Autism
CENTER OF EXCELLENCE

A Parent's Guide to Autism



If your child has recently been diagnosed with an autism spectrum disorder, you have come to the right place. A Parent's Guide to Autism was designed and developed by AutismCOE, specially for the parents to support you and promote a positive future for your child and family during an often challenging time.

THIS TOOL KIT IS SPECIALLY DESIGNED FOR PARENTS OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH AUTISM.

This Tool Kit will help you:

- Understand autism and its potential impact on your family.
- Discover strategies and resources for raising a child with autism.
- Connect with support to avoid feelings of loneliness or isolation.
- Minimize the negative effects of the diagnosis on your family.
- Promote a positive future for both your child and your family.

Response to the Diagnosis

Discovering that your child has received an autism diagnosis is a profound moment that can reshape your life. Suddenly, the reality may differ significantly from your expectations.



Your initial concerns revolve around your child and the potential impact on their life. Questions about how you and your family will navigate these changes in the years ahead, and the day-to-day challenges of caring for a child with autism, become immediate worries. This juncture is pivotal, not just for your child but also for you and other family members. Accessing emotional support and accurate information becomes crucial for coping and fostering a positive future for both your child and your family.

Common Reactions to the Diagnosis

Discovering that your child has autism can be an overwhelming experience for parents, evoking a range of emotions. Initially, the news may leave you in a state of shock, struggling to grasp the reality of the diagnosis. This might be followed by periods of deep sadness and grief as you adjust to the altered expectations you had for your child's future.

It's normal to experience anger, a natural response to the feelings of loss and stress that come with an autism diagnosis. This anger may be directed at various aspects of the situation, including your child, your spouse, or close friends. Expressing these emotions is a healthy part of coping.

Denial can also play a role as a coping mechanism. Some parents may go through phases of refusing to accept the diagnosis, a way of navigating through the difficulties. However, being aware of this phase is crucial to making informed decisions about your child's treatment.

Feelings of loneliness and isolation may arise during this time, originating from various sources associated with significant loss. However, as parents progress through this emotional journey, they may eventually find a sense of acceptance. Acceptance doesn't mean embracing autism; rather, it involves being ready to advocate for your child and actively engage in promoting a positive future for the entire family. This acceptance is a key milestone in understanding and supporting a child with autism.

Common Areas of Concern

Similar to any stressful event in your life, discovering that your child has autism will impact not just you but everyone in your family and network of friends. It's expected that your role as a parent will undergo changes, leading to a mix of positive and negative experiences in this new chapter. Below are examples of new feelings you may encounter:

- May feel burdened by the everyday responsibilities of caring for a child with autism.
- May feel pressure to become an expert on autism and learn everything overnight.
- May worry about the future of the family.

- May facing difficulty to find balance and time to manage household tasks, attend to other children, and handle daily activities.
- May feel less inclined to openly share emotions.
- May experiencing stress related to family finances and the uncertainties of the situation.
- May worry about the long-term future of the child.
- May facing additional challenges such as stress and anxiety that can impact work life.

When to Seek Professional Help

If you're noticing persistent signs and symptoms affecting your well-being, seeking professional counseling might be beneficial. These signs include:

- Difficulty sleeping and feeling unrested
- Inability to control negative thoughts
- Changes in appetite, either loss or increase
- Increased irritability or aggression noticed by others
- Excessive alcohol consumption
- Thoughts of life not being worth living



Recognizing these signs is important, and seeking professional help can empower you to navigate through these challenges effectively. Early intervention and support contribute to improved mental health and overall well-being.

Your Role as a Parent

When your child is first diagnosed, parents often step into various roles, becoming caregivers, therapists, educators, and more. Among these roles, one of the most crucial is that of an advocate for your child. Acting as your child's advocate is a long-term commitment, demanding various skills depending on your child's evolving needs. This role involves navigating the complexities of healthcare, education, and social services to ensure your child receives the support necessary for their well-being and development. As an advocate, you play a pivotal role in securing the resources and accommodations that will contribute to your child's success on their unique journey.



1. Take Responsibility - Be a leader
2. Learn - Be an expert
3. Think Critically - Be discerning
4. Speak with Authority- Be proactive
5. Document - Be prepared
6. Collaborate - Be a team builder
7. Educate - Be a voice for your child

Keep your Marriage Strong

Maintaining a strong connection with your spouse and ensuring open communication is crucial. Beyond the typical challenges of marriage, parents raising a child with autism may encounter additional experiences:

- Additional stress from navigating agencies, funding sources, and paperwork.
- Potential loss of income if one parent must stop working to care for the child.
- Added expense of hiring and managing specialized caretakers.
- Different points of view on the child's challenges and treatment decisions.
- Risk of losing friendships or lacking time and energy for external connections.
- Worries about the long-term future of the family.
- Adjustments in retirement plans, vacation possibilities, and other enrichment activities

Tips to keep your marriage strong while dealing with the everyday challenges of living with autism:



Maintaining a strong marriage while navigating the challenges of living with autism requires dedication and understanding. Here are some tips to help you and your spouse strengthen your relationship:

- **Communication is Key:** Keep the lines of communication open. Share your thoughts, concerns, and feelings with each other regularly. A strong foundation of communication can help both partners feel supported.

- **Work as a Team:** Approach the challenges as a team. Collaborate on decision-making regarding your child's care, therapies, and interventions. A united front can provide a sense of security for both you and your child.

- **Take Breaks:** Balancing the demands of caring for a child with autism can be overwhelming. Make time for breaks, both individually and as a couple. Recharge and support each other to prevent burnout.

- **Seek Professional Help:** Don't hesitate to seek professional help, such as couples therapy, to navigate challenges together. A therapist can provide valuable insights and strategies for coping with stress.

- **Celebrate Achievements:** Acknowledge and celebrate the achievements, no matter how small. Recognizing progress and positive moments can create a more positive atmosphere at home.

- **Prioritize Self-Care:** Take care of yourselves individually. Pay attention to your physical and mental well-being. Supporting each other's self-care contributes to a healthier partnership.

- **Build a Support Network:** Connect with other parents who have children with autism. Building a support network can offer understanding, shared experiences, and valuable advice.

Remember, every marriage is unique, and finding what works best for both partners is essential. Patience, empathy, and mutual support play vital roles in maintaining a strong and resilient relationship.

Support for Single Parents

Being a single parent raising a child with autism can be challenging, but there are ways to navigate this journey effectively. Here are some tips to make the process a bit smoother:

1. Connect with Others: Join online forums, support groups, or local community organizations to connect with other parents facing similar challenges. Shared experiences and emotional support can make a significant difference.

2. Seek Professional Advice: Consult healthcare professionals and specialists in autism. They can provide valuable guidance on therapies, educational resources, and strategies tailored to your child's needs.

3. Explore Local Resources: Look into local resources available for families with special needs. This might include support services, respite care, or community programs designed to assist parents like you.

4. Establish a Routine: Create a consistent daily routine for both you and your child. Predictable schedules can help manage daily tasks and reduce stress.

5. Prioritize Self-Care: As a single parent, taking care of yourself is essential. Ensure you have time for relaxation, hobbies, and personal well-being. Your well-being directly impacts your ability to support your child.

6. Leverage Technology: Use technology to connect with online support groups, access educational materials, or explore apps designed for children with autism. Technology can be a helpful tool in managing various aspects of daily life.

7. Investigate Assistance Programs: Explore legal and financial assistance programs available for single parents. This could include government support, grants, or community services to alleviate financial burdens.

8. Stay Informed: Educate yourself about autism spectrum disorder, available therapies, and educational approaches. The more you understand, the better you can advocate for your child's needs.

9. Collaborate with School: Maintain open communication with your child's school. Collaborate with teachers and administrators to create an educational plan that accommodates your child's unique requirements.

10. Celebrate Achievements: Focus on celebrating both yours and your child's successes, no matter how small. Acknowledge your resilience as a single parent and the progress your child makes along the way.

Remember, seeking support is a strength, and by building a network, staying informed, and taking care of yourself, you can provide the best possible environment for your child with autism.

Support for Siblings

Supporting siblings of a child with autism is crucial to ensure a healthy family dynamic. Here are some practical ways to provide support for siblings:

- Make sure your family encourages open communication. Siblings may have questions or concerns, and it's important to create an environment where they feel comfortable expressing themselves.

- Look for local or online support groups designed for siblings of individuals with autism. These groups offer a space for sharing experiences and getting advice from others facing similar situations.
- Provide age-appropriate information about autism to siblings. Understanding the condition can reduce confusion and help them better comprehend their sibling's behavior.
- Set aside dedicated quality time for each sibling. Balancing attention ensures that all children feel valued and helps foster a strong sibling bond.
- Encourage and support each sibling's individual interests and hobbies. This promotes a sense of identity and accomplishment outside the family context.
- Depending on their age, involve siblings in the care and support of their brother or sister with autism. This participation can create a sense of responsibility and empathy.
- Acknowledge and address any feelings of resentment, confusion, or frustration that siblings may experience. Providing a safe space for them to express these emotions is crucial.



- Celebrate milestones and achievements together as a family. This not only acknowledges the accomplishments of the child with autism but also reinforces the importance of unity and support.
- If needed, consider seeking the help of a family counselor or therapist. Professional guidance can assist siblings in navigating complex emotions and provide strategies for coping with any challenges.
- Foster a sense of advocacy within siblings. Encourage them to be advocates for their brother or sister with autism, promoting understanding and acceptance both within and outside the family.

Remember, every family is unique, and the level of support needed may vary. By creating an open and understanding environment, you can help siblings navigate the complexities of having a brother or sister with autism.

Taking Care of Yourself

Caring for a child with autism can be demanding, and it's crucial for parents to prioritize self-care. Here are some strategies to help you take care of yourself:

1. Respite Care: Arrange for respite care to give yourself regular breaks. Whether it's a friend, family member, or professional caregiver, having time for yourself is essential.

2. Establish a Support System: Build a support network of friends, family, or fellow parents of children with autism. Sharing experiences and seeking advice can provide emotional support.



3. Prioritize Sleep: Ensure you get sufficient sleep. Lack of sleep can negatively impact your physical and mental well-being. Create a sleep routine and consider seeking help if sleep issues persist.

4. Healthy Lifestyle: Maintain a healthy lifestyle by incorporating regular exercise and a balanced diet into your routine. Physical activity can be a great stress reliever.

5. Set Realistic Goals: Be realistic about what you can accomplish. Set achievable goals for yourself and recognize that it's okay to ask for help when needed.

6. Pursue Hobbies: Engage in activities you enjoy. Pursuing hobbies can provide a much-needed escape and contribute to your overall well-being.

7. Schedule "Me" Time: Dedicate specific time in your schedule for self-care. Whether it's reading a book, taking a walk, or simply relaxing, prioritizing "me" time is crucial.

8. Seek Professional Help: Don't hesitate to seek therapy or counseling for yourself. Talking to a professional can offer valuable insights and coping strategies.

9. Learn to Say No: It's important to recognize your limits. Learn to say no when necessary and avoid overcommitting yourself.

10. Practice Mindfulness: Incorporate mindfulness or relaxation techniques into your routine. These practices can help manage stress and promote a sense of calm.

Remember, taking care of yourself is not selfish but a necessary part of being an effective caregiver. By prioritizing your well-being, you can better support your child with autism and navigate the challenges that come with parenting.

Ten Things a Parent Can Do to Help Their Child with Autism

Supporting a child with autism involves a combination of patience, understanding, and tailored strategies. Here are ten things parents can do to help their child with autism:

1. Understand Their Unique Needs: Recognize that each child with autism is unique. Learn about your child's strengths, challenges, and sensory preferences to tailor support.

2. Establish Routine: Create a structured daily routine. Consistency provides a sense of predictability that can be comforting for children with autism.

3. Effective Communication: Develop clear and concise communication strategies. Use visual aids, social stories, and gestures to enhance understanding.

4. Encourage Social Interaction: Support social development by facilitating positive interactions. Encourage playdates, social skills training, and participation in group activities.

5. Sensory-Friendly Environment: Create a sensory-friendly environment at home. Be mindful of lighting, noise levels, and textures to accommodate your child's sensory sensitivities.

6. Provide Clear Instructions: Give simple and explicit instructions. Break tasks into manageable steps and offer positive reinforcement for completing them.

7. Individualized Education Plan (IEP): Work closely with your child's school to develop an individualized education plan (IEP). Collaborate with teachers to address specific learning needs.

8. Behavioral Interventions: Implement evidence-based behavioral interventions. Positive reinforcement, token systems, and applied behavior analysis (ABA) can be effective.

9. Foster Independence: Encourage independence by teaching essential life skills. Gradually introduce tasks and activities that promote self-reliance.

10. Stay Informed: Stay informed about autism-related resources, therapies, and support networks. Attend workshops, connect with other parents, and remain actively involved in your child's journey.

Remember, the key is to approach each child as an individual and adapt strategies based on their unique profile. Tailoring support to their specific needs can contribute to their overall well-being and development.

Frequently Asked Questions From Parents

1. What is autism, and how is it diagnosed?
Autism is a neurodevelopmental disorder characterized by challenges in communication, social interaction, and behavior. Diagnosis typically involves evaluations by healthcare professionals, including developmental pediatricians and psychologists.

2. What causes autism, and is it preventable?
The exact cause of autism is unknown, but it is believed to involve a combination of genetic and environmental factors. Currently, there is no known way to prevent autism.

3. What early signs of autism should I look for in my child?
Early signs may include delayed speech, lack of eye contact, limited social interactions, and repetitive behaviors. However, it's important to note that each child is unique, and symptoms can vary.

4. How can I get support for my child and family?
Seek support from professionals, such as pediatricians, therapists, and educators. Explore local autism organizations, support groups, and online communities for guidance and connection with other families.

5. What therapies and interventions are effective for children with autism?
Applied Behavior Analysis (ABA), speech therapy, occupational therapy, and social skills training are commonly used interventions. The effectiveness of each approach depends on the individual's needs.

6. How can I help my child with sensory challenges?
Create a sensory-friendly environment, use sensory tools, and work with therapists to develop coping strategies. Understanding your child's sensory sensitivities is crucial for providing effective support.

7. Can my child go to a mainstream school, and what support is available?
Many children with autism successfully attend mainstream schools with appropriate support. Individualized Education Programs (IEPs), classroom accommodations, and support from special education professionals can enhance the learning experience.

8. Will my child with autism ever be independent?
Independence varies for each individual. Early intervention, life skills training, and ongoing support can enhance the potential for independence in daily activities and future endeavors.

9. How can I explain autism to siblings and friends?
Use age-appropriate language, focus on strengths, and emphasize understanding and acceptance. Encourage open communication and provide resources to help siblings and friends learn about autism.

10. What resources are available for parents of children with autism?
Numerous resources, including Autism Centers of Excellence, offer a range of services, support groups, and educational materials. Government agencies, nonprofits, and online platforms provide valuable information and assistance for families navigating the challenges of autism.

Have more questions or need assistance?
Please contact the Autism Center of Excellence Team

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Autism Center of Excellence offers ABA Therapy, Early Intervention, School Readiness Program, Speech Therapy, and Occupational Therapy to children from 2 to 14 years old in-home and center-based environments.

To learn more about Autism Center of Excellence, please visit autismcoe.com