



## What is Autism

## Diagnosis

## Treatment

## Your Child's Rights

## Your Family & Autism



[ Meet Adam ]

## Coping

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. Please be sure to check in with us often.

*Read the first installment in our series of coping strategies about coming to terms with your child's diagnosis of autism. We would like to hear your story about what you experienced when you first heard that your child was diagnosed with autism. What did you go through? What helped you cope? Do you have any advice that might help someone going through this right now? Please send your stories to [editors@autismspeaks.org](mailto:editors@autismspeaks.org).*

## Coming to Terms with the Diagnosis

No matter how well-prepared you thought you were after months spent worrying about your child's development, and seemingly endless visits with specialists, hearing that your child has autism is usually devastating. Many parents and psychologists describe the diagnosis as a kind of "death." As Sharon Rosenbloom writes in *Souls: Beneath and Beyond Autism*, "With the diagnosis of autism, the dream dies." While of course your child is very much alive, the feeling of loss is nonetheless very real for most parents and families. In many ways, the diagnosis of autism represents the death of both your idealized child and your life as you imagined it would be, full of soccer games and school plays, ballet classes and sleepovers. The diagnosis leaves you facing something entirely new and unknown, and it can feel very scary indeed.

### What to Expect

You will most likely experience a wide range of emotions. These may range from shock, anger, and resentment, to fear, worry, and profound sadness. Some parents may feel guilt, while others may actually feel some relief at finally having a diagnosis. One minute you may feel like screaming, and the next minute all you want to do is cry. Each person displays his or her own range and intensity of emotions. Still, you may go through something similar to that of others who suffer a great loss:

**Shock:** You may feel confused or frightened, or you may

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... in order to better understand the diagnosis or searching for another doctor who will tell you something different.

**Profound sadness or grief:** As the shock subsides, these feelings may engulf you as you mourn the loss of your idealized baby.

**Anger:** With time, your grief may turn into anger toward your child, your spouse, or whoever may be close at hand. You may also feel resentment toward other parents with healthy children.

**Acceptance:** Ultimately, you begin to accept your child's diagnosis and the changes that living with autism brings.

This can be a very challenging time. The main thing to remember is that all of these emotions you're feeling are normal. Be patient with yourself. It can be a long time before you are able to feel a sense of acceptance about your child's disability. But most parents who have been through this already will assure you that eventually that time does come.

#### Help Yourself Adjust

In the meantime, there are some strategies that can help you. Psychologist Judith Grossman, of the Ackerman Institute in New York City, recommends a preventionist approach. In other words, don't let yourself fall apart. While you may be on an emotional roller-coaster ride, your child needs you now more than ever.

- **Give yourself time to heal.** You may need to take time off from work while you are grieving. Let yourself cry, scream, or anything else that helps you release your emotions.
- **Write in 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.
- **Begin treatment for your child immediately.** Bryna Siegel, in *The World of the Autistic Child*, writes that "starting with treatment is the best way to work through the acceptance of the diagnosis. . . . The sooner the treatment begins, the sooner there will be some positive change in the child and the parents can begin to see that the child's situation is not hopeless."
- **Talk about your feelings.** Discussions with someone you trust, whether a partner, friend, family member, or religious leader, can be a tremendous relief.
- **Learn facts about autism.** With information you will feel more capable to make the right decisions for your child. Take care not to become overwhelmed, though. You don't need to solve all your child's problems at once.

family life at a time when it may feel chaotic and overwhelming.

- **Join a support group.** Find other parents who understand what you're going through and can give you advice and direct you to resources. Don't let yourself become isolated.
- **Do something for yourself every day.** Gardening, exercise, art, prayer, anything that makes you feel good.
- **Don't forget to appreciate your child's gifts.** Don't let the word "autism" cloud your feelings toward your child. This is the same little person you loved and appreciated before the diagnosis
- **Get help when necessary.** Following the above strategies should help keep you from falling apart. However, if you do find yourself so overwhelmed that you are unable to function or care for your child or children, consider seeing a trained psychotherapist who can help you work through your difficult emotions.

