holds the couple together or the stress that pulls the marriage apart.

Marriage and childbirth are supposed to be happy moments in our lives, and we await the birth of a healthy child with great anticipation. When our child is diagnosed with an ASD, that happy picture gets shattered. Parents have said it feels as if their child has been kidnapped by an ASD in the middle of the night. The picture of the child is replaced with a picture of an ASD. The diagnosis of an ASD becomes the newest member of the family.

One of the causes of stress in marriages is the way parents react to the diagnosis. A grieving process may set in for one parent and not another. Highly charged emotions may be misunderstood or displaced onto one spouse, who

becomes the scapegoat. The search for information about and appropriate treatments for ASDs could be a bonding experience, but teamwork is thwarted when one parent is in denial or chooses to not participate while the other parent is forced to do all the work. This trend can snowball, and resentments can build. In many cases, it is reported that the mother puts all her energy into the child with an ASD, while the father distances himself through work, creating a divide in the relationship.

Even if both parents do accept their child's diagnosis, there can still be undue stress on the marriage. Parents often devote all their energy to helping their children with ASDs and have none left to devote to their marriages. Romance becomes a thing of the past, and social lives and sex lives become non-existent.

## WHAT CAN YOU DO TO HELP YOUR MARRIAGE?

- *Remind yourself what attracted you to your spouse in the first place.* Try to unearth those qualities from the layers of hurt and anger that may have built up as a result of the diagnosis.
- *Ask for what you need.* We often expect our spouses to know how we are feeling and what we are thinking without telling them, thus setting ourselves up for disappointment if they don't meet our needs. Instead of blaming your partner for your unmet needs, ask for support. Say, "I need for you to listen to how I feel—even if you don't agree," or "I need your help in taking care of our son," or simply, "I need a hug." In addition to asking for support, be open to receiving it. Some people think that accepting emotional support is a sign of weakness, when in fact it's the opposite. Accepting support comes from a position of strength. Accepting support from your spouse can help cement your relationship.
- *Listen openly.* Most of us are so consumed with our own feelings and points of view that we don't take the time to stop talking and just listen. Listen openly to your partner. Don't blame. Don't attack. Don't say, "You always do this" or "You never do that." Marriage counselors recommend a helpful exercise for active listening. Sit facing your spouse, and let him or her talk. Don't interrupt or formulate your next argument. Just focus on paying attention to what your partner is saying. Don't jump into your point of view until your partner is finished speaking. When your partner

is finished, it is your turn to speak while your partner listens. Although this simple exercise can be difficult to do, it is an incredibly effective way to improve communication between partners.

- *Communicate on a daily basis.* Express your feelings. Talk about problems or issues as they arise. Many times we ignore or repress feelings toward our spouses for fear of hurting the relationship, when in fact our unexpressed feelings are driving a huge wedge into it. We put off talking about problems or issues because we don't want to rock the boat and become angry when these problems are not addressed. Don't wait to communicate your feelings and address problems. The longer you wait, the more they will fester.
- *Use "I" statements.* Rather than saying, "You make me feel stressed," say, "I feel stressed when you say (or do) that." Be specific about what upsets you. Take responsibility for your own feelings. Even if the other person is causing you to feel stressed, you are the one who is responding in that way. You're entitled to your feelings, but the use of "you" at the beginning of a statement can sound accusatory and may automatically put the other person on the defensive. Begin statements with "I" so that the listener will be more open to hearing what you are saying.
- *Make time for your marriage.* Get a babysitter, relative, or respite care for your child with an ASD and go out to dinner or a movie. If possible, try to take a weekend away for just the two of you. Carve out time in your busy day for each other. Call each other on the phone. Come home from work on time or even early. Turn off the computer and get away from the websites about ASDs and chat rooms so that you can spend time with your spouse when he or she gets home from work. Designate nights when you take a break from ASDs and make a pact not to talk about them. Discuss sports or world events or plan a vacation. Rekindle your romantic relationship.
- *Make a conscious effort to work on your relationship.* All marriages require work, and when a marriage involves a child with an ASD, it requires even more work. About three months after Jake was diagnosed, Franklin and I sat down on the sofa in the living room and discussed whether or not our marriage would survive; the diagnosis was clearly

tearing us apart. I spent all my time researching ASDs, Franklin spent more and more time away from home at work. I'd go to bed early; Franklin would come home late. We barely spoke. What conversations we did have were about Jake's diagnosis of an ASD—and we seemed to speak *at* rather than *to* each other. We were growing estranged. In that one conversation in our living room, we made the conscious decision to work at our marriage together. We still loved each other and maintained a sense of good will underneath all of the anguish. Honestly, in some ways it almost seemed easier to give up on the marriage. I wasn't sure if I had any more energy to work at one more thing in my life. We sought out the help of a couples' therapist who helped us through our difficult time.

Success in anything requires practice and hard work. Marriage is no different. In his book *The Seven Habits of Highly Effective People*, psychologist Stephen R. Covey tells the story of a man who asked for advice on his marriage. "My wife and I just don't have the same feelings for each other we used to have. I guess I just don't love her anymore and she doesn't love me. What can I do?" Covey listened patiently and said, "Love her." The man didn't understand. Covey went on to explain. Love is a verb; it's an action. It's not something that magically takes over you. It's something you do. It is a value that is actualized through loving actions.<sup>1</sup> Like anything else in life, if you want to be good at it, you need to work at it. Make an effort to show your partner that you care. A couple who works as a team to raise their child with an ASD can actually strengthen their marriage. They truly can create a deep and meaningful bonding experience.

Sometimes, however, the stress of the diagnosis can be so overwhelming that even the most well-intended couples don't make it. The reality of marriage is that sometimes it just doesn't work out, whether or not you have a child with an ASD. If this is the case, as in any divorce, try to make sure the child doesn't feel responsible for the breakup. Work together to come up with financial solutions and caretaking responsibilities that will benefit the child with an ASD.

Cindy N. Ariel, Ph.D., and Robert A. Naseef, Ph.D., are psychologists who specialize in helping couples cope with special needs in their families. This is what they wrote about the reality of marriage for parents of children with disabilities.

For a relationship that is fragile or unstable, a disability can be "the last straw." On the other hand, challenging life events can serve as catalysts for change. Some families disintegrate while others thrive despite their hard-

ships. People can emerge from crisis revitalized and enriched. Hope for relationships really can spring from the crises people experience when their child has a disability.<sup>2</sup>

**My husband is out of the house and at work the entire day while I'm trying to manage all of our son's treatment needs. I'm growing resentful. My husband says he wants to help out and be more a part of his son's life, but he doesn't know what to do. Any suggestions?**

While in some cases, fathers are the primary caretakers of children with ASDs, mothers are more often the primary caretakers. "Caring for an autistic child can be a relentless and labor-intensive task—one that is overwhelmingly performed by mothers," says Jennifer Elder, a nursing researcher at the University of Florida's (UF) Center for Autism and Related Disabilities. In studies at UF, it was found that fathers were frustrated because they didn't know how to relate with children with ASDs. Fathers in the study were taught how to interact with their children using building blocks, bubbles, puppets, and toy cars and trucks. Once they learned how to relate to their children—through communication and play skills—they felt more empowered and connected to them. The study also indicated that these children showed tremendous improvement in their communication skills. In fact, it was reported that there was a 50 percent increase in the number of intelligible words the children spoke once their fathers had established good relationships with them. While your child may or may not experience such dramatic results, one thing is clear: A father plays an important role in helping a child with an ASD.

"It is important for both the child's mother and father to be involved in parent training whenever possible," said Jaime Winter, a research scientist at the University of Washington Autism Center. "Potential benefits that may follow from father participation include increased frequency of interaction and quality of interaction between fathers and their child with autism, increased treatment time for the child, and support for the child's mother."<sup>3</sup>

For more information on how to become more involved in helping out your child, talk to the best resources you have: your child's treatment providers. They are familiar with his specific needs and can offer great tips on games and activities that both you and your spouse can do at home with your child.

## **I love my son so much, but I'm feeling disconnected from him. How can I feel more connected?**

It's often difficult to feel connected to your child if he rejects your hugs or seems indifferent to affection. It's painful when you say, "I love you," and your child can't say it back. And it's difficult to not take all of this personally, even when you know that you shouldn't. But there are ways to connect with your child—you just have to tune into your child's specific needs.

One of the best ways to establish a connection with your child is through laughter and play. Figure out what makes your child smile. Is it a favorite toy? Playing peekaboo? Jumping on the trampoline? Being tickled? If your child is in school or treatment sessions all day, it may seem like there's no time for fun, so it's up to you to make time for fun. Tune into to your child's sense of playfulness.

One mother found that her son who was overly sensitive to gentle touch but loved to wrestle. He was a big ten-year-old boy who weighed almost as much as his petite mom. She discovered his love of wrestling one day when they were sitting on the sofa. Usually, he didn't like it when someone sat too close to him, so his mother kept her distance. But on this day, she happened to reach over him to get the remote control for the TV, and as she did, she accidentally nudged him. He nudged her back. She looked at his face and noticed that he seemed to be playing a game. She nudged him a little harder, he nudged back, and before she knew it, they were rolling around on the living room rug in a playful wrestling match. The two of them laughed. It was an emotional moment for the mom. She was finally able to hold her son and be held by him. It had been a long time since they had hugged. After that, her son would actually initiate the wrestling match. He would approach his mom and give her a nudge. This became a mom/son special bonding activity. The boy's father reports that his son didn't want to wrestle with him. So he found his own special way to bond. His son loved the trampoline, so the two of them would go out in the backyard and jump together.

One great way to connect with your child is to figure out his communication preference. For example, is your child a visual, auditory, or kinesthetic learner? All of us have each of these senses, but there's always one that emerges as the dominant one. Visual learners like pictures and storybooks. Auditory learners like music and sounds. Kinesthetic learners prefer hands-on, tactile activities, like sculpting with clay or playing with Play-Doh. Sometimes, if you're not sure what your child's communication preference is, you can get clues from their stimulating behaviors. A boy who taps on windows and loves

music is most likely an auditory learner; a girl who is mesmerized by bright lights or engages in eye tracking is most likely a visual learner; a boy who flicks his fingers is most likely a kinesthetic learner. Within each of these categories, tune into your child's sensitivities. A visual learner may love colors but not bright lights. An auditory child may love music as long as it's not too loud. A kinesthetic child may prefer roughhousing over a gentle caress.

If you're not sure which type of category your child falls into, don't worry. Experiment with different toys and games. Introduce new activities. Just because a child doesn't enjoy an activity initially doesn't mean that he won't ever enjoy it. Jake was initially afraid of the swings at the playground, but when he learned how to swing in his OT sessions, he began to love swinging. "Mo! Mo!" he used to say, indicating that he wanted to swing more. So he and I would sit side by side on our swings, pump our legs, and sail into the air. That's how we connected on some days. On other days, when Jake seemed "off" or detached, I'd just sit down near him. Just being in the same room with him often made me feel more connected; even if he was gazing off into space, I liked to believe that he felt my presence and felt more connected to me.

### **People keep telling me to do something nice for myself for a change, but I don't feel like it. Besides, I'd feel too guilty taking time away from my child with an ASD.**

Friends and loved ones will probably recommend that you make time for yourself. This may seem absurd to you, especially if you are inundated with the demands of helping your child. Making time for yourself may also seem selfish, but keep in mind what flight attendants tell you on an airplane: "In case of emergency, parents should put on their oxygen masks first, then their children's." Put on your oxygen mask first! Making time for yourself is not selfish. It's both necessary and practical. If the thought of taking time away from your child makes you uneasy and produces feelings of guilt, think about it in a different way. Carving out time for yourself can actually make you a better parent. In other words, helping yourself will help your child.

I often hear from parents, "But I don't have time for myself!" Then make time. Start out by setting aside ten minutes a day to do something that makes *you* feel good—and that has nothing to do with ASDs. If you're feeling guilty, remind yourself that you are doing the right thing and that attending to your own needs is ultimately good for your child as well. The last thing your child needs right now is a burned-out parent. Keep those daily ten-minute breaks

consistent. Don't skip a day. Try to build up from the ten minutes to fifteen, then twenty, all the way up to one hour a day.

What kinds of things can you do with your time? Create a life outside of ASDs. Take up activities that renew you as an individual. You can take a bath, go for a walk, call a friend, do yoga, play tennis, watch a sitcom on TV, read a novel, or anything else that makes you feel good and renews your spirit. The following are some additional stress-reducing tips from parents of children with ASDs.

–*Don't try to do everything yourself.* One mom's advice: "You may think you're Super Mom but you're not. I thought I was, and I almost went crazy trying to manage the house, my other kids, my job, and my son's therapy. Ask other people for help. Shift around your priorities. So maybe the beds don't get made every day, and there are dishes in the sink from dinner the night before, but there are more important things right now." Another mom said, "If there's something you just can't do with your child, get someone else to do that. I couldn't teach Samantha how to use the computer mouse for one of her treatment programs. It drove me crazy! A sixteen-year-old babysitter had her pointing and clicking in an hour. Best twelve bucks I ever spent!"

–*Breathe.* Seriously, take a few good, deep, cleansing breaths throughout the day to lower your stress level. Believe it or not, most adults don't even know how to take a deep breath. If you ask adults to breathe deeply, you'll see their chests move. Watch how a baby breathes when he's sleeping, and you'll notice his belly moving up and down. That's the correct way to breathe. Put your hands on your abdomen and breathe from your belly. If you can't figure out how to do this at first, try a good old-fashioned yawn. Yawning can also be an effective way to reduce stress.

–*Focus on the here and now.* This is called mindfulness—the art of being in the present moment. Instead of rushing around, take moments throughout the day to calm down and be mindful of the present moment. For example, instead of making phone calls or reading the newspaper while you rush through eating your lunch, just eat. Take the time to smell, taste, and enjoy your food. A simple act like mindfully eating, looking out the window at nature, or taking a walk can help ground you and relieve stress.

- Focus on what you can control in the moment . . . not on what you can't control in the future.* Don't allow yourself to say, "I won't be happy until my child speaks or plays or gets better." Find joy in everyday moments and little victories.
  
- Remember that feelings are not facts.* Just because you feel a certain way doesn't mean you are that way or that you need to act on your feelings.
  
- Find your sense of humor.* Although it may be buried away somewhere, you can sometimes find humor in the midst of everyday stress. The parents of the boy who repeatedly broke the windows in their house eventually reached the point where they had coffee brewing for the window repairmen when they arrived and knew them all by name. "See you next week, Joe!" the parents would say after he fixed another window. One mom who could not get her son to stop squealing loudly in the middle of the mall decided to squeal with him. "What the heck. If people are going to stare, let me double their pleasure. Besides, my kid was so happy! Those were squeals of joy. I wanted to have some of that joy, too!" she said.

### **I know I should make more time for myself and my marriage, but I feel uncomfortable and guilty about leaving my child with a babysitter.**

Parents may feel guilty about leaving their child at all, but it's important to spend time focused on yourself and on your relationship with your spouse. You can teach a babysitter or relative how to take care of your child's special needs. You can also contact teachers at local special education schools or contact psychology departments at local colleges for students majoring in special education. Other contacts include your local autism organizations, chapters of ASA or the ARC (formerly known as the Association for Retarded Citizens).

In addition to babysitting services, you can also opt for respite services. The word *respite* means break or breather—which is exactly what many parents need to relieve their stress and recharge. Respite care refers to short-term, temporary care that is provided for people with disabilities. It can involve daily caretaking in or outside of the house or overnight care for more extended periods of time. Families use respite care when they need a few hours off dur-

ing the day or to take vacations that may be inappropriate for their children with ASDs. Many respite programs also provide caretaking training for parents and family members so that you can learn more techniques and feel more competent about caretaking. If you receive Medicaid, you can access these services through Medicaid service approved providers. There are also free-standing respite houses and respite camps. State respite programs may cover 40 hours per month of respite care. You can find information on respite care in the list of resources in Appendix F.

## ADVICE TO LOVED ONES: COPING TIPS FOR FAMILY AND FRIENDS

### POSITIVE AND HEALTHY WAYS FOR LOVED ONES TO SHOW THEIR SUPPORT

Your friends and loved ones may also need advice on how to cope when your child is diagnosed. They, too, may be trying to sort out their own feelings of sadness or confusion. In addition, they may want to help support you and your family but feel powerless to do so. They may not know what to do or say. Here's some advice to all your loved ones, to help them help you when your child is diagnosed with an ASD. Let them read this list of tips on how to show their support in positive and healthy ways.

- *Try to avoid the clichés.* Speak from your heart. Tell the parents of a child with an ASD that you care and that you are there for them.
- *Reach a place of acceptance.* Acceptance is difficult for everyone who knows and loves the affected family. You may feel guilty or helpless. Deal with your personal acceptance issues on your own. It's enough for parents to have to deal with their own acceptance issues surrounding

their child's diagnosis without the additional stress of taking care of you. Talk to your friends or a therapist to sort out your feelings.

- *Show the family that you accept them and their child with an ASD.* Visit. Call. Invite them over. Ask questions about the diagnosis, treatment, and what you can do to help.
- *Be careful about offering unsolicited advice.* It is not helpful to say, "If you would only do X, your son would be just fine." If you do have suggestions, offer them in a nonjudgmental way, such as, "I read an article about such and such a treatment that may be helpful." If your suggestion is turned down, let it go. Don't persist, and don't take it personally. The parent may not be ready to hear it.
- *Don't play the blame game.* One woman scolded her daughter-in-law for causing her grandson's autism: "If you'd only read to him more often, he wouldn't be in this state." Another in-law blamed the marriage: "I told you not to marry her in the first place." Blaming is completely uncalled for and can damage your relationship with the affected family.
- *Don't criticize.* If the parent chooses an intensive course of treatment that you disagree with, it's not helpful for you to say, "That's not what I would do. When I raised you, I made sure you had playtime. Why aren't you doing that for your own child?" If you want to communicate your point of view, do it in a constructive and appropriate way so that the parent does not feel criticized or rejected.
- *Offer hope but not false hope.* One grandfather of a child with an ASD said, "My grandson's perfect. Just give him some therapy, and he'll grow out of it." It's wonderful to be optimistic, but offering unrealistic expectations can be very difficult for a parent to hear, especially when facing the reality of how much hard work goes into treating their child.
- *Reflect feelings.* That is, when a parent says "I feel terrible," instead of saying "Cheer up, look on the bright side," try saying, "You must feel terrible. This is a really difficult situation." If the parent says, "Sam cried for an hour during his treatment session today," instead of saying, "He'll

get over it” and offering tips on how to help the child get over it, simply say, “It sounds like that must have been emotionally draining for you.” Then let the parent talk.

–*Listen to what the parent has to say.* Most of us like to talk, especially when we’re trying desperately to help someone we love. Make sure to make time to listen. Sometimes, we need to absorb the words and tune into the parent’s tone of voice. Other times, we need to go beyond the words and be sensitive to nonverbal behavior. If you’re face-to-face with the parent, notice what his or her body language is saying. Notice facial expressions. (What do the eyes tell you? Is the brow furrowed?) Notice body posture. (Are the arms crossed? Fists clenched?) These nonverbal cues can signal to you how the parent is really feeling. Using either verbal or nonverbal cues, you can reflect feelings. You can say, “You seem tense” or “You sound anxious” and follow up with “How can I help you?” If the response is “I don’t know” or “There’s nothing you can do,” then offer suggestions, but be specific. Offer to help out with errands, housework, or child care. All of these listening techniques show that you care.

–*Be there.* Leave a phone message saying that you’re around to help even if you don’t get a response. If nothing else, you can sit with the parent and not say a word—just let him or her cry. Drop off a tin of cookies with a note. One family’s neighbors organized a meal delivery. Each neighbor was responsible for dinner one night a week and dropped it off in a cooler that was left at the front door.

–*Don’t take it personally.* Accept the parents for where they are emotionally. If a parent maintains that he or she doesn’t want to talk, reacts angrily to something you say, or rejects your offer to help, don’t take it personally. But don’t just let it go at that, either. Let them know that you’re there for them in the future. Don’t be afraid to follow up again. Just because the parent can’t accept your help at that moment doesn’t mean they will never want your help. Keep in touch.

Showing that you care during this time can be a challenge. Just do what you can and know that your support means a lot. These tips will help make things easier for you and the parents you love.

## HOW LOVED ONES CAN CONNECT TO A CHILD WITH AN ASD

Family and friends may feel awkward or anxious around your child because they want to make a connection but don't know how to go about it. I remember when my friends began having babies while I was still single. I'd visit them in the hospital, ooing and ahing at their newborns from a distance, and pray that they wouldn't ask me to hold their babies or do anything that brought me within three feet of the darling but intimidating creatures. I'd had absolutely no experience with babies and was not planning on having one of my own for years. It wasn't until one of my friends, so sleep-deprived that she had no awareness of my anxiety, walked over to where I was sitting and just put her baby in my arms. I held my breath. What was I supposed to do? I was slouched down in the chair. Could I move? If I moved, would I hurt this tiny, defenseless being? "Here's how you do it," my friend said, and gently adjusted the baby so that her head was supported by the crook of my arm and her tiny feet remained swaddled in her blanket. I began to breathe again. It wasn't so difficult. After that, I actually looked forward to baby visits.

Much of our discomfort in life stems from feeling a lack of control and helpless. This feeling escalates when the stakes are high, especially in situations that involve someone we love. Sometimes, out of fear, family or friends pull away from us after our child is diagnosed, convincing themselves that they're being protective, by shielding the child from their ignorance of ASDs—when in reality, they're hurting the ones they love. Some pull away because they feel rejected; the child doesn't respond when they call her name or doesn't let them hug her.

You can teach your family and friends how to approach your baby, toddler, or child of any age with an ASD. You can teach them what to say, what to do, and how to respond to your child in different situations. Making your family and friends feel comfortable around your child will benefit everyone. It will make them feel more supportive and make you feel more connected.

Explain what the diagnosis means so they can understand your child's symptoms and behaviors. Explain treatments and how they work. Show them how to act around your child. We explained to Jake's grandparents how to interrupt and redirect his behavior when he engaged in self-stimulatory behavior; they learned how to stop Jake mid-cycle while he was spinning and get him to do a puzzle. We showed our family and friends how to hug Jake (firmly and quickly), told them what to avoid in his presence (loud voices and loud noises), and how to interact with him (hold your hand up and say "Give me

five!” then wait for a response). They learned how to crouch down to his eye level to help Jake establish eye contact, guide his hand when he was doing a puzzle, and model social questions and answers that Jake was learning in his treatment sessions (“How are you?” “How old are you?” “What’s your name?”).

Here are some simple tips to pass onto friends and family who want to connect with your child.

- *Crouch down or sit so that you meet the child at eye level.* This will make it easier for the child to establish eye contact. Encourage eye contact when you are communicating with him. Gently guide the child’s face toward yours, or move your head into his field of vision. If your child does not like to be touched, you can create blinders with your hands around the child’s face so that the child will look straight ahead at you. You can also find something that will attract the child’s attention, such as a favorite toy or food treat, and hold it in front of your eyes so that the child will look at you (then lower it slowly while praising the child for looking at you).
- *Be aware of how close you sit or stand to the child.* What is the child’s comfort zone? If you’re not sure, ask the parents. Some children need to be very close to a person, whereas others need distance.
- *Make sure the child is paying attention to you when you speak to him.* Help the child look at you, either by using a verbal prompt (saying the child’s name) or adding a manual prompt (gently placing your hands as blinders on the sides of the child’s face and moving his head so that his eyes are looking at you).
- *Keep it simple!* Speak in simple and clear language, using brief phrases that are specific, such as “Look at me” rather than just “Look.” Use real words rather than cute made-up words, such as “Look at Grandma” rather than “Lookee at Nanna you silly-billy boy.” Use phrases that are familiar to your child. For example, if he is learning to respond to “Do this” in his treatment sessions, don’t say “I want you to do something for me now.” Avoid using ambiguous phrases such as “Let’s call it quits” or adding unnecessary words at the ends of sentences, such as “Do this, sweetie pie.”

- *Respect the parents' wishes and the child's needs.* If a parent tells you that Jonathan doesn't like being hugged, don't hug him. If he doesn't like being patted on the head, don't pat him on the head. Unfortunately, friends and family members sometimes feel a sense of entitlement: "But I always hug all my grandchildren!" Be careful about overstepping boundaries. This may push you away from both the child and the parents.
  
- *Be persistent and patient.* You won't get the same quick response from a child with an ASD as you would from a typical child. Rolling a ball to a child with an ASD and expecting it to come right back to you may be unrealistic. You may have to follow that ball, put it in the child's hand, and guide the child through the entire process of rolling the ball. With most typical children, you'd only need to show them once, and they'd get it. This is not the case for most children with ASDs. You may have to show them again and again.
  
- *Don't act on your hurt feelings.* If you feel rejected because the child is not responding to you, don't give up. Don't take it personally. Just because a child doesn't look at you doesn't mean she doesn't love you. Hang in there. Ask the parent for guidance. Parents may also feel rejected if you give up on trying to connect with their child. They need to see that you are trying and that you care.
  
- *Find and join a support group.* There are wonderful groups that help extended families and friends of children with ASDs. They can be a great place for you to share what you're going through with others who are in similar situations. You can contact your local autism organizations for information (see Appendix D).

## PARTING THOUGHTS ON COPING

Coping with ASDs is in some ways like training for a marathon. Franklin is a marathon runner. He actually just took up running again a few years ago after not having run since college. When Franklin started training, he was fiercely determined. He wanted so much to reach his end goal that he didn't pay much attention to the process of getting there. On his practice runs, he ran too hard and too fast and consequently got leg cramps, sustained a knee injury, and even vomited after one twenty-one-mile practice run. But none of this

deterred Franklin. He kept on going. He overtrained—rarely taking the recommended days off between practice runs. On his first 15K race, he started out sprinting and ended up “hitting the wall” much too early. It wasn’t until he had to drop out of the race from exhaustion that the realization hit him: If he wanted to succeed, he’d have to pace himself. So he slowed down—just enough to regroup, heal, and get himself organized—and he began to practice again. Since then, he has successfully run four marathons over the past four years.

Many parents have similar experiences when they enter the world of ASDs. It’s like they’ve barely tied their shoes before they’re off and running, breaking into a sprint before they’ve even had a chance to warm up or chart their course. Their determination gets the best of them, and they experience early burnout.

I’m not suggesting that “slow and steady” wins the race because in the case of ASDs, it doesn’t. Be aware that the clock is ticking to get your child help, but remember that *working hard* is not the same as *working smart*. If you’re just beginning your journey now, try to take a deep breath and get yourself centered before you make the important decisions. If you’ve already begun your journey, remind yourself to breathe along the way. Give yourself breaks. Keep up your spirits. Surround yourself with people who are going to help you stay positive. Remember that the beginning is the most difficult part. Ask any parent who’s been there—the process of coping does get easier over time. You will figure out how to run your own personal marathon and find victories along the way.