

A Grandparent's Guide to Autism

An Autism Speaks Family Support Tool Kit

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Introduction

If your grandchild has been diagnosed with autism, you have come to the right place for support. The diagnosis may have come as a surprise to you or been something you have suspected for some time. No matter what, the words “your child has autism” have changed your family’s life as you knew it. You are likely worried about your grandchild’s future and about the wellbeing of your child as his or her parent, in addition to other grandchildren you may have. Many questions are likely running through your head during this sometimes difficult time. This guide will help provide you with a better understanding of autism, and arm you with tips, tools and real life stories to guide you as you support your family immediately after the diagnosis and beyond. It will help you form a positive relationship with your grandchild and provide the encouragement your child needs to raise a child with autism.

If you are looking for additional information, the **Autism Speaks Autism Response Team** is here to help connect you with resources to meet your unique needs. They can be reached at

888-288-4762
(en Español 888-772-9050) or
FamilyServices@AutismSpeaks.org.

You can also find many more tool kits and resources at AutismSpeaks.org.

About Autism

Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences. We now know that there is not one autism but many types, caused by different combinations of genetic and environmental influences. The term “spectrum” reflects the wide variation in challenges and strengths possessed by each person with autism.

Some facts about autism

- *The Centers for Disease Control and Prevention (CDC) estimates autism’s prevalence as 1 in 59 children in the United States. This includes 1 in 37 boys and 1 in 151 girls.*
- *An estimated 50,000 teens with autism become adults – and lose school-based autism services – each year.*
- *Around one third of people with autism remain nonverbal.*
- *Around one third of people with autism have an intellectual disability.*
- *Certain medical and mental health issues frequently accompany autism. They include gastrointestinal (GI) disorders, seizures, sleep disturbances, attention deficit and hyperactivity disorder (ADHD), anxiety and phobias.*

Note: *In 2013, the American Psychiatric Association merged four previously distinct diagnoses into one umbrella diagnosis of autism spectrum disorder(ASD). These included autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.*

What Does Autism Look Like?

Autism affects the way an individual perceives the world and makes communication and social interaction difficult. Autism spectrum disorders are characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas. Taken together, they may result in relatively mild challenges for someone less impacted by autism. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interfere with everyday life.

- "IF YOU'VE MET ONE PERSON WITH AUTISM - YOU'VE MET ONE PERSON WITH AUTISM."

Stephen Shore, Ed.D.

POSSIBLE SIGNS OF AUTISM

in babies and toddlers:

By 6 months, no social smiles or other warm, joyful expressions directed at people

By 6 months, limited or no eye contact

By 9 months, no sharing of vocal sounds, smiles or other nonverbal communication

By 12 months, no babbling

By 12 months, no use of gestures to communicate (e.g. pointing, reaching, waving etc.)

By 12 months, no response to name when called

By 16 months, no words

By 24 months, no meaningful, two-word phrases

Any loss of any previously acquired speech, babbling or social skills

at any age:

Avoids eye contact and prefers to be alone

Struggles with understanding other people's feelings

Remains nonverbal or has delayed language development

Repeats words or phrases over and over (echolalia)

Gets upset by minor changes in routine or surroundings

Has highly restricted interests

Performs repetitive behaviors such as flapping, rocking or spinning

Has unusual and often intense reactions to sounds, smells, tastes, textures, lights and/or colors



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.

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 his or her 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 guide will help give you a starting place to adapt to the diagnosis and thrive as the grandparent of child with autism.

Common reactions include:

Denial: *“This cannot be happening to my family.”*

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

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

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

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

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

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

What Causes Autism?

One of the most common questions asked after a diagnosis of autism, is what caused the disorder. We know that there’s no one cause of autism. Research suggests that autism develops from a combination of genetic and nongenetic, or environmental, influences. These influences appear to increase the risk that a child will develop autism. However, it’s important to keep in mind that increased risk is not the same as cause. For example, some gene changes associated with autism can also be found in people who don’t have the disorder. Similarly, not everyone exposed to an environmental risk factor for autism will develop the disorder. In fact, most will not.

Most genetic and nongenetic influences that give rise to autism appear to affect crucial aspects of early brain development. Some appear to affect how brain nerve cells, or neurons, communicate with each other. Others appear to affect how entire regions of the brain communicate with each other. Research continues to explore these differences with an eye to developing treatments and supports that can improve quality of life.

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.

Support for Your Grandchild with Autism

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. Many grandparents experience similar reactions find that 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 a structured activity that your grandchild enjoys. Get some success under your belt and go from there. Your good intentions will be rewarded over time.

Be a 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.

Many grandparents recommend connecting 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 autism organizations or participate in your local Autism Speaks Walk. You can also contact hospitals, pediatricians and other 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. Search the Autism Speaks Resource Guide online for resources in your area.

Support for Your Child

A major concern for grandparents is the wellbeing 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 your child can get a break or enjoy some alone time with his or her 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.*

- *Remember that 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.*
- *If you are interested in public advocacy, 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!*

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.*
- *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.*
- *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 or the future.*
- *Notes of encouragement or just simply listening can be really helpful to your child.*

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 his or her family, 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 major life event, there is no right way to react. However, there are many things you can do to look after yourself and achieve a healthy balance:

Here are some ideas on how you can help:

- *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.*



Five Tips for Grandparents of a Child with Autism

This is a post by Jane Springer, a Certified Life & Style Coach focusing on empowering people to move beyond life's challenges to live life on their own terms. Using her own experiences, she guides people to improved health, increased happiness, and enhanced self-confidence. She relishes her roles as wife, mom, step-mom and grandmother. Learn more at www.JaneSpringer.com.

1. Expect the unexpected – be prepared.

With a child with autism, you never know when something will throw them into a major meltdown. It can happen when you least expect it. Case in point. My grandson is in vacation bible school this week. At the end of the program, there were 300+ kids in the big church with a loud speaker leading the group in song. He had his hands up to his ears, which generally means there is too much noise or he is in unfamiliar territory. The leader said a prayer and then said Amen (Ahmen) He went into complete meltdown mode because he thought it should be pronounced Amen (long A). Tears and yelling. This is typical of children on the autism spectrum. So we roll with the flow as best we can soothe him with the words and actions that work the best in the situation and generally get him out of that space. Humor and making it a game occasionally works. It's best to have your "go to" bag of remedies ready in case an unexpected "crisis" develops.

2. Change what you can and let the rest go (a.k.a using the Serenity Prayer).

"God, grant me the serenity to accept the things I cannot change, The courage to change the things I can, And the wisdom to know the difference."



There have been many times in the six years since my grandson was born that I have wanted to offer my opinion on everything from the food he is being offered, to the vitamins he is taking or not taking, to his bedtime habits to potty training. Most of the time I have kept my mouth shut, because ultimately, unless he is with my husband and me, I have no control over any of these things. Worrying about it all doesn't do me any good, nor would it improve my relationship with my daughter, his mother. Yes, there are times when I gently offer my opinion or ask questions, and yes, my daughter gets impatient with me occasionally. But if I want a good relationship with his parents and want to keep spending time with my grand kids, I am very careful about offering my opinion. I concentrate on what I can do when he is with me. My ultimate desire is to have a close and loving relationship with the parents and my grandchildren. So sometimes, you just have to let it go...

3. Savor the moments and make memories.

My grandson is not particularly affectionate. From the time he was a baby, we waited for kisses and hugs. There were moments when I could get him to come into my arms, but I had made it into a game. But as time has gone on, he has gotten better about doing a half-hug and sometimes a kiss, but I usually have to ask. At some very special moments, he will get up into my lap or in my husband's lap (he seems to gravitate towards him for sitting together) and do a good snuggle. What I have learned is to stop, breathe and just take in the moment when he is snuggled, thank God for the moment, and consider it a memory I can cherish. His unstoppable giggling fits make me giggle, too. An offhand quirky remark I am not expecting can be another memory. Jumping the waves with him in the ocean or his first kicks in the pool without his "swimmies". These are memories one can tuck away to be savored later, especially when he is having a bad day or is in melt-down mode. You can call upon these memories and remember the sweet little rascal he can be.

4. Learn to love the quirks, work with them and use them.

My grandson loves elevators. He likes to know how they work, he likes the feeling of riding in them (especially the glass ones), and he loves to push the buttons. We have used this as an incentive when he balks at something that he needs to do or something we are trying to teach him (like potty training). I have even used it in a meltdown situation to change things up. It generally works like a charm. We have also used it as a method of teaching him his numbers.

In my experience, it is easier to work with the fixations, rather than forcibly try to ignore those quirks. I have even made an outing of it for him and a treasure hunt by going to mall and seeing how many elevators there were there. We had cookie time at the end of the treasure hunt. A fun day with Nana.

5. Be reliable and available, when possible.

It is important to be reliable and dependable for your own children and your grandchildren. Grandparents can play a key role in their grandchildren's lives and relieve the stressed-out parents. Nothing brings home the reality of what it's like to live with a child with autism than to spend time with them and it will give you a new appreciation for what the parents go through. Be there with your wisdom, guidance and presence, if at all possible. This does not mean, however, that you are at their beck and call. It is OK to have boundaries. Do not feel like you have to give up your own life to help them out. A grandparent who has his own interests and life is a happier grandparent. Your children will respect you for it and grandchildren will ultimately know that you offer them love, dependability and a soft, sweet place to fall.



Long-distance Grandparenting: 8 Ways to Stay in Touch with Your Grandchild with Autism

This is a post by Debora L. Smith, founder and executive director of Autism Resource Mom, a nonprofit organization in Southern California that provides support, guidance and hope to individuals on the autism spectrum and their families. She is the mother of a young adult with autism, and as such, is passionate about providing social opportunities for these individuals and informational workshops for their families.

We parents know the vital role grandparents play in the lives of our kids with autism spectrum disorders [ASDs]. They provide patience and understanding, unconditional love and in many cases they help with child care, finances and health care. Studies have even found that as many as one in three grandparents may have noticed autistic-like behaviors in their grandchildren prior to diagnosis. This additional support is invaluable to us.

But not all grandparents live close by. My folks are snowbirds from Michigan – fortunately for my son, they come out to California and live for three months in the winter. My son loves every minute of it.

Over the years, my parents have learned that their grandson requires a few extras from grandma and grandpa – like a mega-dose of perseverance and an uber-willingness to plan ahead to prepare him for what's coming next. And as they've learned about him and his way of being, it has been a special joy of mine to watch my mom and dad as they teach others about autism.

It should come as no surprise that researchers classify diverse forms of grandparenting that include everything from the mentor, nurturer and role model to the hero, playmate and wizard. And these classifications hold whether you live across town or across the country.

Those of you who are “long-distance” grandparents may think you play a lesser role, but that doesn't have to be the case.

Here are eight fun ways to stay in touch with your grand kids – you may be surprised to find that you'll be indirectly helping your children, as well.

SOCIAL SECURITY

If you feel secure enough to venture into social media, communicate using the Internet. Truly, it's not that difficult, as more than half of adults over 65 are online these days. From texting and email to Facebook [FB] and instant messaging, the opportunities are endless. My dad constantly comments on my teenager's FB posts and his encouragement has such a positive impact. You can also agree on a time to call your grandchild's cell phone-or simply call on the home phone-but schedule it. Make a big deal about it. Have “news” and questions ready for an older child; for a young one, keep it simple. And be prepared to listen.

YOU'VE GOT MAIL

Who doesn't love to get mail? Never underestimate the power of a good old-fashioned letter. It doesn't even have to be long – just a few sentences. I've kept some notes my parents sent to my son when he was younger, with pictures or comics they thought he'd enjoy. We treasure these! Postcards are fun, too. Send regularly just to say you're thinking of them. You can even send a packet of self-addressed and stamped postcards for the kids to write/draw on and send back to you.

WHAT'S ALL THE HYPE ABOUT SKYPE?

First of all, it's free! All you need is a computer and a webcam and you can place a video call. This beats the plain old telephone call any day because you get actual face time – and for families separated by miles, there's nothing better.

ONCE UPON A TIME

Every kid enjoys having a loved one read aloud his favorite book. This is not just for grandparents who live nearby. You can do this via Skype. Or you can record yourself (audio/video/both) reading the child's beloved story-and mail it to him, along with a handmade bookmark or a photo of you.

SHARE AN INTEREST, PERIODICALLY

Another way to thrill the grand kids with mail is to buy them a subscription to a special magazine – and ask them to call, Skype or email you each time a new issue arrives. Invite them to tell you about the page they liked best.

PICTURE THIS

Send a disposable camera and ask your grandchild to take pictures of herself, her family, friends, pets and favorite things to do. Get the parents to mail the camera back to you. You can develop the photos and make a little album to send as a gift-or bring it with you on your next visit. You and your grandchild can spend time together while she explains each photo.

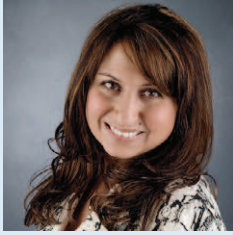
CELEBRATE THE DAY

Nowadays there's an "awareness day" for practically everything. Did you know that June 21 is National Flip Flop Day? Bet you didn't know that July 28 is National Day of the Cowboy! All it takes is knowing what your grand kid likes and this website address: <http://www.national-awareness-days.com> and you'll be "in the know." Share this site with the parents and get their input. Your grand kids will be delightfully surprised and they'll be left wondering, "How did Grandma know...?" when you send them a card or email noting the special day. Or kick it up a notch and send your grandchild a copy of "*Matilda*" by Roald Dahl on September 13 – Roald Dahl Day, of course!

SAY CHEESE!

Every time you are together with your grandchild(ren), take lots of photos, for sure, but always take a certain identical pose. For example, a picture of you and your grandchild sitting together reading, talking, eating, laughing. Whatever. The child will always know what it looks like to be with you. Frame the photos so they can surround him. If you do this each time you're together, the child will "grow up with you" in the pictures. Both you and he will enjoy them.

Down the block or thousands of miles away, we couldn't do it without you – the mentors and nurturers, role models and heroes, playmates and wizards. Nana and poppa, gram and gramps, whatever you are called, you are a wonderful asset in our lives. From the bottom of our hearts, we thank you for everything.



A Letter to Grandparents of Children with Autism

This guest post is from Linda Mastroianni who is the founder of SpeakingAutism.ca and a contributing blogger for Huffington Post Canada.

I am blessed in my life that I have a very strong support system with my family. If it wasn't for my parents and my sister, I don't know how I would have managed half of what I needed to do for son. They were (and still are) always there for me and for my kids.

Today I'd like to pay a tribute to all the grandparents of children with autism because they too help raise autism awareness and understanding. They play such a critical role in the family and especially in supporting us with our children.

To all the grandparents and step-grandparents, this one is for you:

Thank you for being the rock that kept us grounded when our world was turned upside down.

Thank you for adapting your home before anyone even asked you to.

Thank you for the times we found unexpected cooked meals, a clean house and the laundry done; we are grateful.

Thank you for being there to pick them up at school after a meltdown because we couldn't leave work.

Thank you for coming with us at therapy for the moral support and to not feel so alone.

Thank you for keeping them overnight so we could sleep in; the respite was much needed.

Thank you for your encouraging words and your endless supply of unconditional love to all of us.

Thank you for making more than one meal because you wanted to make sure they ate something.

Thank you for buying the identical items to keep at your home so we didn't have carry them around.

Thank you for taking the time to understand the triggers that can cause a meltdown.

Thank you for the countless times you held us while we wept out of frustration and helplessness that we felt at the lack of services for our children.

Thank you for not judging us when we lost it.

Thank you for educating others about autism because we know it affects you too.

Thank you for always staying strong and never showing your fear or concern in front of us. We couldn't have done this without you.

Your strength and unwavering support is what got us through this.

We shine a spotlight on you because you all have played a very significant role in the lives of your grandchildren.

Please never forget how precious you are to them and to us.

**Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.**

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

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Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

To learn more about Autism Speaks, please visit AutismSpeaks.org.