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Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

Twelve Tips for Helping Individuals with Autism Have a Happy Holiday Season

While many happily anticipate the coming holiday season, families of people on the autism spectrum also understand the special challenges that may occur when schedules are disrupted and routines broken. Our hope is that by following these few helpful tips, families may lessen the stress of the holiday season and make it a more enjoyable experience for everyone involved. The following tips were developed with input from the Autism Society, the Indiana Resource Center for Autism, Easter Seals Crossroads, the Sonya Ansari Center for Autism at Logan and the Indiana Autism Leadership Network..

1. **Preparation is crucial for many individuals.** At the same time, it is important to determine how much preparation a specific person may need. For example, if your son or daughter has a tendency to become anxious when anticipating an event that is to occur in the future, you may want to adjust how many days in advance you prepare him or her. Preparation can occur in various ways by using a calendar and marking the dates of various holiday events, or by creating a social story that highlights what will happen at a given event.
2. **Decorations around the house may be disruptive for some.** It may be helpful to revisit pictures from previous holidays that show decorations in the house. If such a photo book does not exist, use this holiday season to create one. For some it may also be helpful to take them shopping with you for holiday decorations so that they are engaged in the process. Or involve them in the process of decorating the house. And once holiday decorations have been put up, you may need to create rules about those that can and cannot be touched. Be direct, specific and consistent.
3. **If a person with autism has difficulty with change, you may want to gradually decorate the house.** For example, on the first day, put up the Christmas tree, then on the next day, decorate the tree and so on. And again, engage them as much as possible in this process. It may be helpful to develop a visual schedule or calendar that shows what will be done on each day.
4. **If a person with autism begins to obsess about a particular gift or item they want, it may be helpful to be specific and direct about the number of times they can mention the gift.** One suggestion is to give them five chips. They are allowed to exchange one chip for five minutes of talking about the desired gift. Also, if you have no intention of purchasing a specific item, it serves no purpose to tell them that maybe they will get the gift. This will only lead to problems in the future. Always choose to be direct and specific about your intentions.



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12 HOLIDAY TIPS CONTINUED...

- 5. Teach them how to leave a situation and/or how to access support when an event becomes overwhelming.** For example, if you are having visitors, have a space set aside for the child as his/her safe/calm space. The individual should be taught ahead of time that they should go to their space when feeling overwhelmed. This self-management tool will serve the individual into adulthood. For those who are not at that level of self-management, develop a signal or cue for them to show when they are getting anxious, and prompt them to use the space. For individuals with more significant challenges, practice using this space in a calm manner at various times prior to your guests' arrival. Take them into the room and engage them in calming activities (e.g., play soft music, rub his/her back, turn down the lights, etc.). Then when you notice the individual becoming anxious, calmly remove him/her from the anxiety-provoking setting immediately and take him/her into the calming environment.
- 6. If you are traveling for the holidays, make sure you have their favorite foods, books or toys available.** Having familiar items readily available can help to calm stressful situations. Also, prepare them via social stories or other communication systems for any unexpected delays in travel. If you are flying for the first time, it may be helpful to bring the individual to the airport in advance and help him/her to become accustomed to airports and planes. Use social stories and pictures to rehearse what will happen when boarding and flying.
- 7. Be prepared and stand firm.** Accept well-meaning but unwanted advice with the phrase, "I'll have to think about that," and smile.
- 8. Prepare a photo album in advance of the relatives and other guests who will be visiting during the holidays.** Allow the person with autism access to these photos at all times and also go through the photo album with him/her while talking briefly about each family member.
- 9. Practice opening gifts, taking turns and waiting for others, and giving gifts. Role play scenarios with your child in preparation for him/her getting a gift they do not want.** Talk through this process to avoid embarrassing moments with family members. You might also choose to practice certain religious rituals. Work with a speech language pathologist to construct pages of vocabulary or topic boards that relate to the holidays and family traditions.
- 10. Prepare family members for strategies to use to minimize anxiety or behavioral incidents, and to enhance participation.** Help them to understand if the person with autism prefers to be hugged or not, needs calm discussions or provide other suggestions that will facilitate a smoother holiday season. If the individual becomes upset, it might also be helpful to coach others to remain calm and neutral in an effort to minimize behavioral outbursts.
- 11. If the person with autism is on special diet, make sure there is food available that he/she can eat.** And even if they are not on a special diet, be cautious of the amount of sugar consumed. And try to maintain a sleep and meal routine.
- 12. Above all, know your loved one with autism.** Know how much noise and other sensory input they can tolerate. Know their level of anxiety and the amount of preparation it may take. If you detect that a situation may be becoming overwhelming, help them find a quiet area in which to regroup. And there may be some situations that you simply avoid (e.g., crowded shopping malls the day after Thanksgiving). Know their fears and those things that will make the season more enjoyable for them.

Don't stress. Plan in advance. And most of all have a wonderful holiday season!

<https://www.autism-society.org/holiday-tips/>



16 Tips for Enjoying the Holidays With an Autistic Child

Smart Ways to Save Your Holidays

By Lisa Jo Rudy

Holidays can be tough for children with autism. They may be even tougher on their parents and siblings. But the good news is that for every problem you might encounter, there are real-world solutions you can put in place to make the season bright!

Sensory Issues

Many people with autism have [strong negative reactions](#) to bright lights, loud noises, strong flavors and smells. The holidays can sometimes feel like a sensory assault! When you're facing the probability of a sensory meltdown, here are some strategies to try:

- 1. Avoid the [sensory challenges](#).** Do you really need to take your child shopping with you, or could you possibly shop online, find a sitter, or ask someone else to pick up some items for you? These days, Internet options are just as good as in-person shopping; you can even get the grocery store to deliver.
- 2. Choose sensory-friendly options.** While flashing lights on a Christmas tree might overwhelm your child, gently changing lights might charm him. Luckily, modern LED Christmas lights offer multiple ways to enjoy the twinkling. You can also, in many cities, find ["sensory friendly" Santas, shops](#), and other holidays offerings. If these aren't available in your hometown, consider having a small, low-key "visit from Santa" in your own home.
- 3. Have a plan B in case of sensory overload.** Some children can handle crowds and noise, but only for a limited amount of time. If you decide to take your autistic child to a big holiday event, be sure to have an alternate "plan B" just in case it turns out to be too much for him. If it's just the two of you, you can simply leave. If other siblings or friends are coming along, know in advance which adult will take your autistic child out of the difficult situation while others can stay and enjoy the experience.

Need for Routine and Predictability

Most kids with autism thrive in situations that are consistent and predictable. The holidays, of course, are precisely the opposite. Many families welcome new people, new sounds, new smells, new things in the house, and major changes to routines of eating, sleeping, and playing. How can you help your autistic child enjoy these special annual experiences?

- 1. Pick and choose.** Most people with autism can handle some change to their routines, but very few can flexibly handle complete disruption. Knowing your child as you do, you can pick and choose the kinds of changes he or she can handle most easily. For example, you may decide to put up a tree but stay at home at Christmas, or travel for Christmas but pack along your child's favorite toys and videos and stick to his usual schedule.
- 2. Practice.** If you're heading for a special event or experience, plan and practice behaviors ahead of time so your child is ready to handle something new. For example, if you're going to church for Christmas services, take your child to the decorated church at a quiet time. Talk with the minister or priest about songs and prayers to expect. How will the Christmas service be the same as or different from other services? If there's an order of service, share it and walk through it with your child. And, as always, have a Plan B just in case your child can't make it through the entire service.
- 3. Say "no thanks" when necessary.** You're invited to a holiday party and the "whole family" is asked to come. It'll be crowded and loud, and it will keep your child up past bedtime. In cases like this, the best option is usually to just say no (or to hire a sitter if that's a practical option).

Continued on page 4.



16 TIPS FOR ENJOYING THE HOLIDAYS CONTINUED....

Coping with Extended Family

Holidays are especially [tough with extended family](#). That's because every family has traditions and expectations, and few families really understand the special needs of an autistic child. Your mom may feel hurt that your child doesn't like her cranberry sauce, while your dad can't figure out why he doesn't want to watch the football game. Your sister may be angry because your child won't play with his cousins, while your brother is sure your child just needs a little "tough love." How can you cope with so many challenges and expectations, all at the same time?

1. **Pre-plan and stick to your guns.** You already know which traditions are going to create problems, and you probably have a good idea about how your child will react to each one. Knowing all this, you can make a plan ahead of time and share it with family. The key, of course, is that you'll have to stick to your plan even when family members would rather you didn't. For example, you may need to say "we'll be delighted to open Christmas presents with you in the morning, but then Bobby needs downtime until dinner." You may even need to firmly tell family members that you will stay in a hotel rather than joining cousins at Grandma's house for the weekend.
2. **Bring your own necessities.** If you're leaving home for the holidays, don't assume that anyone else will have what your child needs to maintain his or her equilibrium. Bring along a DVD player and videos. Pack your child's favorite foods, blankets, pillow, and other paraphernalia.
3. **Explain your child's needs.** Before your mom has a chance to get hurt feelings, be sure she understands that, for example, your child is on a [gluten-free diet](#), or won't eat new foods, or will [love a Christmas present](#) provided it's exactly the toy he's expecting and nothing else. Help extended family by giving them some hints and tips about how best to reach out to and include your child (and you) by modifying expectations, choosing specific foods, or turning on particular TV shows.
4. **Help your family to help you.** Most families want to do all they can to make you and your child feel welcome, but they need to know what's helpful. Help them to help you! Let family members know which Christmas presents would be most welcome, which kinds of games and activities your child enjoys, and how to tempt your child with his favorite foods. If it's appropriate in your family, you can also ask for time off so that you, too, can enjoy time with relatives without your child in tow.
5. **Have an escape route.** Both you and your child need to know what will happen if you get too much of family fun. What will you tell your family, and where will you go to get away? Is there a quiet room available? If not, can you head home or to a hotel room?

More Holiday Tips

Here are a few more ideas for staying calm and happy during holidays on the autism spectrum.

1. **Keep it simple.** You have enough on your plate without having to become Martha Stewart too! Put up a tree, wrap some presents, and stick a turkey in the oven. You're done!
2. **Establish your own traditions.** Kids with autism love traditions, and so does everyone else. Try creating your own family traditions that are easy and fun for everyone, including your autistic child.
3. **Lower your expectations.** Sure, Christmas can be a time when family and friends get together for a joyous celebration. But it can also be a time of quiet contemplation, or mellow family afternoons, or even an evening [in front of the TV](#) watching favorite movies.
4. **Take care of your other kids.** If your autistic child has siblings, be sure they don't get pushed aside as you take care of your child with special needs. If there are traditions or experiences they love, they should get the chance to enjoy them. That may mean a little juggling and hard work, but your children will thank you!
5. **Take care of yourself.** It's easy to get so busy with your autistic child's needs that you forget your own. But, of course, your child's experience will depend a great deal on your own feelings of calm and seasonal joy. That means you, too, need a chance to experience your favorite holiday events, movies, and food. Call on the help of friends and family, if you need to, but be sure you get that special shot of holiday cheer that makes season bright!

<https://www.verywellhealth.com/holidays-with-an-autistic-child-4156462>



DANA'S VIEW ON HOLIDAYS

Autism and Holiday Gatherings

"Dear Family and Friends" Tips for relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism.

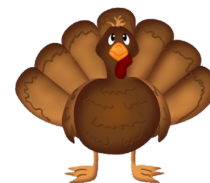
This article appeared in the [holiday 1999 issue of ASAP News!](#) (Volume 3.5), the Autism Support and Advocacy Project and Potential Unlimited Publishing. It was originally reprinted by permission of editor/author, Viki Gayhardt, in the FEAT Daily Newsletter November 28, 1999

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 parents will handle the situation the best way they know.

Continued on page 6.

DANA'S VIEW ON HOLIDAYS CONTINUED.....

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 food 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.

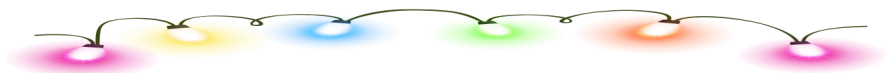
Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kind of like self-regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable, and I don't want to come out of 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.

I am a unique person--an interesting person. 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!

<http://www.danasview.net/holiday1.htm>



HOLIDAY SURVIVAL GUIDE

Holiday Survival Guide



1. Take two cars, so one of you can leave early if need be.
2. Bring a sensory fidget bag (Koosh balls vibrating pens, etc).
3. Bring child's favorite DVD, If staying overnight bring portable DVD player.
4. Bring Ear plugs to block noise.
5. Offer to host the dinner since your child will be more comfortable at home. The extra work will be worth your sanity. Ask everyone to bring a dish.
6. Simplify the Tree (perhaps with no lights and unbreakable ornaments). Keep the Menorah up high or have a children's menorah.
7. Decorate only one room and keep it blocked off.
8. Decide to do only one outing either Christmas Eve or Christmas Day or one night with extended family for Chanukah.
9. Talk with extended family members ahead of time put a sign up sheet on the fridge for relatives to sign up to spend 1:1 time with your child in a room that has less stimulation, and his/her favorite activities. Be sure to sign up yourself, this way relatives get to spend quality time with your child and see them at their best. You get to enjoy the gathering as well. A win-win. Failing that Tag Team with your spouse or family member.
10. Limit the number of people invited to make the group smaller.
11. Let relatives know ahead of time not to be disappointed with your child's reaction to their gifts.
12. Bring your child's favorite foods and snacks .
13. Leave when things are going well, right after the party's peak.
14. Order a readymade Holiday Dinner.
15. Always have your stuff packed and by the door so that you can make a quick exit.
16. Set up a system ahead of time for your other children who may want to stay longer.
17. Take your child for a car ride to give them a break in the action.
18. Give your child a job to do with the company such as passing out treats.
19. Give your child a disposable camera and designate him as the official photographer. For those who like to role-play you can provide scripted questions and the child can interview each person. Pair with an older child who can be the journal-keeper.
20. Get a sitter and plan at least one night out with some adult company.
21. For the child who is sensitive to clothing, have scissors handy to snip the tags out right away.
22. Enjoy some quiet time with your immediate family.

<http://arccm2015.wpengine.com/wp-content/uploads/2014/05/Holiday-Survival-Guide.pdf>

BOOK REVIEWS

The holidays are a good time to think about how autism impacts the entire family. The following books help family members better understand their loved one with autism and how to support him/her, as well as address other family-related issues.

Grandparent's Guide to Autism Spectrum Disorders

Making the Most of the Time at Nana's House

Nancy Mucklow



Grandparent's Guide to Autism Spectrum Disorders: Making the Most of the Time at Nana's House

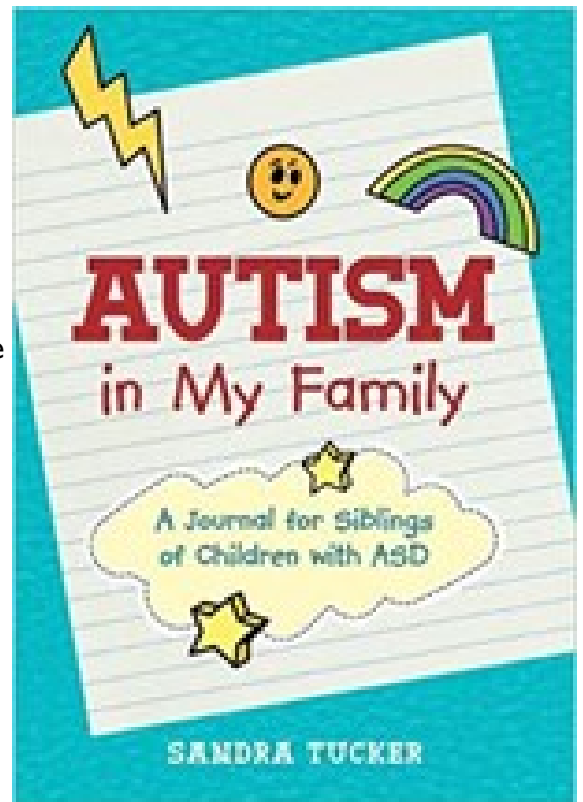
by Nancy Mucklow

Help make time at grandma and grandpa's house better for everyone! Most children fit almost instinctively into grandma's house - obeying, trying to please, and finding their groove. Children with ASD have a harder time adjusting and even a brief visit can leave a grandparent mentally and physically exhausted. But it doesn't have to be that way! Nancy Mucklow's book serves as a practical guide to turning grandparents' concern, confusion and initial sadness for their grandchild with ASD into a relationship of acceptance, confidence, and realistic expectations. Full of intriguing and thought-provoking anecdotes and rules of thumb, **Grandparent's Guide to ASD** includes tried-and-true recommendations on how to deal with sensory issues, new and unfamiliar environments, dietary considerations, emotional meltdowns, communication, selecting the right toys, participating in school and family events, and much more. More knowledgeable and better prepared after reading this positive and upbeat book, grandparents can stay relaxed as they use the helpful strategies that allow them to better connect with their unique grandchild.

Autism in My Family: A Journal for Siblings of Children with ASD

by Sandra Tucker

The relationship between siblings can be tough, and the sibling dynamic can be further challenged when one child has autism. This interactive workbook is designed to help siblings of children with autism navigate that relationship. Introducing the experience of autism in simple language, children are encouraged to complete activities that identify differences and strengthen relationships. This book is focused on understanding and supporting a sibling while developing individual emotions and identity. The pages are designed to be drawn on and personalized by the child. Ideal for young people aged 8-12 who have a sibling with autism, the activities can be completed with a parent's guidance or on their own. Full of resources, strategies, and exercises, this workbook can support parents or professionals working with children and facilitate healthy sibling relationships.





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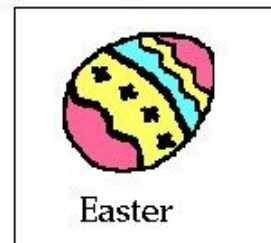
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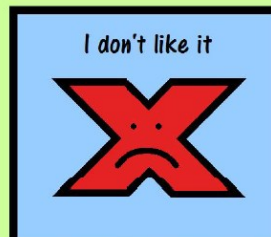
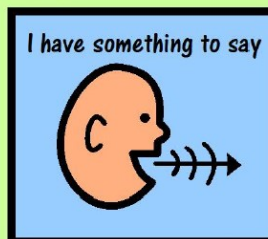
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VISUALS



Holiday Pragmatic Communication Support Cards



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