



# A Grandparent's Guide to Autism

*Autism Speaks Family Support Tool Kit*



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# ABOUT THIS KIT

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This Tool Kit is specially designed for grandparents of children who have been diagnosed with autism.

*This Tool Kit will help you to:*

- Learn about autism and its impact on your family.
- Discover ways to support your children who may be struggling with their child's autism diagnosis.
- Find out ways to develop the best relationship you can with your grandchild.
- Feel supported and encouraged so you do not feel lonely or overwhelmed.

Thank you to the members of the community who reviewed this Tool Kit and shared resources for this project:

Connie Anderson, Ph.D., Community Scientific Liaison, Interactive Autism Network (IAN).

Shirley Craven, Ph.D., Autism Speaks Chicagoland Chapter, Fearless Grandparents Against Autism Support Group, Chicago, IL

Bonnie Gillman, Founder and Executive Director, Grandparent Autism Network, Irvine, CA

Nan Goldberg, Founder, Our Special Grandkids, St Louis, MO

Bob and Jan Kaufman, Founder, Our Special Grandkids, St Louis, MO

Ilene Litvag, Founder, Our Special Grandkids, St Louis, MO

Nancy Miltenberger, Volunteer Chair, Walk Now for Autism Speaks, Lehigh Valley, PA

*\*For the purposes of this tool kit, the term "autism" will be used to describe children with all types of autism spectrum disorders, including Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).*

# ABOUT AUTISM

## What Is Autism?

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders.

People with autism have symptoms or difficulty in three areas:

- Social interaction
- Language as used for social communication
- Repetitive interests or behaviors.



## How common is Autism?

Today, it is estimated that one in every 88 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is not established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 54 boys is diagnosed with autism.

## What causes autism?

The simple answer is we don't know. The vast majority of cases of autism are idiopathic, which means the cause is unknown.

The more complex answer is that just as there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. The best

scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when combined with exposure to as yet undetermined environmental factors. Timing of exposure during the child's development (before, during, or after birth) may also play a role in the development or final presentation of the disorder.

### What does autism look like?

While all children with autism have problems in three main areas, appearance and severity of symptoms is different in each child. No two children with autism are exactly alike.

Core symptoms might look like:

SOCIAL	<ul style="list-style-type: none"><li>• Less eye contact, use of gestures or facial expression</li><li>• Difficulty understanding the emotions and feelings of others</li><li>• Difficulty playing with same age children</li><li>• Problems making and keeping friends</li><li>• Less sharing of interests with others</li></ul>
COMMUNICATION	<ul style="list-style-type: none"><li>• Lack of speech</li><li>• Slow to learn speech</li><li>• Unusual speech (repeats things, speech sounds unusual)</li><li>• Difficulty making conversation</li><li>• Less imitation and pretend play</li></ul>
REPETITIVE BEHAVIOR	<ul style="list-style-type: none"><li>• Repeating activities or movements (rocks, spins, flaps hands, flicks fingers)</li><li>• Uncommon, strong, limited interests (often talks about the same topic or plays with same item, knows a great amount of information on topic)</li><li>• Plays with parts of toy rather than the toy as a whole (i.e. spins wheels of toy car)</li></ul>

Source: National Institute of Mental Health (NIMH). For more information on autism visit: [www.nimh.nih.gov](http://www.nimh.nih.gov)

# REACTION TO THE DIAGNOSIS

Most grandparents are shocked when they hear their grandchild has been diagnosed with autism. You may experience a full range of emotions including sadness, blame, embarrassment, and anger. You may find yourself going through a period of mourning very similar to that of parents.

## COMMON REACTIONS

Anger – “This comes from my daughter’s spouse’s side of the family.”

Confusion – “I am overwhelmed by all of this new information.”

Denial – “This cannot be happening to my family.”

Disappointment – “Will I be able to have a relationship with my grandchild?”

Fear – “What will happen to my grandchild when I can no longer help?”

Guilt – “Did I do something to cause this? Should I have helped my daughter more during her pregnancy?”

Powerlessness- “I wish I could change what is happening to my family.”

Each person responds to the news of an autism diagnosis in a very personal manner. You may be concerned for your son or daughter and their spouse, worried about how they are coping, and unsure of how best to help. You probably have many questions, and it may take some time to find the answers. This Tool Kit will help give you find a starting place to adapt to the diagnosis, and thrive as a grandparent of child with autism.

Download the [100 Day Kit](#) created by Autism Speaks for families whose child has been recently diagnosed.

# YOUR ROLE AS A GRANDPARENT

If your grandchild has recently been diagnosed with autism you are probably feeling overwhelmed. It may take some time to figure out your role as a grandparent to a child with autism. It is likely that you still have the same priorities you had before the diagnosis.

In 2009, the [Interactive Autism Network](#) (IAN) conducted a survey of 2,600 grandparents of children with autism to learn how having a grandchild with autism changed their lives and how they supported the emotional and economic needs of their adult children and grandchildren.

Highlights of what was learned from grandparents in this survey include:

- About 30% of grandparents were the first to notice that there was a problem with their grandchild's development.
- Nearly 90% felt that the experience of facing their grandchild's situation together had brought them and their adult child closer.
- 72% of grandparents said they play some role in making treatment decisions for their grandchild.
- More than 7% said they had actually combined households with their grandchild's family so they could help them manage all that's involved in raising a child with autism , while 14% had moved closer (but not into the same home) for the same reason.
- Over 34% said they take care of their grandchild at least once a week and about one in five grandparents indicated that they provide regular transportation for the child.
- About 6% of grandparents said that a family situation had become so untenable they had taken on the role of parent.
- A quarter of grandparents reported spending up to \$99 a month on their grandchild's autism-related needs, with some contributing more than \$500 or \$1,000 monthly.

For more information please visit the [IAN Survey](#)

Many grandparents report their values have shifted to include more family commitment and family activities, that leaves them feeling content and fulfilled.

# SUPPORT FOR YOUR GRANDCHILD

After your grandchild is diagnosed with autism, you may feel unsure of how to help. It is likely that the supports your grandchild with autism needs may differ from those of your other grandchildren. Your relationship may be different but it will be equally as special and rewarding.

Be an active part of your grandchild's life. If possible, carve out special time for your grandchild on a regular schedule. Children with autism do well with predictable and consistent schedules. Try to find activities that you can do together that are structured and do them regularly. Ask the parents about your grandchild's favorite activities, ones that he or she enjoys and doesn't get frustrated with.

## WHAT GRANDPARENT GROUPS HAVE TO SAY!

- Connect with other grandparents who have children with autism in their lives!
- Ask your children if they know of other families with local grandparents.
- Join local chapters of national autism organizations, i.e. participate in your local [Walk Now for Autism Speaks](#).
- Contact hospitals, pediatricians, neurologists and autism service providers to determine if they are aware of other grandparents who may be interested in speaking with you or starting a support group.

Know that there are many treatment options and resources available to your family. For more information on autism and treatment options, visit:

[www.autismspeaks.org](http://www.autismspeaks.org)

It is also important to find service providers that work successfully with individuals with autism in your local area. Visit the Autism Speaks Resource Guide to search for resources in your area:

[www.autismspeaks.org/community/fsdb/search.php](http://www.autismspeaks.org/community/fsdb/search.php)

The [Grandparent Autism Network](#) offers some useful and practical tips on making the most of the time you spend with your grandchild with autism:

- When grandchildren visit, designate a special area for them where they can play with their favorite toys or work with their crafts. Mark the area with a sign, picture, or symbol they will recognize and return to on future visits. Use the same signage technique to indicate where they should hang their clothing; sit at the table for meals, etc.
- Prepare children for new experiences or family celebrations well in advance by frequently describing the details of the upcoming event. It will help relieve their anxieties when the event takes place. It will also help the children to understand what behavior is appropriate for the occasion.
- Post photographs or pictures of local places to visit or shop on the refrigerator or on a piece of paper and ask grandchildren to choose where they would like to go. Prepare a day schedule using the pictures in sequential order so children can anticipate the time lines for activities.
- Use the child's special interests as a basis for an activity. Keep in mind, you may not know what a child is interested in until they have tried a variety of things, and that their interests will change over time. If your grandchild is disinterested in something, try again at a later date. Since children and their preferences change regularly, so keep trying again and again.
- When dining out with your grandchildren, go to restaurants that do not require long waits or structured table behavior. Consider calling ahead to restaurants to order food if you anticipate a long or difficult wait for meals to be served.
- If you will be separated from your grandchildren for a while, put your picture on the calendar on the date you will be reunited. The child can then anticipate when you will be together again.



For additional tips visit: [www.ganinfo.org](http://www.ganinfo.org)



# SUPPORT FOR YOUR FAMILY

A major concern for grandparents is the well-being of their adult children who are parenting a child with autism. Because a child's autism diagnosis can lead to emotional, financial, and marital stress, grandparents frequently play a significant role in helping their families.



Here are some ideas on how you can help:

- Ask if you can babysit your grandchild for a few hours, or overnight, so that the parents can get a break or enjoy some alone time with their spouse.
- If you live at a distance or are not comfortable babysitting your grandchild, you may want to offer to pay for respite services if possible.
- Educate yourself and your extended family about autism. Attend seminars, read books, call or email your family to get frequent updates on your grandchild's progress.
- Become active in your grandchild's treatment and development. If you live nearby, offer to accompany your grandchild to his or her therapy appointments to observe these sessions and learn effective techniques for interacting with your grandchild.

Some ways you can emotionally support your adult children:

- Keep the door open to genuine communication by sharing your own sadness, fears, and joy. Be open and honest about how you feel about interacting with your grandchild. Relating to a child with autism can be draining and stressful. It's okay to admit that at times you feel frustrated or frazzled.
- Respect the decisions they make for their child with autism. They will appreciate your support. Ask for clarification or more information if you have specific questions.
- Share a sense of hope with your family. There is promising research underway, with many possibilities for the future. To receive updates on science and research news sign up for [e-Speaks](#), Autism Speaks e-newsletter.

# TAKING CARE OF YOURSELF

As a grandparent, you can and often do play an important role in the lives of your grandchild with autism and their families, but it is also important to take care of yourself so you can help care for your family. Balancing the time and energy spent with your grandchild and your personal needs is not easy. It takes time to achieve a balance. As with any crisis, there is no right way to react. However, there are many things you can do to look after yourself and achieve a healthy balance:

- Take time for yourself and enjoy your personal life. Stay strong and healthy. Get the physical exercise you need for good health.
- Join a grandparent support group. Talking with others who are going through the same things can help you to feel you are not alone.
- Don't hesitate to seek professional help. You may benefit from talking with a social worker, counselor, or clergy member who is objective and there to support you.
- Do something to renew your energy and give yourself a break! Reclaim past hobbies or explore new ones.

## Online Support Networks



Many grandparents are going online to connect with others and find support. The internet offers 24 hour access, requires no transportation, and provides a level of anonymity that some grandparents may find appealing.

The Autism Speaks Family Services department offers online ["Office Hours"](#) each week. Anyone can sign on, share a story or ask a question. Participants feel empowered by the ease with which they can access and share information.

# FREQUENTLY ASKED QUESTIONS FROM GRANDPARENTS

**Q:** I just found out my grandson has been diagnosed with autism. I want to help as much as I can. What can I do to help my daughter's family?

**A:** Step back and take a deep breath! Your daughter's family will need your support, but don't forget to take some time to process your own feelings about the diagnosis. Your daughter's family may also need some time to process this news before they know what types of support they will need from you. You and your daughter's family will go through a range of emotions, including sadness, shock, and anger. As a grandparent, you may grieve not only for your grandchild and how you thought things should have been for him or her, but also for your



adult child, and the more 'normal' parenting experience you'd hoped they would have. In terms of your daughter and her family, don't wait too long if you don't get a response to your offer of help. There are many ways you can be of support, such as babysitting your other grandchildren, cooking dinner once a week, helping with household

shopping and other chores. Anything that you can do to help will make their lives a bit easier during this challenging time.

**Q:** My son and daughter-in-law have their heads in the sand when it comes to getting help for my grandson, who was just diagnosed with autism. I don't want to over-step my boundary, but this is my grandson.

**A:** Be open to hearing about their emotions and be honest in sharing your concerns. Try to avoid judgments unless you feel strongly that your grandchild might be endangered by some choice his parents have made. Being patient at a time like this is very difficult, but you will get better results in the long run-if you don't force your point of view on them.

**Q:** I have a hard time connecting with my grandchild with autism. I want to have a relationship, but his behavior makes it difficult. What can I do to have a better connection?

**A:** Many grandparents experience similar reactions. It can be difficult to build a relationship and connection with a child with autism, as the very nature of the disorder complicates their social interactions.

In addition, a child's behavior may be off-putting. Some socially unacceptable behaviors can be an embarrassment in public. Be patient, and ask the parents for help. Start out spending short periods of time participating in structured activity that your grandchild enjoys. Get some success under your belt and go from there. Your good intentions will be rewarded over time.



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**Q:** What can I do to promote public awareness of autism and actively support government legislation for autism research and more adequate services?

**A:** Grandparents are in a unique position to help fight social stigmas associated with autism. Disclosing that you have a family member with autism can encourage

others to ask questions so they become better informed and aware of the disorder.

Because we live in a time of limited government funding for necessary services, your public advocacy is vital to ensure appropriate funding for research and services. Meet with, talk to, and write to legislators, government officials, public school teachers and administrators, insurance company managers, and other professionals involved in education, housing, and public transportation. Everyone listens to a grandparent, so take advantage of this!

To learn more about Government Relations and Autism State Insurance reform visit: [www.autismvotes.org](http://www.autismvotes.org)



# ADDITIONAL RESOURCES

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## Websites

Autism Speaks Family Services

[www.autismspeaks.org/family-services](http://www.autismspeaks.org/family-services)

Autism Grandparents Support Group

[www.orgsites.com/fl/autismgrandparents](http://www.orgsites.com/fl/autismgrandparents)

AARP Grandparents of Special Needs Kids

[www-static-w2-md.aarp.org/family/grandparenting/articles/grandparents-special-needs.html](http://www-static-w2-md.aarp.org/family/grandparenting/articles/grandparents-special-needs.html)

Grandparent Autism Network

[www.ganinfo.org](http://www.ganinfo.org)

[IAN Grandparents Survey Discussed on National Public Radio \(NPR\)](#)

## Books

Grandparenting A Child with Special Needs

*by Charlotte E. Thompson, MD*

The Grandparent Connection

*By Jennifer Krumins*

Letters to Sam: A Grandfather's Lessons on Love, Loss, and the Gifts of Life

*by Daniel Gottlieb*

A Practical Guide to Autism: What Every Parent, Family Member and Teacher Needs to Know

*by Fred R. Volkmar*

Your Special Grandchild: A Book for Grandparents of Children Diagnosed with Asperger Syndrome

*By Josie Santomauro*


# GRANDPARENT STORIES

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“As a grandmother with a beautiful 5 year old grandson with autism I have made it a point to learn all I can about Autism Spectrum Disorders and what I can do to help him. I do believe that it does take a village to raise any child in these tough times but it especially pertains to a child on the autism spectrum. I know that my grandparent role has changed. I will help them in any and every way I can. Myself and my family raised money for the Autism Speaks event in Atlanta on May 22, 2011 for the first time. We need funding for research and we need insurance reform here in Georgia to cover therapies and treatments for these children. Please be an active grandparent!”

- *Teresa Steppe, Atlanta GA*


“My husband and I observed our grandson (daughter and son-in-law) from birth and continued discussing his differences from other babies. (No eye contact, did not like his skin touched, continuous bowel problems, did not like cuddling, stopped talking...). His pediatrician kept saying to his parents "Give him time. He was a premie". We finally googled his symptoms and autism was the answer. His parents sprang into action learning what is autism, who did they need to help them and along came Dr. Mary and ABA!!! (Parents here no longer are on their own because Nationwide Children's Hospital has a Center for Autism Spectrum Disorders and ATN) We made ourselves available from birth to sit anytime. We followed his parent's instructions for care. Our son-in-law has great ideas about nurturing. He once told me to "swaddle" our grandson to keep him from crying. It worked! He also showed us how to hold him -- not upon our shoulder (too close), but laid out on our laps (much more comfortable for our grandson). Upon diagnosis of autism and Fragile X at 2 years, we sat in on ABA training and WOW did that help us. We learned to concentrate on our grandson's abilities rather than his disabilities. When our grandson was about 5 years, I was sitting with him and taught him to play poker. My thoughts were cards have numbers and shapes. Poker would be educational. The next morning our daughter called and asked if we had played poker last night, because at breakfast, our grandson had said, "I have a full house." 😊 When Nana arrived to sit with him after that, he pulled out the cards and we played poker. He will soon be 16



years. We have been playing double and triple solitaire and other card games ever since. I remember the first time he took my hand to go upstairs to take his bath! I had almost given up asking him, but mighty glad I did not stop. My tears just flowed. We shoot hoops. Since he was 7 or 8 years, he could out-shoot me! We have enjoyed watching him play by himself when he was a toddler. Little-by-little he allowed us to join his play. His parents strive to have him involved with age-appropriate activities, i.e. games, TV, parties...he, even though he is moderately mentally challenged, he loves music, "plays" drums, still shoots hoops, swims, joins other kids his age in activities and is thriving in his ABA program and education. Just yesterday, when asked, he told his cousin (20 years) he is in 10th grade. Why is that important? Because we had never asked him. I always asked his Mother, "At what grade is he reading now?" There is a very big difference in the answers! Mom answers, "Sixth grade". Grandson answers, "10th grade". Both are correct.

To all of those parents and grandparents who do not know what to do or how to get started, I say remember your role as a grandparent (I know some grandparents are wearing both hats.). We offer to sit; we offer to cook a meal or lots of meals; we learn what are the cue words being used now; we continue to love and cherish; we expect more and are happy when small strides are made. We know our lives have been changed; we can make a difference in our grandson's life by doing what is necessary and natural. Love enough to change yourself into the grandparent your grandchild needs."

*-Barbara Peacock, Columbus Walk Now For Autism Speaks Community Outreach Co-Chair (with husband, Roger)*



"Our 3 1/2 year old grandson Charlie is autistic. He was diagnosed at age 2. He had no school in August, so to help out our daughter with his care, we spent three weeks with them. Here are some ways I learned to help:

1. Charlie loves the playground so that is where his granddad and I took him, sometimes two times a day. We worked with him learning to climb and just gaining confidence on the equipment. We discovered that other autistic kids go to the playgrounds, and met some kindred spirits.



2. I made batches and batches of sirloin balls, chicken balls, turkey balls for Charlie...using an egg to a pound of ground meat and adding brown rice and seasonings. Charlie loves them! So does his mom because she can pull them out of the freezer and have them ready to eat in no time. There are all kinds of gluten-free, casein-free, soy-free recipes out there that grandmothers and/or grandfathers can make and freeze!

3. Between her full-time job and taking care of Charlie, our daughter has no time, literally, to research the internet for all the issues parents of autistic kids have to deal with. Charlie needs an iPad. What to do? Everyone says oh, just Google it. It's overwhelming! She said the best way to help is for us to do the research, find a product, buy it and have it shipped to her and she will pay us. So that is what my sister and I are doing for her.

4. Our daughter never has time to get her haircut. We took Charlie to the playground, then to a swimming pool--he loves the water--while our daughter could get her hair done for the first time in months.

5. Our daughter wants to take Charlie to Disneyland. We did a smaller version -- Knott's Berry Farm -- to see how he would get along. He loved Camp Snoopy and all the rides! We went late in the day. I was apprehensive thinking about his behavior at a restaurant at 9 o'clock at night after four hours at the park, but his mom was prepared. He ate first. Then, while we ate, he watched his favorite DVD that his mom had packed. Brilliant, I thought!

After experiencing just a taste of what my daughter goes through each and every day, I am starting therapeutic writing classes for parents of autistic kids to give them a community of emotional support which can be so healing.

Hope these thoughts can help other grandparents!"

- *Mary Lee, Arizona*

## About Autism Speaks

Autism Speaks is the world's largest autism science and advocacy organization. Since its inception in 2005, Autism Speaks has made enormous strides, committing over \$160 million to research and developing innovative new resources for families. The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. In addition to funding research, Autism Speaks has created resources and programs including the Autism Speaks Autism Treatment Network, Autism Speaks Autism Genetic Resource Exchange and several other scientific and clinical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2, which Autism Speaks celebrates through its Light It Up Blue initiative. Also, Autism Speaks' award-winning "Learn the Signs" campaign with the Ad Council has received over \$272 million in donated media. Autism Speaks' family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit and a community grant program. Autism Speaks has played a critical role in securing federal legislation to advance the government's response to autism, and has successfully advocated for insurance reform to cover behavioral treatments in 27 states thus far, with bills pending in an additional 12 states. Each year *Walk Now for Autism Speaks* events are held in more than 80 cities across North America. To learn more about Autism Speaks, please visit [www.autismspeaks.org](http://www.autismspeaks.org).

## About the Co-Founders

Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Senior Advisor at Lee Equity Partners and Chairman and CEO of the Palm Beach Civic Association. He served as Vice Chairman of General Electric; and as the Chief Executive Officer of NBC and NBC Universal for more than twenty years. He also serves on the boards of the Polo Ralph Lauren Corporation, Mission Product, LLC, EMI Group Global Ltd and the New York Presbyterian Hospital. Suzanne Wright is a Trustee Emeritus of Sarah Lawrence College, her alma mater. Suzanne has received numerous awards, the Women of Distinction Award from Palm Beach Atlantic University, the CHILD Magazine Children's Champions Award, Luella Bennack Volunteer Award, Spirit of Achievement award by the Albert Einstein College of Medicine's National Women's Division and The Women of Vision Award from the Weizmann Institute of Science. In 2008, the Wrights were named to the Time 100 Heroes and Pioneers category, a list of the most influential people in the world, for their commitment to global autism advocacy. They have also received the first ever Double Helix Award for Corporate Leadership, the NYU Child Advocacy Award, the Castle Connolly National Health Leadership Award and the American Ireland Fund Humanitarian Award. In the past couple of years the Wrights have received honorary doctorate degrees from St. John's University, St. Joseph's University and UMass Medical School – they delivered respective commencement addresses at the first two of these schools. The Wrights are the first married couple to be bestowed such an honor in St. John's history.