

Autism Spectrum Disorders: Non-Drug Approaches

This handout has been written for parents and other caregivers of children with autism spectrum disorders. It will give you some information on the condition and answer questions about ways to manage the disorder without prescription drugs. It discusses what may be helpful and what is not.

What is autism?

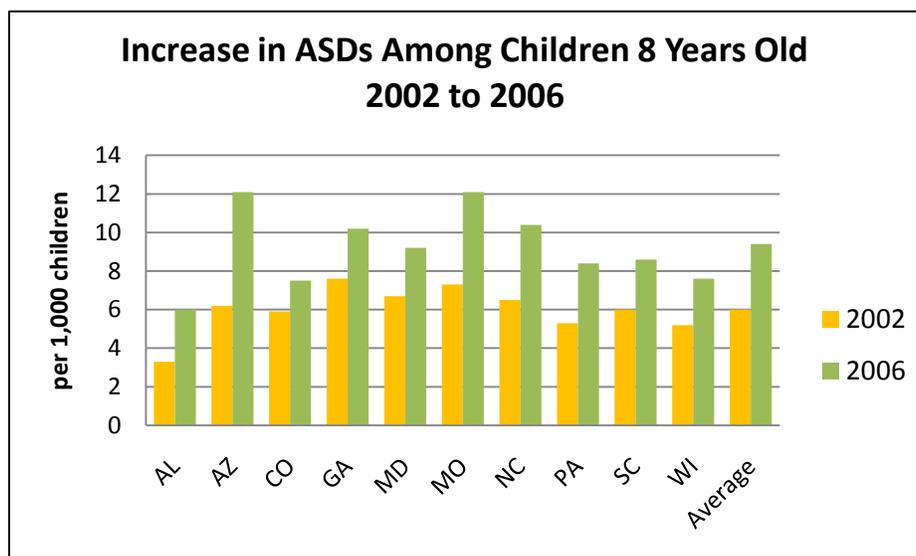
Autism is a type of developmental disability. Developmental disabilities begin early in life. They cause difficulties in the way a person gets along in the world. They usually last lifelong. Symptoms of autism generally show up before age three, often by 18 months of age. They can improve over time with treatment. The main symptoms of autism include: 1) difficulty talking, pointing, and looking someone in the eyes, 2) trouble showing emotions, understanding how others think and feel, and having a conversation 3) very rigid routines or actions that are repeated over and over again.

What are Autism Spectrum Disorders (ASDs)?

The terms *autism* and *autism spectrum disorder* refer to the same condition. The term *autism spectrum disorder* recognizes that people with autism can be affected differently. One can think of it as a group of similar disorders. Some people have only mild symptoms. Others have great difficulty throughout life. A person with symptoms anywhere in this range is said to have an Autism Spectrum Disorder.

How common are Autism Spectrum Disorders?

In 2006, the Centers for Disease Control (CDC) estimated that in the United States, one child in every 110 eight years of age had an ASD. It is more common in boys (about one in 70). About one girl in 315 has an ASD. Autism seems to be increasing. ASDs increased 57% in 10 of the 11 sites studied from 2002 to 2006. Some of this increase may be due to better efforts in diagnosing the condition.



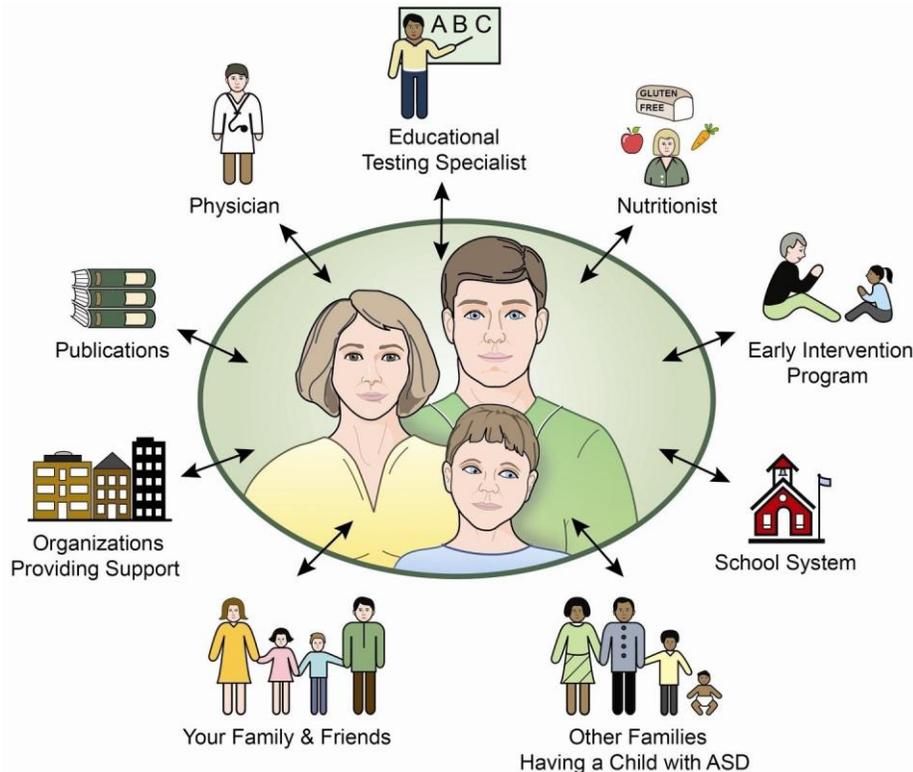


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What is being done about Autism Spectrum Disorders?

The CDC regards ASDs as an urgent public health concern. The following are all important:

- **Early screening** is now done in primary care clinics. Some clinics use a questionnaire for parents called the Modified Checklist for Autism in Toddlers (M-CHAT for short). The M-CHAT asks parents 23 questions about their child. A clinician will refer a child for further testing if results of the M-CHAT suggest the child is at risk for ASD. Not all children who are at risk will develop ASD. It is important to diagnose ASDs as soon as possible. Because a young child's brain is still forming, early intervention will give a child the best chance of developing her/his full potential. However, it is never too late to benefit from intervention.
- **Research** is needed to learn the possible causes of ASD, to try to prevent the condition. The CDC is doing research to learn what things might increase a child's chance of having an ASD.
- **Support** from others is important for persons with ASDs, their families, and communities. It helps give people with ASDs the best possible quality of life while helping families and communities cope with the challenges of ASD. **Please see page 9 for a list of resources.**



Resources for Families

You are not alone. Others can help.

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If I think my child could have an ASD or if the child has been diagnosed with an ASD, where should I turn first?

- Physician. If you have not already done so, schedule an appointment with the child's pediatrician or family medicine physician. Share your concerns and symptoms you see.
- Specialist. Ask for the names of specialists in your area who can do further testing. This educational testing is different than the screening done by your doctor. Specialists include: developmental pediatricians, pediatric neurologists, psychologists, or psychiatrists. Each state has a lead contact agency that will provide further guidance to families on the process. The National Dissemination Center for Children with Disabilities can help you identify your state's lead contact agency. Go to: <http://www.nichcy.org/FamiliesAndCommunity/Pages/Default.aspx>. Click on **State Specific Info**. Or you can call **1-800-695-0285** to find someone you can speak to in your area. Request that your child be evaluated under the Individuals with Disabilities Education Act (IDEA).
- Early intervention program. If your child is diagnosed with an ASD or is at risk for ASD, request early intervention (for birth through 3 years of age). Your state's lead contact agency can help you locate services. Go to: <http://www.nichcy.org/FamiliesAndCommunity/Pages/Default.aspx>. Click on **State Specific Info** to find where to go for early intervention services. Or you can call **1-800-695-0285** to find someone you can speak to in your area.
- School system. Your local school system will also be helpful over time.

What treatments can help the behavior of a person with ASD?

It is very important to diagnose and treat autism early in life. This gives children the best chance to develop as much as possible. Currently most treatments to encourage behavior change use aspects from two approaches: Applied Behavior Analysis (ABA) and Greenspan's Floortime Approach.

- Applied Behavior Analysis (ABA). ABA is a treatment that teaches children to change their behavior through rewards and consequences. (Consequences involve not giving rewards). Children are asked to do something. If they do the action, they are given a small reward that means something to them. If they do not do what is asked, they don't receive the reward. This process is then repeated. This may be done many hours a day.

A psychologist, Dr. Ivar Lovaas, first used ABA with children with autism. In 2010, a review was published that looked at the results of many studies done using ABA with children who have autism. The results suggest that a full ABA approach used for a long time can be very helpful. It can result in medium to large improvements in intellectual functioning, language, development of daily living skills and social skills in children with autism. Language and communication improved the most. The more hours the children were treated, the better the results.



What treatments help behavior (con't.)

- Greenspan's Floortime Approach. (Also called DIR for “**D**evelopmental, **I**ndividual **D**ifferences, **R**elationship-Based Approach). Stanley Greenspan, MD, was a professor of psychiatry and a leading authority on infants and young children with problems during development. His approach focuses on interacting with the child while playing on the floor. Floortime is a process that follows a child's lead. It encourages the child to initiate play and interaction. The child is immediately rewarded for attempts to interact and play with others. Then the child is gently challenged to master new milestones. Yet, no demands are made. The person playing with the child pays attention to the way a child responds. If the child is overly sensitive, the person may need to be soothing. If the child does not respond very much, the person may need to be more energetic. Floortime focuses on the child's feelings and relationships with caregivers. It also focuses on how the child deals with sights, sounds, and smells.

Do people with ASDs have more stomach/intestinal problems than others?

People with ASDs seem to have more gastrointestinal (GI) diseases (problems in the stomach and intestines) than the general public. Studies show that as many as 85% of children with ASDs may develop one GI illness. This compares with 12% of the general public. The American Academy of Pediatrics (AAP) recommends testing for GI problems only if a person with an ASD has symptoms that last a long time or keep coming back. People with ASDs may not be able to talk about their discomfort. For this reason, it will be helpful to give a clinician information about any family history of GI problems or food allergies. Testing for food allergies may also be helpful.

How can diseases be diagnosed in people with ASDs, since communication can be so difficult?

Diagnosing medical issues in patients with ASDs can be challenging. Sometimes difficult behavior is the only symptom of a medical condition. Knowing some common ways people with ASDs react when they have an illness can aid diagnosis. You can help by telling the clinician any behavior that is new or that has increased.

- GI disease. The following can all be symptoms of discomfort or pain in the abdomen: tantrums, aggressive behavior, injuring oneself, tics, throat-clearing, screaming, whining, sighing, moaning, repeating words or sounds made by others, groaning, grimacing, teeth gritting, pushing on abdomen, constant eating/drinking/or chewing on objects, eating things that are not food, constant tapping, arching the back or rotating the trunk of the body in unusual ways, increased movement with jumping or pacing, an increase in repetitive behaviors, irritability, an increase in challenging behaviors. One type of GI problem, gastroesophageal reflux disease (GERD), also frequently causes sleep to be disrupted. The person may have difficulty falling asleep or wake up frequently.
- Changes in the way the body regulates the hormone melatonin. This condition also can show up as a sleep disturbance. It can be treated with a melatonin supplement.
- Sleep apnea. A disturbance in sleep could also be due to sleep apnea. This is a condition where the person momentarily stops breathing many times during the night. A person with this condition may be very tired during the day.



How can diseases be diagnosed (con't.)

- **Menstruation.** You may see changes in behavior for females during menstruation. Over-the-counter pain medication or birth control pills may relieve discomfort.
- **Pain anywhere.** Changes in behavior can be a sign of pain anywhere in the body. Besides the abdomen, other possible sources of the pain should be considered, such as ears, dental, muscles and bones, urinary tract and skin. A person with ASD can have challenging behaviors during any routine situation that s/he associates with pain. The person can be taught methods to cope with the pain. This can lead to a decrease in the difficult behavior.

Should I be concerned about the food a person with ASDs eats?

Individuals with ASD may not want to try new foods. They may not like the texture, temperature or something else about a new food. Some children may eat only five foods or less. People with ASDs may have low vitamin D and iron levels and too little amino acid in their bodies. (Amino acids help the body grow and repair.) They may also eat less dairy products, so get less calcium in their diets. Some people worry that special diets recommended for people with ASD may lead to even less amino acid in the body or to bone loss. Research has shown that the diets developed for people with ASDs that do not allow certain foods do not seem to reduce the nutrients that 3- to 16-year-old children with ASDs have in their bodies. Neither children with ASDs nor the general public may be getting enough fiber, calcium, iron, vitamin E or vitamin B₁₂.

It may be very helpful for parents/caregivers to meet with a nutritionist. This specialist will help develop a healthy eating plan. The child's primary care clinician should check height and weight regularly. Growth can be affected if the child's body does not absorb or digest food properly or if the child eats only unhealthy foods. Children with ASDs who are 12- to 19-years-old tend to be more overweight than the general public.

Can it be helpful for a person with ASD to eat a special diet?

Up to 38% of people with ASD have used a special diet. One of the most well known diets for children with ASDs is the Gluten-Free-Casein-free (GFCF) diet. The GFCF diet removes two things: 1) gluten in wheat, which is found in cereals, breads, soups and snacks and 2) casein found in dairy products.

In a study published in 2006, children's scores on the Child Autism Rating Scale (CARS) and the Autism Diagnostic Interview-Revised (ADI-R) remained the same after 12 weeks on the diet. However, 9 out of 15 families in this study decided to keep their children on the GFCF diet. Parents of 7 of the 15 children reported that the language and behavior of their children improved. This included decreased tantrums and hyperactivity.

In 2010, the results of another study (the ScanBrit trial) investigating the GFCF diet were published. Seventy-two Danish children were assigned randomly to either be on the GFCF diet for 12 months or in a control group who did not go on the diet. At 12 months, 26 children were on the diet and 29 were in the control group. The study was extended to 24 months because the results were encouraging. Researchers found that children on the diet had better scores on the Autism Diagnostic Observation Schedule (ADOS) and the Gilliam Autism Rating Scale. (GARS).



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Helpful to eat a special diet? (con't.)

This improvement was seen after the children were on the diet for 8 - 12 months. This shows the importance of not giving up the diet too quickly. In the study, improvements were seen in the children's attention, concentration, social interaction and hyperactivity. After 24 months on the diet, the children also had less repeating behaviors.

If you are considering this diet for a child with ASD, first make a clinic appointment. A clinician should carefully evaluate the child's health and diet habits before the diet is started. It will take about 3 hours for you to learn about the diet. While the child is on the diet, schedule regular check-ups, so that health and growth can be monitored. You might want to ask if the clinician can put you in touch with other families following the diet and with professionals who have experience with it. This support can be very helpful. You will also find some very good information on the diet on the website of an organization called Talk about Curing Autism. Go to:

<http://www.tacanow.org/tag/gfcl/> .

The following smoothie recipe provides good nutrition, and your child may find it appealing.

Smoothie Recipe with Supplements

Use organic ingredients when possible. Makes about 1 liter which can be divided into 4 servings, or 2 days worth (a glass in the AM and PM).

- About 2 tablespoons (20 mL) of organic cold pressed extra virgin olive oil
- ½ avocado
- About 4 tablespoons (40g) of **Whey protein powder** (helps the liver make more of a natural substance called glutathione, which helps get rid of toxins. Some children with an ASD have too little glutathione in their bodies.) **Caution: you may want to omit the whey because it can be contaminated with casein during processing. If you include whey, look for a brand that is casein-free.**
- About 4 tablespoons (40g) of **PectaSol** (a supplement made from citrus fruit that can help bind toxins such as heavy metals, so the body can more easily get rid of them)
- ½ cup of orange juice (or 100% organic juice of your choice)
- ½ cup of vanilla flavored soy milk, rice milk, or almond milk
- About 4 tablespoons (40g) of flax seed (or psyllium)
- 8-10 ice cubes (or ½ cup of filtered water)
- 1 organic banana (sliced)
- 1 organic apple with peel (sliced)
- ½ cup organic frozen or fresh blueberries (and/or seasonal berries of your choice)
- Optional: can add fish oil to recipe as well.

Place ingredients in a blender and grind up until smooth. Enjoy 1 tall glass twice a day with or between meals. Store remaining mix in the refrigerator. Add more water for desired consistency. Be creative, this can be varied according to taste and availability of various fruit.

from Luke Fortney, MD

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What is antifungal therapy, and is it helpful?

Some clinicians think that a fungus, candida albicans, a type of yeast, may help cause ASDs. Or they think that the fungus makes the behavior and health problems of people with ASDs worse. There have been a few reports that the symptoms of some children improved following treatment with antibiotics for infections or drugs to kill fungus (antifungals). One child who had long-term constipation and infections from fungus or bacteria improved greatly when given a diet without yeast, sugar, and refined starches (those that are processed to remove impurities). For example, they would not be given food such as candy or white bread. Some specialists think this diet might reduce inflammation (pain, redness, swelling) and the growth of yeast and bacteria in the intestines. This could lead to less bloating, constipation and diarrhea. Some clinicians believe that yeast may cause infections throughout the body. They suggest treatment with a drug such as fluconazole that kills fungus.

At this time, these are theories, but there is no solid evidence. Antibiotics and antifungal treatment for ASDs are not recommended. It is recommended that treatment, which would change the normal bacteria in the intestines, be given only if the results of lab tests are not normal.

What is chelation therapy, and is it helpful?

Some people believe that heavy metals help cause ASDs or make them worse. They think that children with ASDs may be especially sensitive to some chemicals. Children with ASD may have higher levels of mercury in their bodies. They may also be more likely to develop mercury poisoning because their bodies are unable to get rid of the mercury.

Chelation (pronounced “key-lay-shun”) therapy is a medical treatment to help someone who has been poisoned by a heavy metal. A substance is given to bind the heavy metal, so it cannot harm the body. The U.S. Food and Drug Administration (FDA) has approved chelation therapy for metal poisoning that begins quickly and is severe. Physicians can use chelation for other purposes. This is called “off-label” use. Using chelation therapy off-label has resulted in problems for patients requiring 800,000 physician visits per year.

Critics say that chelation therapy is risky and is not likely to help patients with ASDs. They also argue that even if ASDs were caused by mercury poisoning, the damage to the cells would be permanent and could not be improved with chelation therapy. A risk of this therapy includes reducing elements needed by the body, such as copper, zinc, selenium and calcium.

Higher levels of a substance that colors the urine (porphyrin) in patients with ASDs may mean they have higher levels of mercury in their bodies. Three studies have shown that chelation therapy can reduce the level of porphyrin in children with ASDs. But there is no evidence to show that reducing porphyrin in urine improves ASD symptoms.

Research studies funded by the National Institutes of Health (NIH) on chelation therapy were stopped due to ethical concerns with the consent process to participate in the study. Because of this, it is not likely that we will see research on this topic in the near future.



Is it helpful for a person with an ASD to be given Vitamin B?

There is some thought that people with ASDs may have problems with Vitamin B₁₂ and folate, another B vitamin. These vitamins are needed for growth and overall health. While the levels of these vitamins in the body may be normal, the body may not be able to move the vitamins between cells in the way it should. Some people with an ASD may be helped by receiving shots of Vitamin B₁₂ or by taking folic acid either as a pill or a liquid by mouth. In one case, a child who had normal levels of folate and B₁₂ in the blood was found to have levels too low in the central nervous system. After she was treated with folinic acid for one year, she was able to feed herself and move about—skills that she could not previously do. (Folinic acid is a form of folate found naturally in foods. It helps the liver make more of a natural substance called glutathione, which helps get rid of toxins.) Her parents also reported that she responded more to them. She was still found to have many symptoms of autism. Unfortunately, at this time lab testing cannot determine which children may or may not be helped by additional Vitamin B. Prescribing additional Vitamin B is not standard medical practice. Until further studies are done, additional Vitamin B is not routinely recommended.

Would taking fish oil reduce symptoms for people with ASDs?

Omega 3 fatty acids are important for growth and to keep the body working right. Our bodies get omega 3 fatty acids by eating foods such as fish, fish oil, vegetable oil, and leafy green vegetables. Several studies have shown that children with ASDs have abnormally low levels of omega 3 fatty acids in their bodies. Yet other studies have found these levels to be normal in children with ASDs. This may mean that some children with ASDs, but not all, might benefit from receiving additional omega 3 fatty acids. One way to do this is by taking fish oil liquid or capsules. ([See handout on Omega 3 Fats](#)).

A few studies have been done to research this issue. Several have suggested that symptoms improved when children took fish oil. A pilot study done in 2009 showed that the ASD symptoms of 8 out of 9 children improved when they were tested at 6 and 12 weeks after they had taken 500 mg of omega 3 fatty acids via a capsule of fish oil twice a day.

These are very early studies, which have been done with just a few people. These studies also did not compare test results for children taking the fish oil to others who did not. So, at this time there is not enough evidence to recommend fish oil for children with ASDs. But the little bit of research done has been encouraging. The lack of research has been surprising because fish oil is considered safe and because it is a common complementary and alternative medicine offered for ASDs. Further research is needed, especially because fish oil has few side effects and does not cost a lot.

What are probiotics, and do these help children with ASDs?

Probiotics are good bacteria found in the intestines of healthy people and in certain foods, such as yogurt. Probiotics are often used to treat GI problems in patients with ASDs. Many stories from families suggest that symptoms improve with probiotics. Unfortunately there have been no good research studies proving this. Probiotics are generally considered safe, but they cannot be recommended until more research is done.



Where can parents/caregivers go for more information and help?

There are a number of places where you can turn for help and information. Here are a few:

- National Dissemination Center for Children with Disabilities. There is a wealth of information at this website for families and community agencies: <http://www.nichcy.org/FamiliesAndCommunity/Pages/Default.aspx> (Check to make certain you are on the “Families and Communities” tab.). You’ll find information about ASDs, places to go for help, laws on disability, and sources of support. Click on **State Specific Info** to find where to go for early intervention services. You can also call **1-800-695-0285** to find someone you can speak to in your area.
- First Signs, Inc. First Signs is a national, non-profit organization dedicated to educating parents and professionals about the early warning signs of autism and related disorders. The organization provides parents/caregivers with information and support. Go to: <http://www.firstsigns.org/concerns/index.htm>
- Talk about Curing Autism. This organization involves families with autism helping other families with autism. See their website at <http://www.tacanow.org>. Click on the *Family Resources* tab at the top. This site includes some great, no-cost information on the GFCF diet.
- Centers for Disease Control and Prevention (CDC). This website has tools and information about ASDs for families. <http://www.cdc.gov/ncbddd/autism/families.html>
- Autism Society. The goal of this organization is to improve the lives of all people affected by autism. They provide information, resources, and support. See their website at: <http://www.autism-society.org/a-family-member.html> . Click on **Resources in Your Area** to find organizations that provide support and services in your area.

What are some books I could read on ASD?

You may find the following books inspiring and helpful.

- ***A Friend Like Henry*** by Nuala Gardner. Published by Sourcebooks, Inc. in 2008. The true story of a boy with autism and the dog who unlocked his world.
- ***The Horse Boy*** by Rupert Isaacson. Published by Little, Brown and Company in 2009. The story of a family who goes to the ends of the earth to find a way into their son’s life.
- ***Engaging Autism*** by Stanley Greenspan, MD and Serena Wieder, PhD. Published by First Da Capo Press in 2006. Describes how to use the floortime approach to help children with ASDs relate, communicate and think.



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Books (con't.)

- ***Changing the Course of Autism*** by Bryan Jepson, MD, with Jane Johnson. Published by First Sentient Publications in 2007.
Describes a scientific approach to autism for parents and physicians.
- ***Autism: Effective Biomedical Treatments*** by Jon Pangborn, PhD and Sidney MacDonald Baker, MD. Published by the Autism Research Institute in 2005.
Gives information on testing and treatments.

The information in this handout is for general education. It is not meant to be used by a patient alone. Please work with your health care practitioner to use this information in the best way possible to promote your child's health.

This handout was created by Charlene Luchterhand, MSSW, Integrative Medicine Program Development Coordinator, adapted from a version written for clinicians by Robert Edwards, MD, Asst. Professor, Dept. of Family Medicine, and Amie Harvey, third-year medical student. All three are at the University of Wisconsin-Madison School of Medicine and Public Health.

References, if needed, can be found in the clinician version of this handout.

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Notes: