

# How will I deal with this diagnosis?

You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much, to want something so much, and not quite get it. You want your child to get better so much you may feel some of the stages commonly associated with grieving. You may “revisit” these feelings from time to time in the future. Part of moving forward, is dealing with your own needs and emotions along the way.

## Stages Associated with Grieving

### Shock

Immediately after the diagnosis you may feel stunned or confused. The reality of the diagnosis may be so overwhelming that you’re not ready to accept it or you initially ignore it. You may also question the diagnosis or search for another doctor who will tell you something different.

### Sadness or Grief

Many parents must mourn some of the hopes and dreams they held for their child before they can move on. There will probably be many times when you feel extremely sad. Friends may refer to this as being “depressed,” which can sound frightening.

There is, however, a difference between sadness and depression. Depression often stands in the way of moving forward. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Crying can help release some of the tension that builds up when you try to hold in sadness. A good cry can get you over one hurdle and help you face the next.

### Anger

With time, your sadness may give way to anger. Although anger is a natural part of the process, you may find that it’s directed at those closest to you – your child, your spouse, your friend or at the world in general. You may also feel resentment toward parents of typical children. Your anger may come out in different ways – snapping at people, overreacting at small things, even screaming and yelling. Anger is normal.


It is a healthy and expected reaction to feelings of loss and stress that come with this diagnosis. Expressing your anger releases tension. It’s an attempt to tell the people around you that you hurt, that you are outraged that this diagnosis has happened to your child.

“I felt angry when a child at my son’s school was diagnosed with Leukemia around the time our son was diagnosed with autism. Everyone sent cards and cooked dinners for them. They didn’t know I needed that kind of help too. When I let people know I needed help they came through for me.”

### Denial

You may go through periods of refusing to believe what is happening to your child. You don’t consciously choose this reaction; like anger, it just happens. During this time, you may not be able to hear the facts as they related to your child’s diagnosis. Don’t be critical of yourself for reacting this way. Denial is a way of coping. It may be what gets you through a particularly difficult period. You must, however, be aware of that you may be experiencing denial so that it doesn’t cause you to lose focus on your child’s treatment.

Try not to “shoot the messenger.” When someone, a professional, a therapist or a teacher, tells you something that is hard to hear about your child, consider that they are trying to help you so that you can address the problem. It is important not to alienate people who can give you helpful feedback and monitoring of your child’s progress. Whether you agree or not, try to thank them for the information. If you are upset, try considering their information when you have had a chance to calm down.



“My husband had a harder time accepting our son’s diagnosis at first. When Max began making progress in his ABA program, everything changed for the better. For a while, I was the one holding everything together for all of us.”

## Loneliness

You may feel isolated and lonely. These feelings may have many causes. Loneliness may also come from the fact that in your new situation you simply don’t feel you have the time to contact friends or family for company or that, if you did reach out, they wouldn’t understand or be supportive. In the pages that follow, we have some suggestions for taking care of yourself and for getting the support you need.

## Acceptance

Ultimately, you may feel a sense of acceptance. It’s helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to advocate for your child. The period following an autism diagnosis can be very challenging, even for the most harmonious families. Although the child affected by autism may never experience the negative emotions associated with the diagnosis, parents, siblings and extended family members may each process the diagnosis in different ways, and at different rates.



## Give yourself time to adjust

Be patient with yourself. It will take some time to understand your child’s disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than you had planned. But you will also experience feelings of hope as your child begins to make progress.

# Caring for the Caregiver

Changing the course of your child's life with autism can be a very rewarding experience. You are making an enormous difference in his or her life. To make it happen, you need to take care of yourself. Take a moment to answer these questions: Where does your support and strength come from? How are you really doing? Do you need to cry? Complain? Scream? Would you like some help but don't know who to ask?

Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself.

Parents often fail to evaluate their own sources of strength, coping skills, or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax, cry, or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is bad for you and for your family.

You may feel that your child needs you right now, more than ever. Your "to do" list may be what is driving you forward right now. Or, you may feel completely overwhelmed and not know where to start. There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better.

Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. As some parents may tell you, you may be a better person for it. The love and hope that you have for your child is probably stronger than you realize.

## Here are some tips

from parents who have experienced what you are going through:

### Get going.

Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child, and take care of yourself so that you can keep going.

### Ask for help.

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning: Can they pick a few things up for you at the store or do a load of laundry? Can they let other people know you are going through a difficult time and could use a hand?

### Talk to someone.

Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.

At my support group I met a group of women who were juggling the same things I am. It felt so good not to feel like I was from another planet!

### Consider joining

a support group. It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources for information about what services are available in your area and who provides them. You may have to try more than one to find a group that feels right to you. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

## Try to take a break.

If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, getting out to a movie, going shopping, or visiting a friend can make a world of difference. If you feel guilty about taking a break, try to remind yourself that it will help you to be renewed for the things you need to do when you get back.

## Try to get some rest.

If you are getting regular sleep, you will be better prepared to make good decisions, be more patient with your child and deal with the stress in your life.

## Consider keeping a journal.

Louise DeSalvo, in *Writing as a Way of Healing*, notes that studies have shown that "writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health," and positive behavioral changes. Some parents have found a journaling a helpful tool for keeping track of their children's progress, what's working and what isn't.

## Be mindful of the time you spend on the Internet.

The Internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.

Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation. Right now, while you are trying to make the most of every minute, keep an eye on the clock and frequently ask yourself these important questions:

- Is what I'm reading right now very likely to be relevant to my child?
- Is it new information?
- Is it helpful?
- Is it from a reliable source?

Sometimes, the time you spend on the Internet will be incredibly valuable. Other times, it may be better for you and your child if you use that time to take care of yourself.

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# What should we know about our younger or future children?

Although autism is believed to have a strong environmental component, there is little doubt that autism is a disorder with a strong genetic basis. If you are expecting another child, or have plans to expand your family in the future, you may be concerned about the development of any younger siblings of your child with autism.

Studies have estimated that families affected with one child with autism have roughly a 5-10% percent chance of having a second child with autism. This risk increases if two or more children in the family are already affected.

More recent evidence has suggests that early signs of autism may be seen in some children as young as 8-10 months of age. For example, infants who later develop autism may be more passive, are more difficult to soothe, or fail to orient when their name is called. Some of these early signs may be noticed by parents, others may only be observed with the help of a trained clinician.

Through a joint venture between *Autism Speaks* and the National Institute of Child Health and Human Development, research on the early signs and symptoms of autism has been accelerated. Called the High Risk Baby Siblings Research Consortium, or BSRC, the collaboration is comprised of over 20 researchers at a dozen different sites in the US, Canada and Israel, with a similar effort in the United Kingdom. The purpose of this collaborative effort is to help identify behavioral and biological markers for autism so that diagnosis can be made earlier than ever before, leading to improved and more specific behavioral intervention in young children and even infants.

While there is a general acceptance in the scientific community that "earlier is better", this research will provide evidence on different therapies which partner therapist time and parent training. Recently, a group of researchers within the BSRC, together with psychologists from around the US, has formed the

Autism Speaks Toddler Treatment Network (TTN). The goal of the network is to determine whether intervention between the ages of 18 to 24 months of age affects developmental outcome at an age when autism can be more reliably diagnosed.

A number of other projects are underway to better identify developmental paths of children with autism, as well as potential risk factors, and common neurobiological markers. If you are interested in participating in a research project studying the earliest signs of autism, visit [www.AutismSpeaks.org/science/research/initiatives/babysibs.php](http://www.AutismSpeaks.org/science/research/initiatives/babysibs.php) or Family Services at [www.AutismSpeak.org/participate/index.php](http://www.AutismSpeak.org/participate/index.php) to find a project in your area. These studies provide intense observation, documentation, and feedback by experts in the field on the development of your child with autism, and any other children at risk for autism.

If you are interested in other intervention programs that are not part these studies, contact Family Services at *Autism Speaks* to help identify an early intervention program in your area.

## How will this affect our Family?

Even though it is your child who has the diagnosis, it is important to acknowledge that autism “happens” to the whole family. It affects every member of the household. This section of your handbook may help you anticipate some of the emotions you and other people in your family will experience.

The following article, adapted from *Does My Child Have Autism?* By Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the diagnosis.

### Breaking the news.

Sometimes telling your parents about your child’s diagnosis can be extremely difficult, especially with your own emotions running so high. It’s hard to know what to expect; I’ve seen that parental reactions to this news can vary dramatically. One young mother told me, “My mother-in-law told us that we shouldn’t bring my son to family gatherings until he grows up. It’s heartbreaking to hear her say that she would rather not see any of us for years instead of trying to understand her own

grandson.” But then I’ve also been told, “We were very touched by how our family reacted to my son’s diagnosis. Everyone asked what they could do to help, and they showed us so much support. I know his grandparents read books and articles on the disorder so they could better understand him. My mother even quit her job to help me through this very difficult time.” Yes, reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis.

To begin your discussion, you might talk about specific behaviors. For example: “You know those behaviors we’ve been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn’t act the way he does because he’s spoiled or because he’s shy or because he doesn’t like us – he acts that way because he has autism. Autism explains why he doesn’t speak or use gestures and why he doesn’t seem to understand what we say. It explains why he’s not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys.

I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early, and there are a lot of things we can do to help him. He’ll be starting some therapies soon, and I’ll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I’ll be glad to try my best to answer them. I know we’re all hoping for the best outcome possible.”

After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop. Autism doesn’t affect only one child. It affects the entire family.

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# Sharing your struggle with family & friends

The following article by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, from the book *Overcoming Autism*, offers a suggestion for how to tell people and explains why, for some people, it can make life easier for you and your friends.

## Telling People You should, you know.

**Tell people.** You don't have to walk up to strangers on the street or anything, but confide in the people who love you. That was one thing we did right: we told our families and our friends right away. First we called them, and then we copied a good comprehensive article someone wrote about autism and annotated it with specifics about Andrew, and we mailed it out to everyone we knew. (You could do the same things with sections from this book, by the way.)

**None** of our good friends pulled away from us because our kid had autism. Just the opposite – our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress on year after year.

**In all honesty**, telling people what we were going through only made our lives easier. Before then, we worried that Andrew's occasionally aberrant behavior was off-putting. But once he had a formal diagnosis, everyone cut us a lot of slack, and instead of wondering what the hell was wrong with us as parents, most people we knew admitted to a newfound respect for us for dealing with so much.

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**Real friends** don't love you more for being successful or less for having problems. If anything, it works the opposite way – we're all so busy that sometimes we forget to stay in touch with friends when everything's fine for them, but we rush forward when they need us. Now is the time to take advantage of that. Talk your friends' ears off, complain, bitch and moan to them. You're dealing with a huge challenge – take advantage of every minor plus it has to offer.

# Fifteen Tips for Your Family

As a result of her work with many families who deal so gracefully with the challenges of autism, Family Therapist, Kathryn Smerling, Ph.D., offers these five tips for parents, five for siblings and five for extended family members:

## 5 Tips for Parents

**Learn** to be the best advocate you can be for your child. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.

**Don't** push your feelings away. Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's OK to feel conflicting emotions. Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry.

**Try** to have some semblance of an adult life. Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse, and refrain from constantly talking about autism. Everyone in your family needs support, and to be happy despite the circumstances.

**Appreciate** the small victories your child may achieve. Love your child and take great pride in each small accomplishment. Focus on what they can do instead of making comparisons with a typically developing child. Love them for who they are rather than what they should be.

**Get involved** with the Autism community. Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

## 5 Tips for Brothers & Sisters

**Remember** that you are not alone! Every family is confronted with life's challenges... and yes, autism is challenging... but, if you look closely, nearly everyone has something difficult to face in their families.

**Be proud** of your brother or sister. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic...they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister, and sometimes you will hate them. It's okay to feel your feelings. And, often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way they are.

**While it is OK** to be sad that you have a brother or sister affected by autism it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.

**Spend time** with your Mom and Dad alone. Doing things together as a family with and without your brother or sister strengthens your family bond. It's OK for you to want alone time. Having a family member with autism can often be very time consuming, and attention grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.

**Find an activity** you can do with your brother or sister. You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired they may be, doing something together creates a closeness. They will look forward to these shared activities and greet you with a special smile.

## 5 Tips for Grandparents and Extended Family

**Family members** have a lot to offer. Each family member is able to offer the things they have learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner, or raising money for the special school that helps your family's child. Organize a lunch, a theatre benefit, a carnival, or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.

**Seek out** your own support. If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that

kind of support so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face.

**Be open and honest** about the disorder. The more you talk about the matter, the better you will feel. Your friends and family can become your support system...but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on it will be easier. In the end your experience with autism will end up teaching you and your family profound life lessons.

**Put judgment** aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options, and are typically coming to well thought out conclusions. Try not to compare children (this goes for typically developing kids as well). Children with autism can be brought up to achieve their personal best.

**Learn** more about Autism. It affects people of all social and economic standing. There is promising research, with many possibilities for the future. Share that sense of hope with your family while educating yourself about the best ways to help manage this disorder.

**Carve out special time** for each child. You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different but both children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for fifteen minutes. If you go to the same park every week, chances are over time that activity will become easier and easier...it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate that you are making.