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## What It's Like to Have Autism

### For caregivers, understanding autism symptoms is key to coping with them.

By [R. Morgan Griffin](#)

WebMD Feature

Reviewed by [Brunilda Nazario, MD](#)

One of the most difficult aspects of being a caregiver for someone with autism – whether a child or an adult – is the inability to understand what it's really like for him. Autism is a condition that can be isolating for the person who has it, and autism symptoms are tough to understand from the outside.

"I like to think of autism as a different way of being," says Stephen Shore, PhD, who was diagnosed with autism at age 2. "It's a nonstandard way of perceiving and interpreting the environment."

Every person with autism is different, and there is no single autistic perspective. But experts and people who have the condition say that there are some issues that are shared by many on the autistic spectrum. What are they? WebMD asked doctors, caregivers, and people with autism what it's like to live with the condition.

#### 2 Keys to Understanding Autism Symptoms

According to experts, the first key to understanding autism is to recognize that it profoundly alters how a person perceives the world.

"You could think of a person with autism as having an imbalanced set of senses," says Shore, who is an assistant professor in the School of Education at Adelphi University in Garden City, N.Y. "Some senses may be turned up too high and some turned down too low. As a result, the data that comes in tends to be distorted, and it's very hard to perceive a person's environment accurately."

People who don't have autism -- sometimes called "neurotypicals" -- are naturally good at filtering out what doesn't matter. Their senses work in unison to focus on what's relevant. "When an average person walks into a roomful of people, he notices who they are and what they are doing, and figures out how he fits in," says Geraldine Dawson, PhD, chief science officer for the education and advocacy group Autism Speaks.

"But when a person with autism walks into the room, he notices things that aren't as relevant – the sound coming from outside the window, a pattern in the carpet, a flickering light bulb," Dawson tells WebMD. "He's missing out on the relevant details that would help him understand the situation. So for him, the world is a lot more confusing."

The second key is to understand that people with autism are desperately trying to make sense of this chaos. Experts see many autism symptoms that are difficult for others to understand as attempts to communicate or to assert control over a baffling and disorderly universe.

"Most of the time, these behaviors are really an attempt to convey something," says Dawson. "As a caregiver, the important thing is to recognize that and try to figure out what it is."

What are some aspects of life that are difficult for people on the autistic spectrum?

**Sound.** Intense sensitivity to sound is a common autism symptom.

Loud noises may be painful. The din of a city street or a mall can be too much. When overwhelmed, people on the autistic spectrum may cover their ears to try to block out the noise. They may also start up self-soothing behaviors such as rocking or shaking their hands. Some people with autism also have central auditory processing disorder (CAPD), a condition that makes it difficult for them to perceive subtle differences in sound and language.

**Touch.** Just like sound, physical sensations can be exaggerated and overwhelming to people with autism. Feelings that most people barely register -- the sensation of clothing on the body, a breeze -- can be unpleasant.

Janice McGreevy, of Browns Mills, NJ, has an 8-year-old son with autism. Since age 1, his haircuts have been a terrible ordeal, but only recently could he explain why. "He told me that the individual hairs, when they touch his skin, feel like needles," she says.

**Communication.** Difficulty communicating is a common autism symptom – one of the early signs of the condition is a delay in speech. But this doesn't indicate a lack of intelligence. Instead, many children with autism simply can't discern how language works. That can be terribly difficult and isolating.

"I remember a lot of frustration when I was nonverbal as a child and couldn't communicate my needs," says Shore, who did not speak until he was 4. Although some people with autism never learn to speak, most do. But even in those who master language, communication – real understanding – can still be a problem. "One of the hardest things for many people with autism is expressing or even recognizing how they feel," says Dawson. "They're often really out of touch with their internal states and feelings." That's why some who are very bright -- with

awe-inspiring vocabularies -- may still retreat when overwhelmed, engaging in autism symptoms such as repetitive behaviors instead of explaining what's bothering them. They're simply unable to articulate it, even internally.

**Socialization.** People with autism are sometimes pegged as loners who want to keep to themselves. But Shore disagrees.

"There's this myth that people with autism don't want to socialize," says Shore. "The problem is that they don't know *how* to socialize." The unspoken rules of social behavior -- things that most other people pick up and use unconsciously -- may remain mysteries to people with autism. The result is that socializing, both as a child and an adult, is difficult and frustrating. It can lead to a lot of anxiety.

Some people with autism are forthright to a fault, says Adam Berman, a 22-year-old from Potomac, MD, who was diagnosed with autism at 18 months. "A kid with autism might walk up to a woman and just tell her she's ugly," Berman tells WebMD. "We sometimes tell the truth too much."

On the other hand, Berman says that there's an implicit advantage for parents from this particular autism symptom. "I see a lot of [neurotypical] kids who can sweet talk their way out of anything," Berman says. "But kids with autism are terrible liars. I can't lie my way out of a paper bag."

People with autism may use some of these behaviors to try to impose order on their world:

**"Stimming."** Short for self-stimulatory behaviors, this includes all sorts of things: flapping hands, echoing phrases, making noises, and walking in circles. Sometimes, these autism symptoms can be self-injurious, like head banging.

To outsiders, these may seem some of the strangest autism symptoms. But Dawson points out that they're really not so different from all sorts of habits that lots of people have -- biting fingernails, fidgeting, or bouncing a knee. People with autism might have more severe versions of these behaviors.

Many with autism characterize stimming as pleasurable; for some, stimming is a way of coping with a stressful or overwhelming situation. It can also help them concentrate. McGreevy says that her son's particular habit is to rub the back of his neck -- even to the point where it's raw or bleeding -- especially when he's reading. "I think it somehow helps him focus on the book instead of the 15 other things that are going on around him," she says.

**Compulsive organization.** Caregivers are sometimes confused, and awed, by the obsessions and compulsions that people with autism exhibit. "As soon as my son gets home from school -- within 15 minutes -- he'll have a hundred toy dinosaurs lined up in a single file in his room," says McGreevy. "It's so bizarre and it still astounds me."

A seemingly compulsive need to organize and arrange objects is a pretty common autism symptom. "We like order," says Berman. "Some kids arrange items by size, some by the same sequence of colors. They do it the exact same way, day in and day out." That organization can extend to how they break up their days. People with autism may rigidly adhere to a schedule. If it's disrupted, they can become distraught.

For a caregiver, accommodating these needs can be difficult. A very minor alteration -- a single book put upside down on the shelf, a cabinet door left open, an unexpected day off from school -- can trigger panic. But to people with autism, the disruption might feel like much more than it would to you. Seeing that single upside down book might make them feel as if the entire bookcase had been ransacked and its contents scattered.

It's difficult to say exactly what motivates these obsessions and compulsions. But Shore believes that these autism symptoms are a reaction against the disorder they perceive in the world. "I think it's another attempt to bring order and sense to an environment that seems chaotic," says Shore.

**Intellectual obsessions.** This is another common autism symptom: an exhaustive and staggering knowledge of a particular subject. To outsiders, these interests can seem baffling. And when communication is so difficult already, it can be frustrating when all your loved one wants to talk about are baseball stats or the nuances of the side arms of different *Star Wars* characters.

Again, it's important to understand that these obsessions might serve a function. In a confusing world, a specific interest -- over which the person with autism has total mastery -- can be like an anchor, grounding him. And while these autism symptoms may sometimes be frustrating for a caregiver, they also have a benefit: They offer a way in.

"If you have a child with autism who's obsessed with SpongeBob, then you had better learn a lot about SpongeBob too," says Berman, "because that's how you can talk to him."

Shore agrees. "I think the best thing for a caregiver is to find out what a child's interests are and to start interacting through those interests," says Shore.

How? McGreevy gives one example. When her son gets overwhelmed by a situation, she talks to him about his favorite subjects, animals and dinosaurs. Her effort to connect with him on one of those topics -- on his own terms -- can really help calm him down.

Caregiving for a loved one with autism can be tremendously difficult. But happily, treatment can often make a difference.

"The good thing is that people with autism can learn many of the things that they don't know intuitively," says Shore. "It just requires direct instruction." Skills that neurotypical children learn unconsciously -- such as evaluating a social situation or reading a person's behavior -- can be taught, step-by-step.

There are many different approaches to instructing children with autism, including the Applied Behavior Analysis (ABA), the Miller Method, and the Floortime method. Shore says that there is no single best approach. As a caregiver, the key is to be flexible, to try different approaches, and see what works best with your child.

### The Importance of the Autism Caregiver

Caregivers also need to understand how important they are. Both Berman and Shore give a lot of credit to their parents for their tenacity and dedication. In the early 1960s, experts told Shore's parents that their son's autism symptoms were so severe that his case was hopeless and he needed to be institutionalized. But his parents defied the experts and kept fighting, and they were right.

McGreevy is a passionate advocate for her son too. While she tries to accommodate his autism symptoms and keep a home environment in which he feels safe, she's also working constantly to expand his horizons. "I think because of his condition, my son would be fine being stagnant," she tells WebMD. "If he's going to experience new things and grow and take the next step, I need to push him."

For a caregiver, empathy is key. Just forcing a person with autism into the "real world" won't work. Instead, the first step is to try to understand his perspective a little better.

"As a parent or caregiver, you need to go into the world of the person with autism first," says Shore. "Then you can start guiding that person out."

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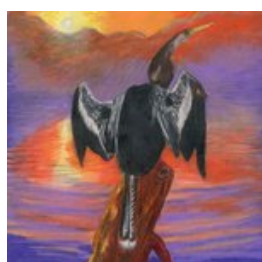


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