

# Traveling, Trips & Dining Out

## Life with A Child with ASD, One Mother's View

*Raising a child with Autism Spectrum Disorder (ASD) isn't always easy, and you shouldn't feel that taking care of yourself is an act of selfishness—it's a necessity. Because, being emotionally strong will not only better prepare you to care for your child but also give you the focus and understanding you need when your child throws you a curveball. With children on the autism spectrum, there are no consistent expectations or habits. It is a spectrum, and every child has varying abilities and challenges, and handles situations differently. Keeping an open mind and retooling information to fit your family's needs is some of the best advice. Read on to share in our family's journey and, I hope, take away some ideas and tips to ease you on your own parenting path, wherever it may lead.*



**F**ifteen years ago, we adopted Matthew, our son with special needs from Russia. He was 3 years old at the time. While

I had grown up with a brother with Down syndrome, I never imagined that I would learn so much in such a short period of time. Being an architect, I tend to constantly focus on environmental issues and spatial strategies that support the success of our three children living together. Why would this be an issue? Well, our son with ASD can struggle with good choices, and during the bad choices,

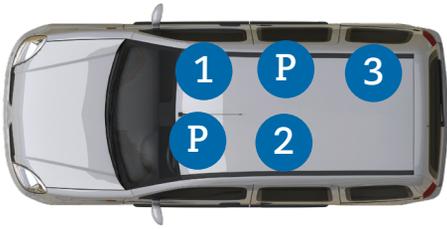
he can cause incredible frustration for our younger children, which can result in conflict. Learning strategies and maturing with age, our life with Matthew has become simpler. But, especially during the early years, these practices really helped our family.

Starting from the early years, our two younger children continuously experienced invasion of their personal space or trespassing in their room. Matthew would steal or break their belongings (though rarely with malicious intent). In addition, Matthew would

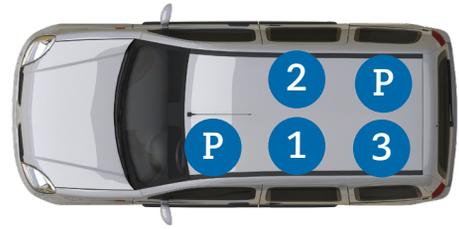


by Cathy Purple Cherry, ALA, LEED AP

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**Seating Strategy  
Car Travel**  
P = Parent  
1, 2 = Non ASD Child  
3 = ASD Child



abruptly interrupt their conversations and most often ignore their topic of conversation to focus solely on his perseverating thoughts. I have watched how these repeated behaviors have had a permanent impact on the rest of the family. We have lived in a heightened state like a tightly wound rubber band on the propeller of a paper plane always waiting for the next explosion. We lost the ability to allow ourselves to relax.

I caught myself applying strategies to spatial areas that, at a minimum, permitted a slightly reduced chance of violent interactions. Now, I want to share a few of these basic strategies with

other families who are faced with similar circumstances—ones I wish I had known when I first started to tackle these issues.

**BUYING A CAR.** This is something to carefully consider. For our family, limited space was stressful, so if you have the choice, I'd suggest buying a car that has three rows of seats. If you believe that you can somehow teach your young, still-developing children how not to negatively react to the behaviors of your child with ASD or not be impacted by them, then it is my opinion that you are expecting too much maturity from your young children. I call my current 13-year-old son an "old man." Why? Because he has been forced

to witness things in his life that many other children will never experience in their lifetime. Like what? He's endured punching, body slamming and head banging—all hard. The positive outcome is that I have two children who are becoming compassionate of all differences and who will become incredible advocates for their brother and others as they mature.

Okay, back to the car. I found at various times through the last 25 years that it was basically impossible for my child with ASD to be seated next to my other children. It certainly depended upon the age of the kids and the length of the trip. Strategically, 80 percent of the time I sat

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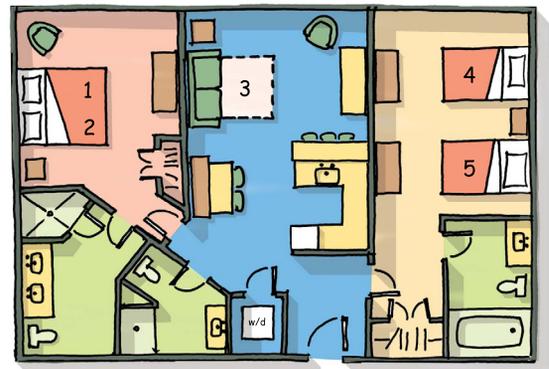
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in the back rows with my children so that the front row always separated one of them from him, and I was at an arm's reach to deal with any other issues. What worked best for our family was to always announce the seating arrangement while still in the house or as we exited the door. I would then make sure to reverse that seating assignment on the return trip in fairness to the children. I had a Suburban with a video screen so that I could use this as a distraction. If we were traveling in a two-bench seated car (my husband's or a rental), then I always sat in the back between my children. You may think this sounds extreme, but my goal was to find small amounts of peace for our family in a life of constant challenges.

For long trips, we ultimately came to accept the fact that the trip either could not include our child with ASD or we had to fly him ahead to someone (Grandpa) waiting on the other end while we drove. Otherwise, after about two to three hours, the togetherness did not work for us. Now, there was nothing about this decision that harmed my son Matthew. He loved

flying! He thought it was special. He loved talking the ear off of the person next to him on the plane, and he loved arriving early to a relative's house. If we chose not to have him come, he was also okay because he always had the choice. When the option was to see a new movie and play his computerized games at home or go camping, he chose to stay home. So, as a family, we began trips without him when he was about 14 years old, and he chose to stay home with a dear family friend (who was also his autism technician). The hardest part of this decision was that we as his parents had to learn how not to feel guilty. We quickly learned he was as happy as a lark for the break from all of us as well as for the respite that he likely experienced.

**RESERVING A HOTEL ROOM.** Here was another experience where we had to live and learn. When making your hotel reservations, I urge you to ask



**Sleeping Strategy  
Hotel Room**

1, 2 = Parents    4, 5 = Non ASD Child    3 = ASD Child

the reservation specialist on the phone for 30 minutes. I can remember when reserving at a large national lodge, I called them three times with questions before I made the reservation (there are only two rooms in this huge lodge that support us). When you decide that you are going on a special trip together as a family, you need to make sure that the room supports success, not failure. How so? I knew that anything I could do to have a room with

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more floor area and two bathrooms was very important. I learned the hard way when we had one of our worst nights as a family in a single hotel room. From that point forward, I vowed to make sure that the architecture of the room supported the best stay. I only wish hotels would design rooms specifically for families like ours. And wouldn't it be grand if Disney had a resort for families with children with special needs!

What do you need spatially for success? For your child with ASD, I

recommend you get a bathroom just for him or her. All others in the family can share a bathroom if needed. This helps allow the child the time to do their routine, which often can require multiple prompts. I also recommend a truly separate sleeping area for your child with ASD, not just a separate bed. Our son rocks himself to sleep every night. This motion and related noise can be annoying to his siblings. It is just best to give him the space he needs along with space for everyone else's needs. Matthew also hoards stuff and organizes his possessions in an obsessive way (OCD). So, if the other children touched his items, things would explode, which is all the more reason to give our son his own defined space with separating walls.

Watch the circulation patterns, too. This will help avoid conflict. I would often set up Matthew's snacks in a certain area and make it clear that they were his. This prevented him from crossing his siblings' path abruptly, which might lead to physical contact. After I had these extensive conversations with reservation

clerks, sometimes even having them fax room layouts to me, I then noted in my address book as to specifically which rooms (or cabins when camping) supported our family. Now I have a record of them. What I know our family cannot do is stay in one hotel room with two queen beds and a roll out. Our kids do best when we have more than one room for them. Oh my, I learned that the hard way.

**DINING OUT.** Please remember that finding humor in everything keeps you and everyone else sane in difficult situations. You first need to understand that Matthew chews with his mouth open. He also often does not wipe his mouth without us prompting him, even though he feels the food on his lips. He tends not to use his knife and frequently picks up whole food items with his fork to then place the item in his mouth. So, I know he can put a whole waffle in his mouth as I've seen it many times now. French toast and large potatoes also fit. These table manners have led to a lot of yelling at the table among our children. As his

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**Anna has big brown eyes, a dog named Mo and has never spoken a word.**



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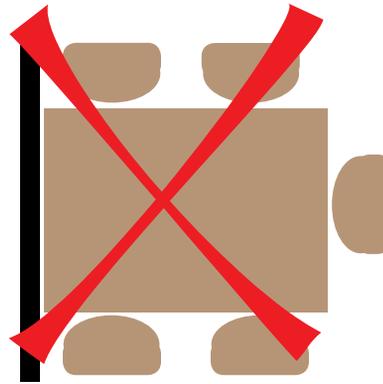
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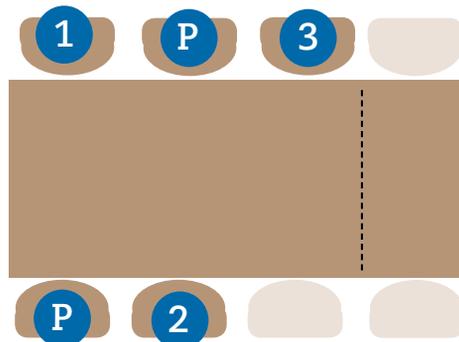
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NO

**Seating Strategy Dining Out**  
P = Parent  
1, 2 = Non ASD Child  
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YES

siblings would ask him to close his mouth, Matthew would frequently open his mouth even more to irritate them. At home, this ultimately led to different dining times for our kids, as this was the best solution for reducing the conflict, and picking and choosing battles.

When dining in public, the social pressure of strangers watching us helped with controlling these poor manners. However, his brother and sister had experienced the conflict so many times that their expectations were always that he would slip up. Therefore, I learned several tricks for us to dine out more successfully.

**First:** I recommend you always get a table large enough for your child with ASD to sit across from you and next to the other parent—not across from or next to his sibling if the relational times are bad. I always ask for a table for six even though we are five. If I asked for five, they would always seat us at a four-top with a chair on the end. Well, that just set us up for a big disaster. I remember once being at a lodge that only had four-tops (thus five with a chair) or eight-tops. I ultimately insisted on an eight-top, but they wanted to argue with me that this larger table was

for larger parties. I had to explain exactly what happened when my three children were placed in tight quarters. With detailed explanation, they accommodated us.

Matthew's movements are also always broadly stroked, somewhat like a bull in a china shop. His judgment for placement of things on the table or for reaching over full glasses of water with coat sleeves is poor. He might pick up the salt and think it is funny to shake it at his brother. So, as long as I can get him seated in such a way that his feet will not touch his siblings' feet and they do not have direct eye contact without turning their heads, I can reduce the opportunity for conflict.

**Second:** Determine your child's menu choice before going into the restaurant. I have learned to ask Matthew what he wants to eat before we enter a restaurant. He struggles greatly with his processing, so giving him a menu filled with options is not a good choice. Identifying to him three things and asking which one of the three he wants allows this decision to be easier for him and causes us all much less stress

**Third:** Restaurant choice is key. Loud and casual restaurants are also always a must for success for our family. If conflict

or arguments do occur, they are not quiet. "Reserved" is not a word that will ever describe the way our children behave together when out in public or at home. Should conflicts begin, I have also found that removing one of the children as soon as possible assists in controlling the escalation that occurs.

When Matthew was younger, I would place a mirror in front of him at the table so that he could see how his habits impacted his presentation at the table. He never liked this, as he was honestly disgusted with seeing his food. This allowed him to see what others were seeing and ended up being a constructive tool. Ultimately, while he has improved his skills, the reality is that he will always struggle with remembering to wipe or close his mouth, so we have better success if we strategically place our other two children in such a way that direct visual contact is not easy.

In closing, I hope you find these tips and techniques useful and that they lead you to happy family travels and dining. Raising a child with any special need isn't easy, and you need to remember that you and your family's health and well-being are always a top priority. Just as I tend to change our environment to help create a more successful experience, you too can find ways to improve your family's experiences together. I realize now that with my son being 25, I have learned incredible lessons over the many years that have gone so quickly. Today, Matthew lives independently in a fully-funded group home and has a full-time job. We couldn't be more proud!



Cathy, principal of Purple Cherry Architects, is the mother of an 25-year-old on the autism spectrum and her brother has Down syndrome. Through her lifelong interactions and observations of her brother and son, and her educational advocacy for her son, she has an acute awareness of relevant triggers and environmental issues that impact individuals with disabilities. For more information, see [purplecherry.com](http://purplecherry.com) to visit her Purposeful Architecture work or read other articles she has written.



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