

A Parent's Guide to Understanding and Coping with an Autism Diagnosis

When a child is diagnosed with an autism spectrum disorder (ASD), many parents feel overwhelmed and experience high levels of stress. While this is a very challenging time, there are steps parents can take to accept the diagnosis and move forward. Parents typically want to spring into action to help their child, but taking time for themselves has long-term benefits for the entire family.

According to Dr. Amy Keefer, a clinical psychologist in the Center for Autism and Related Disorders (CARD) at Kennedy Krieger Institute, "While it's natural for parents to put their child first, parents often don't realize that they should let themselves experience the range of emotions that may accompany the diagnosis. There are a number of coping strategies parents should consider to help alleviate stress and continue on with their lives."

Kennedy Krieger Institute's psychologists treat thousands of children with developmental disorders ranging from autism to Down syndrome, and they are experts on helping parents to manage the stress of caring for a child with special needs. Dr. Keefer offers the following advice to parents:

- 1. Take time to accept the diagnosis.** It is important that parents take time to experience the feelings that accompany an ASD diagnosis. Sometimes parents rush through this stage, which can backfire, as these feelings will re-emerge in the future and can prevent parents from moving forward with their lives. After learning the diagnosis, many parents experience all the stages of grief (denial, anger, bargaining, depression, and acceptance). This is a natural, healthy process that helps lead to acceptance and hope for the future.
- 2. Remember that a diagnosis does not define your child.** Your child is still the same person as before the diagnosis. Being diagnosed simply provides a medical explanation for why your child has a certain set of strengths and weaknesses.



- 3. Reach out to local support and advocacy groups.** Many of these groups have helpful information online; one is includes the **IAN Project (IANProject.org)**. Through the IAN Project, parents can engage with others in the autism community, access evidence-based information, and register to participate in autism research. Another resource is the **First 100 Days Kit** at the Autism Speaks website (**AutismSpeaks.org**). Other parents can also be one of the best sources of support, understanding, and information. However, it is important to remember that parents are often at different stages and have different reactions to their child's individual diagnosis and experience.

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4. **Do not focus on the past.** Some parents attempt to identify the cause of their child's diagnosis or worry that they should have noticed their child's symptoms sooner. This often leads to feelings of guilt or shame, or believing that they are somehow to blame for their child's current difficulties. This type of thinking is never productive and keeps parents trapped, worrying about what they believe they should have done, and prevents them from focusing on their child's present needs.

5. **Keep life in balance.** Learning about autism and attending therapy appointments should not be all-consuming. It is important to keep as much balance as possible in your family's life. Although initially educating yourself about ASD, scheduling evaluations, and developing a treatment plan will take large amounts of time, you should continue to maintain important relationships with your spouse, your other children, and your friends. Make sure to maintain times for regular family life.

6. **Identify others who can help care for your child.** Parents often worry that they are burdening others or that others will not provide appropriate care for their child. However, caregiver burnout is a real issue and can affect your health and relationships with others. If family and friends are unable to care for your child, there are organizations that offer respite care with trained care providers.

7. **Monitor and care for your emotional needs.** Don't ignore your own emotional health. Although many parents sacrifice their needs to focus exclusively on their children, they are likely doing more harm than good. The depression and fatigue that follow limit your ability to effectively parent. Share your feelings and needs with others. Friends and family often are more supportive than you expect (even if they initially need some time to adjust to your child's diagnosis). If you notice that you are feeling sad, hopeless, or irritable for significant periods of time, seek professional help.

8. **Focus on your child's individual achievements.** Don't constantly focus on the differences between your child and his typically developing peers. Instead, focus on positive changes and your child's individual accomplishments.

9. **Get help for difficult behaviors.** Sometimes children with ASD display difficult behaviors, such as aggression and sleep disturbance, which can be extremely stressful for families.

These difficulties don't respond to typical parenting strategies, so parents often believe they have failed when their child doesn't improve. However, trained professionals can provide you with many effective strategies for managing these behaviors.

10. **Help educate others about autism.** One of the biggest barriers that parents face is that others around them don't understand what it's like having a child with autism. Provide basic education to others by distributing reading materials or even having family members attend doctor appointments.

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– Dr. Amy Keefer

Contact Information

Center for Autism and Related Disorders at Kennedy Krieger Institute

To make a referral or schedule an appointment, please call **888-554-2080**.
For more information about our program, call **443-923-7680**.
TTY: **443-923-2645** or Maryland Relay **711**

CARD.KennedyKrieger.org

Physicians & Healthcare Professionals

To make a referral, call our Physician Referral Line at **443-923-9403**.

Clinic Locations:

3901 Greenspring Avenue
Baltimore, MD 21211

1130 Annapolis Road, Suite 200
Odenton, MD 21113

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