

Living with ASD during the Holidays

By Jeanette McGuire Carman

The holidays can be overwhelming for any of us – and they are far, far more overwhelming for our six year-old daughter Alexys, who was diagnosed with Autism last December. Routines cannot be kept and the hustle and bustle can be just too much for her to take. There are not enough social stories to be told this time of year. I spend more time preparing Lexy for what is coming than I spend preparing our home or cooking food for all the gatherings.

Just recently I was looking at photos from Christmas past. They reminded me that Lexy doesn't show much emotion, certainly not the excitement you would see from a typical child. I remember one year her grandpa got her a bike, and while she smiled, she was not nearly as excited as a parent would expect her to be. This was before her diagnosis, and I remember feeling confused and frightened, wondering why she acted this way.

I feel as though I have to explain to people that even though they can't see it, I can tell she loves the gift. Those who don't know her will not perceive the elation that most children show. But I see her becoming over-stimulated as the excitement rises. At her grandparents' home, as the exchanging of gifts gets closer, she doesn't know what to do with the anticipation, and soon the episode seeking, running around, spinning, jumping and squealing take over. That leads to the inevitable meltdown, and then we find a quiet corner where we can unwrap our gifts.

She becomes so overwhelmed, overloaded by the number of people at family gatherings. Last year, while her cousins played in her room, she retreated to our bedroom. There she shut the door and watched TV by herself for a long while. When I went to check on her, she was perfectly content in her safe place, and did not seem to be bothered by the fact that she could plainly hear the other children playing across the hall. For me this was heartbreaking. I felt all her isolation for her.

Bustling from house to house, from activity to activity, can be extremely stressful for Lexy, especially with all the scary unknowns she knows are coming. I can see her avoiding these unknowns at all costs. Even preparing to go to church on Christmas Eve can be too much for her. We must start the process with plenty of time to spare. Last year we bought a pretty dress and tights that she tried on several times beforehand, and she loved them. But when it came time, with all the chaotic events from the day bearing down on her, she was unable to handle the tights and wore her new dress with leggings. Before the second service began, she was asking for a comfy old outfit. I had seen this reaction coming, and I was prepared with a favorite pair of pajamas and slippers for her.

For us, Christmas can be such a huge struggle. We have to scale back our activities, plan as many of the events at home so she can retreat when needed, so she can feel safe. Turning down invitations, I often feel like I say "we just can't do that with her" far more than I should—as if I am being selfish. I'm not sure everyone understands how every day can be hard on her, and the holidays that much harder.

What is it like living with ASD on the Holidays? It's a stark reminder of our reality, the reality that ASD affects our family, our little girl. How she struggles with a holiday that so many other children love and look forward to. How the anxieties of the upcoming festivities are often just too much for her. How we don't get to see that excitement, that priceless look, that surprise in her face when she unwraps that one special toy.

The real heartbreak is the knowledge that she can't show or feel those emotions. We will not see her wear those super cute striped tights that look so perfect with her dress. As girly as she wants to be, she just can't handle the frilly fabric. It hurts knowing that playing with her cousins isn't nearly as enjoyable as it was for us as children. She will likely not form those bonds that we still share with our cousins. It's a time of heartbreak all over again. It's not the Christmas joy that we envisioned for our family.

All this said, we cherish our holidays with Lexy all the same. She is funny and silly. On Christmas morning, when it's just us, her brother, her Grandma and her Aunt and Uncle, she can be herself. She and her big brother can laugh and argue, enjoy each other. Her Daddy can read her the Birth of Jesus story and she can ask all the questions she wants about the meaning of Christmas: Why did Mary have a baby? Why was He named Jesus? Why was he born in a barn?

She can take breaks when she needs to. She can stop and play with a gift at her own pace before moving on to the next one, and we can share in those perfect moments. We can make new memories and we don't have to worry about feelings getting hurt—the stares we get, even from family, when, in their eyes, she doesn't seem to be acting appropriately. But in our own little time and space, we have our moments that help us get through, that allow us to find joy in the day. Those are the moments that make all the preparation for the big day so very worth it.

So while holidays are hard on her, they are also a blessing because regardless of her diagnosis, we will make the best of everything. We use this time to remind her of the true meaning of Christmas, and that we love and accept her just as she is. She can be exactly who she is, and that just as with every other obstacle that will come her way, we will be right here by her side, seeing her through.

And that's why we do everything we possibly can to make things secure and comfortable for Lexy, and we always will. This is how we enjoy every bit of the holidays and always treasure the memories they create. This is our time to reflect on the very blessing she is. She's not the blessing we expected, but she is still the greatest blessing we could ever have. She is our heart, our pride, our baby, and no diagnosis will ever change that.