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You are here: Marina Sarris Interactive Autism Network at Kennedy Krieger Institute This is the second of two articles on anxiety in autism. The first, "Anxiety's Toll on People with Autism," explores symptoms and diagnosis. This article focuses on treatment. A related blog is The Hardest Part of Having Autism? For years, the Gilroys resisted giving anxiety medication to their daughter, Lindsay. Back then, some 20 years ago, no one knew how these drugs would affect someone with autism, like Lindsay. But her anxiety worsened, affecting her at home and school. "In her late teens, things really started falling apart," said her mother, Susan. At that point, the teen began taking an anti-anxiety drug and later her doctor added a second medication when new symptoms arose. "We've seen a marked improvement, and in my mind, it's about a better quality of life for her," Susan Gilroy said. Scientific research into autism, as well as anxiety, has grown since then, but families and patients still face the same questions as the Gilroys did. That's because research into anxiety treatments for children and adults with autism spectrum disorder is spotty, at best. There are no major clinical trials or proven protocols to guide patients, families, or doctors as to which medications work best, for which symptoms, and in which patients with autism. In fact, no anxiety medication or therapy for children with autism meets the American Psychological Association guidelines for effectiveness.1 Of course, that does not mean that people with autism must suffer with anxiety: that extreme fear and dread, sweating, restlessness, and even chest pain for some.2 Some doctors are promoting research, training others to help these patients, and publishing advice for treating anxiety in people on the spectrum. Investigating Anxiety and Autism Anxiety is one of the most common psychiatric disorders affecting people with autism. About 40 percent of youth – and up to half of adults – meet the clinical criteria of an anxiety disorder, such as social anxiety, phobia, panic disorder, or generalized anxiety, or obsessive-compulsive disorder.3-9 By comparison, the anxiety rates in adults and children who do not have autism is 18 and 25 percent, respectively, according to the U.S. National Institute of Mental Health. A few years ago, a group of researchers working with the Autism Treatment Network wanted to see what science had to say about anxiety treatment for children and teens with autism. The group, led by child psychiatrist Roma A. Vasa, became medical detectives, scouring online libraries to find out. Unfortunately, they could not find a clear answer because little rock-solid research existed. Large, long-term studies – the kind that can provide definitive proof of a treatment's effectiveness – were "sorely needed," they concluded.10 Since that 2014 article, a few more studies have been published, with "promising results" for two school-based behavioral therapies for anxiety in autism.11 In an interview, she explained, "We don't have much data about how we should go about prescribing these medications in autism, so we recommended 'starting low and going slow.'" That means doctors should start with a low dose and slowly increase it, while monitoring the patient's reactions to it. "These kids are very vulnerable to side effects," said Dr. Vasa, director of education and training, and associate professor of psychiatry, at the Johns Hopkins University School of Medicine in Baltimore, and Kennedy Krieger Institute. For core anxiety symptoms, her group listed four possible SSRI antidepressants, sertraline (Zoloft), Prozac, Celexa, or escitalopram (Lexapro). That listing was based upon data on children and teenagers who do not have a developmental disorder. The researchers noted that youth with autism often report one particular side effect with SSRI drugs: "behavioral activation," which may appear as hyperactivity, impulsiveness, or trouble sleeping.14 Other possible side effects, which are not unique to autism, are suicidal thoughts in adolescents, or worsening of mood problems in people with bipolar disorder. So these drugs "should be prescribed cautiously in youth with ASD, with close monitoring," the researchers advised. Their article, in the journal Pediatrics, includes starting and maximum doses for doctors to consider. (See Additional Resources below for a link to the article, to share with your health care provider.) Other medications that might be used to address symptoms of anxiety (not all are proven to help) include: the supplement melatonin or blood pressure medicine clonidine for insomnia, blood pressure medicines clonidine or guanfacine for aggression, self-injury and irritability that may occur with anxiety, and the beta-blocker propranolol, or the tranquilizer lorazepam, for anxiety caused by a temporary situation, such as a medical procedure or stressful event.11 However, before filling a prescription, Dr. Vasa's group suggested that families and providers first address any school and home problems that trigger anxiety, and also try behavioral therapies. For example, youth with autism may experience anxiety due to problems at school, such as bullying, unrecognized learning and speech problems, or inadequate academic and behavioral help, they explained. Health care providers can help by communicating with school staff about ways to help that student. Doctors also can help parents under stress find respite care and behavioral therapy for their child.11 Behavioral Therapy for Anxiety One anxiety treatment has been studied more often than medication, Cognitive Behavioral Therapy, or CBT for short. CBT works by helping someone change the distorted thoughts he has about himself and his life. By changing how he interprets any given situation, he can reduce negative feelings and unhealthy responses. CBT has been proven effective in the treatment of depression, generalized anxiety disorder, panic disorder, and post-traumatic stress disorder in people who do not have a developmental disorder.15 Researchers have been testing some changes to CBT to address the communication and social challenges of autism. These modifications may include using pictures, concrete language, lists, videos and social stories, along with tapping into the special interests common to autism.16 An analysis of 14 studies involving a total of 511 youth with "high-functioning" autism found that individual and group CBT therapy worked to reduce anxiety symptoms by a moderate amount.16 Although high-functioning was not defined, the studies all involved youth with an IQ score above 70, the upper limit for intellectual disability. (An intelligence score of 90 to 110 is generally considered average.17) The CBT programs that were studied varied. They had names like Cool Kids, Building Confidence, Exploring Feelings, Coping Cat, and Facing Fears, and they typically lasted from 12 to 16 weeks.16 The Value of Treatment She is doing more things at home, such as making her lunch for the next day. Treating anxiety – or any psychiatric condition – is important, perhaps especially so in people with autism. Anxiety could spill over into other aspects of a person's life. For example, people with autism often have unusually low "adaptive skills," the so-called skills of daily living, regardless of their IQ scores. Even those with average to above-average intelligence, and autism, may struggle with basic skills such as showering, riding a bus, crossing the street, shopping, or preparing a meal,18 according to a study of 417 teenagers in the Simons Simplex Collection autism project. Poor adaptive skills may affect someone's ability to live and work independently in adulthood. It is not clear why everyday living skills would lag far behind intelligence. However, one study of 52 young adults with autism suggested a link to anxiety and depression. The men and women in the study had an average IQ of 110. Those with the lowest adaptive skills also had higher levels of anxiety, depression, or attention deficit-hyperactivity disorder, according to the researchers, who were based in Washington, DC.19 Susan Gilroy can attest to the value of treating anxiety. As a teenager, her daughter, Lindsay, learned deep breathing and other techniques for managing her symptoms. She also began taking the anti-anxiety drug Buspar. An SSRI medication was later added to address a condition related to obsessive-compulsive disorder. "Overall her functioning has improved so much. I even feel like she has a little more independence. She is doing more things at home, such as making her lunch for the next day," she said. Lindsay Gilroy, now 39, also is more comfortable in restaurants and other public places, which in the past had been stressful for her, her mother said. Looking for Treatment Providers If you suspect an anxiety disorder in yourself, or your child with autism, how do you find treatment? You can start by talking with your primary health care provider, who may refer you to a specialist. Dr. Vasa recommended taking children to a psychiatrist or psychologist, with experience or training in autism, if possible. But she noted that can be difficult due to a shortage of those providers in many parts of the United States. "We need to increase the number of mental health providers trained in working with individuals on the spectrum," she said. She and others are working to increase training in autism and intellectual disability for physicians. Similarly, many U.S. communities do not have therapists trained in CBT for children or adults with autism. (To find a pediatric or general psychiatrist, psychologist, or CBT therapist near you, see the online tools listed in the Additional Resources section below.) A Call to Action In 2016, several dozen health care providers and scientists from multiple countries took part in a survey seeking their priorities for researching anxiety in youth with autism. At the top of their list were: understanding how autism affects treatment for anxiety, implementing treatments that work in "real world settings," developing objective tools for measuring anxiety, and finding ways to separate the sometimes overlapping symptoms of autism and anxiety. The group, led by Dr. Vasa, compiled the results in a recently published article. They concluded, "This study is a call to action for researchers" to work together to increase understanding of anxiety in children and teens with autism.20 People with autism also may heed this call by participating in anxiety research, if they choose. One place to learn about ongoing studies is the U.S. National Institutes of Health website, ClinicalTrials.gov. Please rate the helpfulness of this article: Kerns, C. M., Wood, J. 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