

"The best way out is always through." — Robert Frost

Everyone gets anxious or nervous at times. When this anxiety interferes with an individual's family, school or social life, however, it might be time to seek professional support. Experts estimate that between 11 and 84 percent of autistic individuals live with clinically significant anxiety. This wide range in estimates is due to a number of factors, including how anxiety is assessed, the sensitivity of the assessment used to detect anxiety in autistic youth, and whether or not the assessment asks about verbal reports of anxiety. The latter can be particularly important since some autistic youth don't convey emotions verbally.

I am a Licensed Clinical Psychologist and Assistant Clinical Professor of Pediatrics at the UC Davis MIND Institute in Sacramento, CA, specializing in autism and anxiety. In a recent research study that our team conducted using a semi-structured interview for assessing anxiety in autistic individuals, we found that about 70 percent of the participants had clinically significant anxiety.1

Despite the high prevalence of anxiety in autism, it unfortunately often goes undiagnosed, even though it is treatable. Some clinicians simply view anxiety symptoms as part of autism. Some children with anxiety fall through the cracks due to diagnostic overshadowing, or the failure to recognize mental health symptoms in the presence of a more salient condition, such as autism.<sup>2</sup> Other children's anxiety may go undiagnosed because they were diagnosed with autism when they were toddlers, a time when anxiety might not be as obvious.

It is important for parents to recognize that many autistic children have clinically significant anxiety. The goal in identifying anxiety in autistic individuals is ultimately to be able to provide empirically supported treatments and to help those who need it.

#### **Anxiety in Autism**

There are many different types of anxiety. Traditionally, the most common areas of anxiety, as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), include generalized anxiety, social anxiety, separation anxiety, and specific phobias.<sup>3</sup> However, Dr. Connor Kerns and other researchers have also identified distinct areas of anxiety that are more often seen in individuals with autism.<sup>4</sup> These include uncommon phobias, special interest fears, other social fears, and fears of change.

**Table 1.** DSM and Distinct Anxiety: Descriptions and Examples<sup>5</sup>

Anxiety Disorder	Percentage of Autistic Individuals Affected <sup>1</sup>	Description	Example(s)
Separation Anxiety	7%	Excessive anxiety when separating from home or attachment figures	Clings to parents and follows them around everywhere
Specific Phobia	44%	Significant anxiety induced by exposure to the feared object or situation	Needles, dentists, heights
Social Anxiety Disorder	7%	Significant anxiety induced by exposure to certain social situations	Speaking in front of class
Generalized Anxiety Disorder	15%	Persistent and excessive worry about everyday things	Worrying about possible bad things that can happen in the world
Uncommon Phobia*	15%	Similar to specific phobia but with distinct content	Fears of glasses, beards, toilets, specific sounds
Special Interest Fear*	7%	Excessive anxiety related to a restricted or repetitive interest	Excessive worry about missing the garbage truck
Other Social Fear*	8%	Significant fear around people without evidence of fear of negative evaluation	Anxious confusion, worry, and/or hiding around people
Fear of Change*	23%	Anxious anticipation of and distress following changes or novelty	Worry about changes in schedule or going to new places

<sup>\*</sup>Distinct Anxiety4

#### Signs of Anxiety

Since some autistic children don't talk about their anxiety even if they do have sufficient and complex language abilities, parents may need to rely on behavioral observations. The following are some of the main behaviors that could indicate anxiety.

- Fearful Avoidance Children who fear something will often avoid it. For example, they might avoid the grocery store because they have a fear of particular sounds.
- Anticipatory Anxiety Anxiety is often driven by a fear of uncertainty and can be present in anticipation of something that hasn't happened yet. For example, a child might worry about failing a test or finding an intruder in the house. Observing behavioral signs of anxiety before something occurs, such as when travelling to a social event, could be an indication of anticipatory anxiety.
- Defense Cascade<sup>6</sup> The defense cascade includes freeze, flight, fight, fright, flag and faint. When the body is in an anxious state, it may react in an unconventional way. Individuals might run away, which is flight, or hit someone, which is fight, because they don't feel like they have any other option.

Other behaviors denoting anxiety are described in Table 2.

Table 2. Behavioral examples of anxiety in children with ASD<sup>5,7</sup>

Common Responses	More Nuanced Responses
Avoidance	Repetitive asking for comfort items/foods
• Crying	Repetitive asking to see the schedule
Freezing behavior	"Hiding" behavior, such as covering head with blanket
Fearful effect	Hair pulling/skin picking
• Clinginess	Physical symptoms, like stomachaches, vomiting or
Sleep problems	headaches
Increased repetitive behaviors	
• Irritability	
• Tantrums	
Disruptive behavior	
Aggression	
Self-injury	

## **Treatment for Anxiety**

The two most common empirically supported treatments for anxiety are Cognitive Behavioral Therapy (CBT) and medication. One or both of these treatments may be used depending on the person's type of anxiety and its severity.

CBT usually helps children think about their thoughts and how those can relate to their behaviors and feelings. A key part of the therapy involves helping an individual develop functional coping strategies for when anxiety presents itself instead of always relying on avoidance. Even when children are unable or unwilling to speak about their fears, there are still many techniques that focus on the behaviors, such as gradually helping children face their fears through exposure therapy.

Most professionals who treat anxiety adapt the therapy to the child's specific anxiety. For example, I once treated an autistic preschooler who was terrified of leaves falling out of the sky. I asked her dad to bring a bag of leaves to the therapy session. When she saw her dad holding the closed bag of leaves, she became visibly anxious. She repeatedly asked if I would be taking the leaves out of the bag. This was a difficult situation as I knew that just having a bag of leaves in the room made the child overly anxious. I told her that if she would be brave and let me look in the bag, she would get a sticker for her "Brave" chart. I promised that I would not pull any leaves out of the bag, and simply asked if I could look inside. After she agreed, I looked in the bag. That was the starting point for my work with this preschooler.

It is often important for a child's therapist to use very small and gradual steps, such as seen in the leaf example above. If your child's anxiety is extremely high, baby steps are likely required. If your child is afraid of needles, you might start by showing pictures of needles or videos of people getting a shot. Choose black and white images over color images to start. You might tour a bloodwork lab and practice having the alcohol swab applied to your child's arm. If you take very small steps as part of an exposure plan that the child agrees upon, you will eventually be able to get to the top of the ladder. However, if you place your child in a high-fear situation, you might not be able to get to the first rung and won't be able to move forward at all.



There are a number of CBT programs that share similar concepts and approaches. I often use the Coping Cat and C.A.T. Project programs, and will adapt them to the needs of the autistic individual that I'm treating.<sup>8, 9, 10, 11</sup> These programs use the FEAR Plan to address anxiety issues.<sup>8, 10, 12</sup>

#### The FEAR PLAN

The FEAR plan, which is summarized below, is something that autistic youth and their caregivers can learn from a therapist, and, then continue to use it at home.<sup>8, 10, 12, 13, 14</sup>

## F - Feeling Frightened?

When your children feel anxious or frightened, take a moment to identify what they feel in their body. Is their heart beating fast? Are they sweating? Are they having trouble breathing?

#### **E - Expecting Bad Things to Happen?**

When people are anxious, it is usually because they expect something bad to happen. For example, a teenager might engage in anxious self-talk about asking to sit beside a peer because of a fear of rejection. It is important to identify these thoughts.

## A - Attitudes and Actions that Can Help

#### **Attitudes and Actions:**

- · functional coping thought
- exposure
- · looking for proof
- · externalizing the anxiety
- · deep breathing
- · problem-solving skills
- · change the channel

While the teenager's thoughts are not wrong, there may be more helpful ways to think about the situation. A more **functional coping thought** would be to think that the peer seems like a nice person rather than focusing on a possible rejection. Also, the teenager won't know the peer's response until action is taken. It is important to **expose** your child to his or her fear. Anxiety will lead us to avoid things that scare us, but it is impossible to overcome these fears unless we face them. Ensure that the exposure occurs in a gradual and methodic way. Other attitudes and actions that can help include **looking for proof** of the concerns that cause anxious thoughts, **externalizing the anxiety** by naming it (e.g., anxiety bully) and "fighting" back against it, **practicing deep breathing** with, for example, the "Breathe" app, using **problem-solving skills**, and choosing to "change the channel" in the mind if anxiety is causing stress.

#### **R** - Results and Rewards

Once children start implementing more helpful attitudes and actions, they will feel less anxious. The pride that comes from success can often be reward enough. Recognize these feelings. Parents can also reward positive actions and attitudes by giving a sticker for bravery or offering a treat or prize. Rewards are generally best when they recognize effort rather than outcome.

Other CBT programs that have been developed specifically for autistic individuals with anxiety include <u>Facing Your Fears</u><sup>15</sup> and <u>Behavioral Interventions for Anxiety in Children with Autism</u>. The former is a group CBT manual-based program, while the latter is an individualized CBT manual-based program with a modular treatment algorithm and a high level of parental involvement.

#### Strategies for Use at Home

As professionals, we don't expect parents to feel qualified to use CBT with their children or to be comfortable doing so. However, there are some key strategies that can be used at home to help children cope with anxious situations.



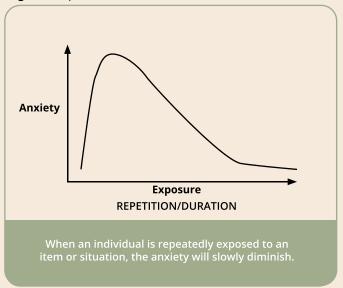
#### **EXPOSURE**

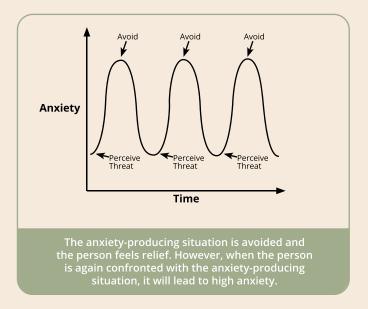
While exposure is very important in overcoming a fear, it is not always an instinctive strategy for parents. It may often be counter-intuitive to what we feel as parents. If children are really scared of something, it is often our instinct to protect them and to pull them back from it. Think about whether your parenting strategy is one of exposure or avoidance. When your child comes in contact with a place, animal or situation that is scary, is your instinct to leave that situation or to safely and gradually expose your child to that fearful item or situation?

A person with low exposure to a situation experiences greater uncertainty and is more likely to have high anxiety. However, those with considerable exposure to a situation will likely have low anxiety. Consider the following example. You take your child sledding for the first time. Your child hasn't been around much snow. You climb to the top of the hill, sit your child on a sled, and tell him or her to hold on tight. If your child gets anxious and does not want to go on the sled, you might avoid the situation by packing up and going home. On the other hand, gradual exposure exercises could help lead your child to be willing to sled down the big hill. You could offer to find a really small hill to start on, let your child sit on your lap, or slow the sled down to a crawl by using your hands and feet. After exposure to the activity three or four times, your child learns what to expect in a slow and systematic way. Over time, your child's anxiety about sledding on a hill will decrease.

The problem with using an avoidance strategy is that your child's anxiety will look more like a roller coaster. If your child is afraid of dogs and you pick him or her up and leave the area every time you see a dog, you are avoiding the anxiety. Your child's anxiety will be high upon seeing a dog, low when you avoid the situation and leave, but will peak again the next time a dog is seen.

Figure 1. Exposure vs Avoidance





#### QUESTION THE ANXIETY AND CONSIDER "FIGHTING BACK"

We can't control whether anxious thoughts come to us but we can choose how we respond to them. If children express anxiety or fear about a situation, try helping them question the anxiety rather than telling them not to worry and that it will be okay. Ask if there is any proof that something bad will happen if they sleep in their own bed, or if they can see anything creepy happening outside. You could ask them if there is any proof that monsters are real. Let them know that the anxiety could be messing with them like a bully. Advise them not to listen to the anxiety but to change the channel and think about something else instead. Have them imagine a world where unicorns, rainbows, and mermaids exist, for example, and to focus on that thought.

#### **REWARD BRAVERY AND FUNCTIONAL COPING**

There is often too much focus on times when children are anxious. Consider switching the focus to celebrating when a child moves to face a fear, even if it is just a tiny step. Teach children who are anxious how to problem-solve on their own, and be sure to praise their accomplishments. Help them set up a "calm corner" with their favorite soothing items, such as blankets, music, fidgets and more. Reward them when they go to the calm corner rather than using an unhelpful strategy, such as having a tantrum.

#### Hope for the Future

Anxiety is too often overlooked in autistic individuals. When parents and professionals watch for the signs of anxiety, it allows for an accurate assessment and diagnosis to be made. Treatments are available that can make a significant difference in the lives of those living with anxiety. If you are concerned that your child might be overly anxious or is exhibiting behaviors that indicate anxiety, consider trying some of the strategies discussed here or talking to your child's health care provider about the options available.



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