

Dear Family and Friends

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"Dear Family and Friends" was written for the purpose of it being sent to relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with Autism Spectrum Disorder. This article was reprinted with permission from editor/author, Viki Gayhardt.

Dear Family and Friends:

" 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 may 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. 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. Also, I have a hard time eating neatly, calling me "pig" just confuses me!

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 kinda 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 awhile 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 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!"