

saying something like, “You must feel terrible, this is a really difficult time for you.” Then let the parent talk.

- **Offer hope—but not false hope.** Lots of grandparents say, “oh, he will grow out of it.” Being optimistic is great, but offering unrealistic expectations can be very difficult for a parent to hear.
- **Be there**—Call or email and let the parent know that you are there and available for them. Even if you don’t get a response, call, drop off cookies or a favorite comfort food with a note.
- **Never take it personally**—allow the parents to process and grieve. If the parent says say don’t want to talk, reacts angrily towards a comment made, rejects your help or withdrawals, don’t take it personally. Follow up at a later time. Let the parent know that you are available to them now and in the future. **Keep in touch.**
- **Teach your children about autism.** This will help explain why their cousin or friend does not always respond to them or acknowledge their presence. Coordinate play sessions and try to incorporate things that are currently being taught. Encourage your kids to be understanding and compassionate of their friend who is different.

## How to love and connect

**Be aware of how close you stand or sit next to a person with autism.** Ask the parents what their child’s comfort zone is. Some kids like to be real close up, others need distance.

**Crouch down or sit at the child’s eye level.** This encourages eye contact. However, remember that eye contact is not necessary for them to be engaged or tuned into you. Some ways you may get eye contact is to lightly turn the child’s head towards yours (if touch is tolerated) while you speak. Or you can put a favorite toy or item near your face when the child looks at it/you, praise him for look at you.

- **Make sure the child is paying attention to you when you speak.** Say the child’s name, or touch the child (if touch is tolerated) before you speak.
- **Keep it simple.** Speak in clear simple language—using brief phrases. Be specific. “ Say look at me.” instead of saying “look.” Use real words, don’t say “ Look at the baba silly willie.” Use phrases that are familiar to the child. Avoid using ambiguous phrases—“let’s call it quits—Let’s call

it a day>“ Don’t add unnecessary words a the end of a sentence. “Finish eating now, sweetie pie”.

- **Respect parent’s wishes and the child’s needs.** If a parent tells you that Bobby does not like hugs—don’t hug him. IF he does not like his hair tussled—don’t do it. Avoid feeling a sense of entitlement: “But I hug all my grandkids!” Be careful not to overstep your bounds. This could push the child and parents away from you.
- **Persist and be patient.** Most typical children learn things quickly and only have to be shown something once. With a autistic child you may have to slow down and show them repeatedly and often hand over hand.
- **Don’t act on your hurt feelings.** Rejection is a strong feeling when you feel like you are not being responded to either by parents or the child. Just because a child does not look at you doesn’t mean he doesn’t like or love you. Hang in there and ask the parent for guidance.
- **Join a support group** To locate a support group go to: [www.autism-society.org](http://www.autism-society.org)
- **Learn as much as possible** Choose a couple of books to start with. Autobiographies of autistic persons are a great source of information. Dr. Temple Grandin is an accomplished autistic adult. Her two books "Thinking in Pictures" and "Emergence, Labeled Autistic", are both excellent. Reading an autobiography will give you the best understanding of the disorder itself. When you have learned about the disorder, you will be better able to effectively help your loved one.

## Great websites

- [autismspeaks.org](http://autismspeaks.org) Check out the video “Autism Everyday”
- [www.autism-society.org](http://www.autism-society.org) Locate support groups and gather the latest information.
- [www.autismwebsite.com](http://www.autismwebsite.com) Comprehensive list of web links
- [www.autismwebsite.com/ARI/index.htm](http://www.autismwebsite.com/ARI/index.htm) Research on the latest biomedical options for treating autism.
- [www.firstsigns.org/](http://www.firstsigns.org/)
- Google the word autism—there is a lot out there!

# Autism

Spectrum Disorders

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## The Extended Family



Autism and it’s related conditions are often misunderstood by the extended family. When a family reaches out to relatives to share this life altering diagnosis, there are many responses varying from denial to blame.

Regardless of whether or not the family relationships are close, many families are torn apart by autism. It is the attempt of this brochure to aid in the process of educating all those who will interact with a family and loved ones dealing with autism.

# Autism Spectrum Disorder

## Frequently Asked Questions

### Q: What exactly is Autism?

Autism is not a mental illness or a disease—but but a complex developmental disability that typically appears during the first three years of life. Autism is a disability that affects a person's ability to communicate, understand language, play, and interact with others. Autism is a behavioral syndrome, which means that its definition is based on patterns of behaviors that a person exhibits. Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

### Q: How did this happen?

**A:** There is no known cause for autism. It is now well established that genes play a major role in the disorder. The genetics is not, however, straightforward. No “autism” gene has been identified — nor is one expected. Autistic tendency runs in families but there are pairs of identical twins, one of whom is autistic while the other is not. Genes predispose to autism but in most cases something more is needed to trigger the development of autism — something in the environment. All sorts of things have been suggested, from infections to diet, complications of pregnancy and birth to vaccines — all of which are currently being investigated.

### Q: My friend has a grandchild with autism and he does not act the way my grandson does. How do they know it is really autism?

**A:** There is no simple test to confirm autism. It is described as a “spectrum” disorder that has no single set of symptoms. Autism affects children in different ways with varying levels of severity. No two autistic children are alike. It is defined only by a collection of behaviors that could have multiple causes. Those with autism often display

- Abnormal reactions to sensory stimuli (i.e., senses may be over- or under active).

Touches may be experienced as painful, smells may be overwhelmingly unpleasant, and ordinary daily noises may be painful. Loud noises (e.g., motorcycle going by, vacuum cleaner) and bright lights may cause inconsolable crying.

- Impaired language development. They often have difficulty expressing needs (i.e., use gestures instead of words) and may laugh, cry, or show distress for unknown reasons.

Other symptoms in young children include the following: Some autistic children do not express interest in other people and often prefer to be alone. They may resist changes in their routine, repeat actions (e.g., turn in circles, flap their arms) over and over, and engage in self-injurious behavior (e.g., bite or scratch themselves, bang their head).

- Avoids cuddling or touching
- Frequent behavioral outbursts, tantrums
- Inappropriate attachments to objects
- Maintains little or no eye contact
- Over- or under-sensitivity to pain, no fear of danger
- Sustained abnormal play
- Uneven motor skills
- Unresponsiveness to normal teaching methods and verbal clues (may appear to be deaf despite normal hearing)

### Q: The kids behavior is so bad, why don't they just spank them?

**A:** Autism is a behavior based disorder. Behaviors that may be deemed impolite and unacceptable are present in many children with autism. It is frustrating and distressing to parents when other people expect their child to act a certain way. Many children with autism are not able to make eye contact, sit still for a family meal, tolerate loud noises, or being touched by non-caregivers. All these behaviors are present for a reason and should be respected and accepted.

### Q: I try to reach out but the family never comes to family events and outings. Why is that?

**A:** If your family declines an invitation to a get together. These situations are very overwhelming for

an autistic child and usually, they will just shut down or worse "melt down". Needless to say, this is stressful for both the child and parents, *and is just no fun*. If the family does not make it, try calling and telling them you understand why they are not able to come, and just wanted to let them know you were thinking of them.

Raising and caring for an autistic child is an enormous challenge. Parents need all the support they can get. When in doubt what to do, ask your family member or friend what the best way to help them is. For parents, it is emotionally draining and a challenge financially. Be understanding and compassionate. Here are few ways you can help.

- **Never play the blame game!** Blaming is completely uncalled for, unfounded and can severely damage your relationship with the family.
- **Don't criticize.** If you disagree with a parents treatment choice, it is not helpful to say “When I raised you, I made sure you ate everything.”
- **Avoid using clichés.** Speak from your heart and the let the parent of the child with ASD know you care and are there for them.
- **Be very careful about offering unsolicited advice.** If you have a suggestion offer it in a non-judgmental way, such as, “I read an article about \_\_\_\_\_ and thought maybe it would be helpful.” If your suggestion is turned down, let it go. Do not nag, persist or take it personally. The parent may not be ready to hear it.
- **Visit, call and invite them over.** Ask questions about the diagnosis, treatment, and what you may do to help. This is one way to show that you care and accept the child.
- **Be a good listener.** Listen to what the parent has to say—taking time to listen shows you care. Allow your loved one or friend a chance to talk as much as needed. Talking helps parents process ideas and emotions. Take notice of tone of voice, body language, and facial expressions. Try to reflect feelings and offer help where you can. An offer to help to do errands, housework, research or child care.
- **Reflect feelings.** That is, when a parent says, “I a feel so sad”, instead of saying “Cheer up, look on the bright side at least he is not dying.” Try

