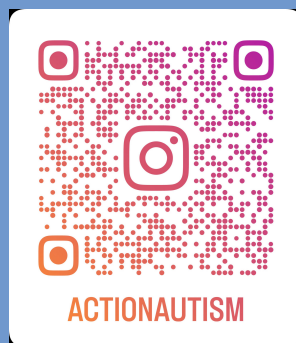


THE EVERYDAY AUTISM CAREGIVER'S GUIDE



www.actionsautism.com

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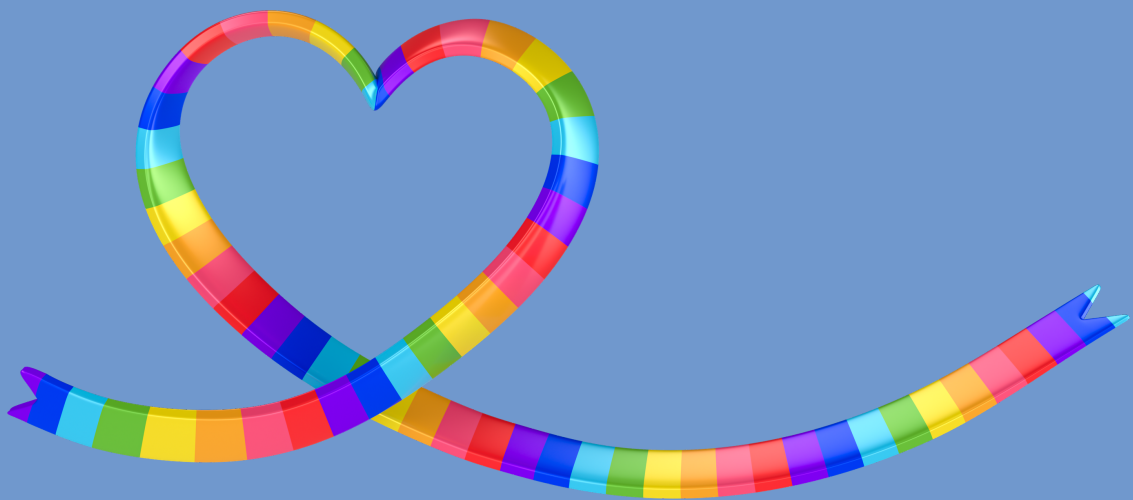
It's Okay If This Diagnosis Feels Scary

If you are reading this after your child's autism diagnosis and are feeling a variety of emotions, none of that means you are doing anything wrong. There is no “right way” to feel. Here are some common reactions that parents often describe:

- **Relief** – Many parents spend months or even years trying to understand why their child is struggling. An autism diagnosis can finally provide answers after a long period of uncertainty and confusion.
- **Grief** – Parents may grieve the loss of the future they had imagined for their child. This does not mean they love their child any less; it is a natural response to adjusting their expectations.
- **Guilt** – Parents may replay moments from early childhood, wondering if they could have done something differently or whether they missed early signs. Some mothers may also wonder whether something during pregnancy contributed to the diagnosis. It is important to remember that autism is not caused by parenting choices.
- **Fear** – Parents often worry about how their child will fit in at school, make friends, and navigate adulthood and the future.
- **Feeling Overwhelmed** – Evaluations, reports, therapies, appointments, and unfamiliar terminology can make everything feel overwhelming, especially in the beginning.
- **Denial** – It is common for parents to initially question or downplay the diagnosis or seek a second opinion. Some may hope their child will simply "grow out of it" as they process the news.
- **Anger** – Parents may feel angry about the challenges their child faces, delays in the diagnostic process, or difficulties navigating school systems and accessing appropriate services.

It's Okay If This Diagnosis Feels Scary

Autism is a neurodevelopmental difference that affects how a person communicates, processes sensory information, and interacts with the world. It also influences social interaction, behavior, and learning, and the way a person experiences their environment. As autism is a spectrum, meaning every autistic individual has their own strengths, challenges, and needs. No one is alike.



Acceptance means getting to know your child as they are, including their strengths, needs, sensory profile, and communication style, rather than measuring them against other children or a timeline. Every autistic child develops at their own pace. It helps to understand that the earlier a child receives support tailored to how they experience the world, the more tools and resources they're likely to have. What matters most is consistency: showing up for your child and adjusting your approach as you learn more about them. You do not need to become an overnight expert; it is normal to learn alongside your child, ask questions, and adjust to the process.

How is autism diagnosed

There is no blood test or brain scan to diagnose autism. The diagnosis is based on observing behavior and development, which is done by a specialist. The specialist gathers information from parents, caregivers, teachers, and standardized assessments to determine whether the child meets the criteria for autism.

Who can diagnose autism

- Child Psychiatrists
- Pediatric Neurologists
- Developmental Pediatricians
- Clinical Psychologists
- Neuropsychologists



Autism Screening

The screening asks about everyday behaviors associated with autism. One common tool is the Modified Checklist for Autism in Toddlers, Revised with Follow-Up, which asks parents simple yes-or-no questions about their child's behavior, such as:

- Does your child respond when you call their name?
- Do they enjoy playing with other children?

What evaluation includes

- Developmental history from parents
- Observation of the child's behavior
- Input from teachers and caregivers
- Assessment of cognitive and language skills

Barriers to diagnosis

- Long waitlists
- Schools not referring to children for evaluation
- Girls diagnosed later or missed
- Parents not knowing they can request an evaluation

Understanding Autism Spectrum Disorder

Autism spectrum disorder is a developmental disability that results in differences in communication, sensory processing, social interaction, and behavior.

According to the CDC, there are 1/36 children in the US are identified with autism.

Signs of Autism

Some common signs to look for include limited eye contact, hand flapping, rocking back and forth, jumping when excited, intense specific interests, and differences in language and social skills. Sensitivity to sensory input is common as well. For example, a child could cover their ears at sounds, refuse certain clothing textures, or seek movement to feel calm. In girls, the signs can be more subtle and may go unrecognized until much later. Because autism is a spectrum, each child is different, and there are no absolute signs, only patterns in behaviors.

Early Intervention

If you notice any of these signs in your child, the most important step is to speak with a pediatrician. Early intervention is valuable because it allows for proper care and earlier access to resources, helping children receive support sooner.

Understanding the Sensory Processing

Sensory processing refers to the way the nervous system interprets the senses: sound, touch, sight, and movement. In autistic individuals, the process is different, which can result in either heightened (over-responsive) or reduced (under-responsive) to stimuli.

Over-responsive

- Ordinary sounds feel too loud
- Certain textures feel painful
- Crowded, busy spaces are distressing
- May cover ears or eyes

Under-responsive

- Seeks spinning, crashing, or fast movement
- Craves deep pressure or hugs
- Seeks loud sounds or bright visuals
- May not notice sensations



Noise-reducing Headphones

- Lowers volume of background noise
- Prevents everyday sounds from being loud
- Gives a sense of control in noisy places



Weighted blanket

- Applies firm pressure across the body
- Can lower heart rate and stress hormones, similar to hugs
- Often used during meltdowns or anxiety



Fidget tools

- Gives hands a controlled action to focus on
- Can reduce anxiety when feeling overstimulated
- Offers alternative to other stimming behaviors



Quiet Space

- Removes multiple sources of input at once
- Gives nervous system a full reset than softening one sense
- Helps prevent a full sensory overload

Interaction and Communication

Interaction

- Use clear, simple, and calm language, and avoid complex phrasing. Instead of "Why don't we go ahead and get ready to head out?" try "Put your shoes on."
- Give time to process and respond. Pause for 5-10 seconds after asking something instead of jumping in to repeat or rephrase right away.
- Use visual cues like pictures, icons, or written instructions. Visual schedules or step-by-step picture cards work well for routines like getting dressed or moving between activities.
- Try to maintain routines. Keep a consistent order for daily activities like meals, homework, and bedtime, and give advance notice before changes.
- Celebrate small wins and victories. Acknowledge effort, not just outcomes, like trying a new food or tolerating a loud environment for a few minutes.

Communication

- Always be patient, respectful, and compassionate. Resist the urge to rush them or finish their sentences.
- Stay positive. Frame things in terms of what to do, like "Walking feet," rather than what not to do, like "Don't run."
- Take care of yourself. Caregiver burnout affects the quality of support you can give, so build in breaks and don't feel guilty about needing them.
- Listen actively, since each child communicates differently. Some use words, some use AAC devices, gestures, or behavior itself to communicate.
- Avoid sarcasm and try to speak directly. Say exactly what you mean, since sarcasm and idioms like "it's raining cats and dogs" can be confusing or taken literally.
- Ask one question at a time, since multiple questions at once can be overwhelming. Instead of "Do you want juice or water, and are you hungry too?" ask one question, wait, then ask the next.

Conditions that often co-occur with Autism

Anxiety

Autistic individuals often rely on predictability to feel safe, so change and uncertainty can trigger intense anxiety. Even small disruptions, a schedule change, unexpected noise, can hit much harder than they would for others. Anxiety disorders show up at notably higher rates in autistic people, so early support matters.

ADHD

ADHD and autism overlap often enough that many clinicians now screen for both together instead of assuming one rules out the other. This can mean real struggles with attention, impulsivity, and hyperactivity, even alongside intense focus on preferred interests. Recognizing both conditions together leads to better support than treating either alone.

Depression

Years of being misunderstood or unsupported can wear an autistic child down into depression. It doesn't always look like sadness, it can show up as irritability, losing interest in a favorite topic, or more frequent meltdowns. Catching these shifts early and seeking support makes a real difference.

Sensory Processing Disorder

Over- or under-sensitivity to sounds, textures, light, and movement reflects real differences in how the nervous system processes input, not a preference. What feels barely noticeable to one person can feel painful to another, or barely register at all for someone seeking more input. Left unaddressed, sensory overload is one of the most common triggers for meltdowns.

Strengths Many Autistic Kids Share

Though autism is often described mainly in terms of challenges, autistic children bring many meaningful strengths and characteristics. Not every child will relate to every strength below, like a range of possibilities than checklist.

- **Attention to Detail:** Some autistic kids notice patterns, inconsistencies, or errors that others might miss. This attention to detail can help them catch discrepancies in text, numbers, or their environment that go unnoticed by most people.
- **Sustained focus:** A special and deep interest in an area, pursued with intensity and persistence. Sustained attention over time can lead to advanced knowledge and creativity that's harder to reach with divided focus.
- **Honesty:** Some autistic people are described as having a strong sense of fairness and truth-telling. This can show up as directness and reluctance to engage in social exaggeration or “white lies,” even when it would be socially easier to do so.
- **Pattern recognition:** Some autistic people often recognize sequences, categories, and structures with notable speed and accuracy. This can show up across numbers, music, language, or visual systems, and is linked to strengths in fields like mathematics, coding, and music theory.
- **Strong memory:** Some autistic kids are detail-oriented and recall dates, statistics, dialogue, or facts long after a typical person would have forgotten, including specific conversations, sequences of events, or facts within a special interest.
- **Meaningful Relationships:** Some autistic people invest deeply in a smaller number of close relationships rather than seeking out large social circles, and they value those friendships once trust is established.

These strengths vary widely from person to person. The goal is not to expect all of them from your child but to notice and nurture whatever comes naturally to them.

Person-First vs. Identity-First Language

- **Person-first language** - “a person with autism”
- **Identity-first language** - “autistic person”

For many years, people tended to use person-first language, reflecting the idea that individuality, not the disability, should describe the person. More recently, many autistic self-advocates have preferred identity-first language, because autism is often described as a fundamental part of how someone thinks, perceives, and experiences the world. Survey research by Kenny and colleagues (2016) found that identity-first language was the more commonly preferred term among autistic adults surveyed, though preferences vary by person, family, and community.

Ultimately, the answer to the question, “what language to use” is about respect and compassion. If you are unsure how someone prefers to be described, the most respectful thing to do is ask them directly, and use whatever term they choose.



What Can I Do Next?

Every family's path looks different, but here are some concrete first steps that many caregivers find helpful.

Getting Support for Your Child

- Ask your pediatrician about referral for developmental evaluation.
- Look into early intervention services in your state - for young children, these are often free or low-cost.
- If your child is school-aged, you can request for a 504 or IEP plan through school district.
- You can look into speech, occupational, and behavioral therapy options in your area.

Supporting Yourself

- Look for local or online support groups to connect with others who understand.
- Consider keeping a simple notebook or folder with evaluations, reports, and appointments as this saves time.
- Give yourself permission to take things one step at a time.

You do not have to figure all of this out today. Small, steady steps are enough

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