

West Virginia Department of Education

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https://wvde.us/special-education/

Information for Caregivers of Children with a New Diagnosis of Autism Spectrum Disorder

Why diagnosis is a good thing

There are several reasons why having a diagnosis is important for your child:

- •A thorough and detailed diagnosis provides important information about a child's behavior and development.
- It can help create a roadmap for treatment by identifying a child's specific strengths as well as providing useful information about which needs, and skills should be targeted for effective intervention.
- •A diagnosis is often required to access autism-specific services through early intervention programs or your local school district.

Information about symptoms of autism

- Autism affects the way an individual perceives the world and makes communication and social interaction difficult.
- Autism spectrum disorders (ASD) are characterized by socialinteraction difficulties, communication challenges and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas.
- •Taken together, they may result in relatively mild challenges for someone on the high functioning end of the autism spectrum. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interferes with everyday life.
- •While autism is usually a lifelong condition, all children and adults benefit from interventions, or therapies, that can reduce symptoms and increase skills and abilities. Although it is best to begin intervention as soon as possible, the benefits of therapy can continue throughout life. The long-term outcome is highly variable.
- Many individuals with autism may have normal cognitive skills, despite challenges in social and language abilities. However, many individuals with autism develop speech and learn to communicate with others.
- Early intervention can make extraordinary differences in a child's development. How a child is functioning at an early age may be very different from how he or she will function later in life.

Tips for families

- •Learn to be the best advocate, be informed, take advantage of all the services that are available in your community.
- Feeling ambivalent and angry are emotions to be expected, be sure to talk about any feeling.
- •Appreciate the small victories.
- •Get involved in the autism community. Don't underestimate the power of a "community"
- Every family is confronted with life's challenges... and yes, autism is challenging, but stay positive and keep moving forward.
- •Carve out special time for all family members.

Caring for the caregiver

Changing the course of the life of a child with autism can be a very rewarding experience. However, through this trying time the caregiver needs to take care of themselves, take a moment to answer these questions:

- Where do your support and strength come from?
- How are you doing?
- Do you need to cry?
- Would you like some help but don't know whom to ask?
- •Take time to relax, cry or simply think.
- •Create a daily schedule or a "to-do list" of things that need to be done each day and don't worry if all tasks are not accomplished.
- •Remember there is no single way to cope, each family is unique and deals with stressful situations differently.
- Develop a treatment plan.
- •Acknowledging the emotional impact of autism.
- •Maintain open and honest communication, as well as discuss fears and concerns.

Tips from other parents

•Get going.

Work with professionals to get a treatment plan started as soon as possible, taking into consideration the special needs of each child. Early intervention is the key.

•Ask for help.

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available.

• Talk to someone.

Everyone needs someone to talk to.

•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 of information about what services are available in an area, and who provides them.

Try to take a break.

Allow 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

• Consider keeping a journal.

Louise DeSalvo, in *Writing as a Way of Healing,* notes that studies have shown that: "Writing that describes significant 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 journal to be a helpful tool for keeping track of their child's progress, what is working and what isn't.

Contributing resources

National Institute of Mental Health · www.nimh.hih .gov Autism Society of America · www.autism -society.org Autism Speaks · www.Autismspeaks.org

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