

Holiday Tips for Families of Children with Autism

HELPful hints

The holidays can be a stressful time for any family and having a loved one with autism adds another dynamic. The holidays can be, however, a time to grow closer with your loved ones, your friends, and your relatives. As with many things in life, preparation is crucial and around the holidays even more so. Here are a few helpful hints to assist with a smooth holiday season.



1. Start decorating early and make it a gradual transition.
2. Know your loved one and how much they can tolerate.
3. Prepare a photo album of relatives and guests.
4. Don't assume anything, explain everything, even to adults.
5. Bring a book that explains autism to children.
6. Practice opening gifts, taking turns, and waiting for others.
7. Prepare a kit with your child's favorite foods and familiar toys.
8. Provide yourself with escape options.
9. Don't be afraid to ask for support.
10. Role play or use video models in advance.

Also, consider having a holiday party at your own home; that way, your loved one is in a familiar environment. Any way of maintaining routines could assist in keeping the holiday season joyously uncomplicated.



Tips for Guests and Relatives

Whether you're visiting a friend or a relative this holiday season, it can be a comforting time to spend in proximity with loved ones. For a child with autism, however, the holidays can prove to be a confusing and overwhelming time. Understanding as much as you can about the child's autism can help the season go a little more smoothly, and allow the focus to center on closeness. The following is a letter authored/edited by Viki Gayhardt that can be sent to guests visiting over the holidays on the subject of what to expect from someone with autism.

"I understand that we will be visiting each other for the holidays this year! Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful.

As you probably know, I am challenged by a hidden disability called autism or what some people refer to as a pervasive developmental disorder (PDD). Autism/PDD is a neurodevelopmental disorder, which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see but which make it difficult for me to adapt to my surroundings.

Sometimes I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: some may not speak, some write beautiful poetry, others are whizzes in math (Albert Einstein was thought to be autistic), or have difficulty making friends. We are all different and need various degrees of support.

Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time, like you would if you landed on an alien planet and didn't understand how the inhabitants communicated. This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by ok. But if something, anything changes, then I have to relearn the situation all over again! It is very hard.

When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time. You might think I am ignoring you--I am not. Rather, I am hearing everything and not knowing what is most important to respond to. Holidays are exceptionally hard because there are so many different people, places and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, it's very hard work and can be extremely stressful. I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat.

If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting

in one place for even 5 minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me and my parent's will handle the situation the best way they know.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky--I literally cannot eat certain foods, as my sensory system and/or oral motor coordination are impaired. Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable! Temple Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed with sandpaper. I often feel the same way in dressy clothes.

When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!) Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things--just please be patient with me and understanding of how I have to cope...mom and dad have no control over how my autism makes me feel inside.

People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "Self regulation," or "stimming". I might rock, hum, flick my fingers in my face, flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to your world. Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kind of like self-regulation or stimming. I do this only because I have found something to occupy myself that... makes me feel comfortable, and I don't want to come out of

"I will find my place at this celebration that is comfortable for us all as long as you'll try to view the world through my eyes!"

that comfortable place and join your hard-to-figure-out-world. Perseverative behaviors are good to a certain degree because they help me calm down. Please be respectful to my mom and dad if they let me "stim" for a while, as they know me best and what helps to calm me.

Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you neurotypical folk!) It hurts my parents' feelings to be criticized for being over protective or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, Sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow tippy rules."□



All of the new sights and smells around the holidays can easily become overwhelming for someone with autism.

Enjoying the Holidays with an Autistic Child

- Robert Naseef, Ph.D.

"Whenever I talk with parents, no other question is pregnant with quite so much emotion. No matter what tradition you celebrate - Chanukah, Christmas, Ramadan, or Kwanza - this can be a difficult time of year. Images of warm cozy family life fill our heads. It's a time to be close, to give thanks, and to look forward. It's a time to celebrate the lives of children, a time that families get together and assess where they are, notice changes and remember losses. There are many dimensions to the holiday season as visions of our own childhood holidays dance in our heads, but there is a special twist when your child is not developing typically. How we handle these times can set us up for a depressing winter season, or it can be

an opportunity for growth and love. To grow, we have to acknowledge the often painful loss of the child we dreamed of and the challenges of having a child who is very different from what we imagined. After all, what parent doesn't look forward and envision an excited child having fun with new toys? A thoughtful mother told me how she was enjoying the holidays this year as opposed to watching her son ignore his toys while she wept. She had learned to be realistic, now that her son who has autism is four. She wanted to buy him that first remote controlled car for four-to-six year olds, but instead she bought him some toys labeled 12-18 months that she knew he would enjoy. She also knows she will enjoy him this way, and she has the hope that he will develop from where he is, especially by becoming interested and having fun interacting with the rest of the family.

This woman loves her son dearly and has learned through her tears and grief to dream new dreams. She is now looking forward to being on the floor with him and following his lead in play. This process of letting go and moving on takes time, but

most people do get there. Children with special needs have so much to teach their parents and the rest of society, particularly about accepting our differences and living in peace and harmony.

Holiday time is exciting for children, and children with special needs are no different. About 10-12 percent of school-aged children have disabilities and will receive holiday gifts this season. As opposed to wishing and pushing for a child to be normal, acceptance of the child where he or she is encourages further development. This brings us to an important lesson that all children can teach us in this current season for giving. More than the new toys, it is their parents' time and attention that is so exciting and wonderful for children. It is the fuel for their development into kind and giving little people. In the consumer-driven rush this holiday season, let's not forget what's really important. Let's connect with mind and heart to our families and friends and all whose lives we touch. Let's spend quality time together. As Ralph Waldo Emerson wrote many years ago, "The only true gift is a portion of thyself." □





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Resources

- Gayhardt, Viki. (2008). Dear Friends and Family. *Autism Society of America*. Retrieved November 16, 2009 from http://www.autism-society.org/site/DocServer/Dear_Friends_and_Family.pdf?docID=11141
- Naseef, Robert. Ph.D. Rudy, Lisa Jo. (2006). Enjoying the Holidays with an Autistic Child. *About.com*. Retrieved on November 17, 2009 from <http://autism.about.com/od/copingwithautism/f/holidayfaq.htm>
- Rosenberg, Squid D'Artagnan. (2006). Autism Families: Surviving the Holidays. *Squidalicious*. Retrieved November 12, 2009 from <http://www.squidalicious.com/2006/12/autism-families-surviving-holidays.html>
- Sayers, Bonnie. (n.d.). Holiday Hints. *Bella online*. Retrieved November 12, 2009 from <http://www.bellaonline.com/articles/art47638.asp>
- Twelve Tips for Helping People with Autism and Their Families Have a Happy Holiday. (n.d.). *Autism Society*. Retrieved November 12, 2009 from http://www.autism-society.org/site/PageServer?pagename=holiday_tips