

## Autism & Your Family

### How will I deal with this diagnosis?

It's not easy to hear the news that your child has autism, and realize that your life will be utterly different than you had expected it to be. Daily life with a special-needs child presents many unique challenges. How do you come to terms with the fact that your child has autism? How do you cope once you get over the initial shock? We aim to help you by providing regular features on topics ranging from how autism affects your family to day-to-day survival strategies.

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.

#### 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.

## **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. [Link to Family Services](#)

*“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. [Link to AS Support Network](#)

**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.

## **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.

(Reprinted from [www.autismspeaks.org](http://www.autismspeaks.org))