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Surviving the Holidays with Special Needs Children

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There are families who enjoy holiday traditions - visits to relatives, caroling with friends, trying new foods, and dressing up in fancy clothes. There are families who pack at the last minute and dash off to Grandma's house, and families who plan the visit for months in advance, eagerly anticipating the journey as well as the destination.

And then there are families with special needs.

While everyone else looks forward to the holiday season with its festivities and excitement, these families face each December with a feeling of growing dread - or at least trepidation. For families with special needs, the thought of leaving the comfort zone of home can be terrifying. Interacting with family members and friends who don't know your child - and perhaps won't see past his g-tube, his stimming, or his wheelchair - isn't easy.



"The holidays can be a nightmare for the delayed child who relies on a schedule and structure for equilibrium," says Lynn M. McLean, LCSW, a child and family psychotherapist in Houston, TX. Changes in schedules, unfamiliar faces, and all the signs of the season can be overwhelming for children with special needs, and knowing how get through - and even enjoy - the holidays doesn't always come naturally.

Add to that the stress that comes with trying to explain your needs to family and friends, and you may be feeling decidedly Grinch-like.

Especially if you're planning to spend time away from home, you do need to take the time to prepare your hosts says Dr. Scott Barkin, a licensed clinical psychologist and certified school psychologist and the executive director of Block Institute, a not-profit New York agency serving developmentally delayed children and adults. He suggests telling people, "Our family has special needs. Should I be diplomatic with you, or can I just say what I need to say and talk bluntly?" It's

a dramatic opening, to be sure, but it sets the tone for an important conversation that has to take place in order for everyone to get on the same page.

Before you head out for the holidays, here's what to do.

Do some soul searching. You can ask friends and relatives to tell you what might make them uncomfortable - but you should only ask the question if you're prepared to hear the answer, cautions Dr. Barkin.

Decide what matters. What are you hoping to accomplish with this trip? "If your goal is to see people, you don't have to make a secondary goal of the trip to try new foods," says Dr. Barkin. Set yourself up for success and stick to what really matters.

If it matters, do it. "If a family tradition feels really important, then pursue it," says McLean - but do so with an exit plan in mind. She suggests taking a close friend or relative along on the trip to see Santa at the mall, for example, so that if a delayed child needs to leave, typically developing siblings can still have their own experience. "I don't think a delayed child should be denied the chance to participate, but I do think parents' expectations should be reasonable," she explains.

Give people a chance to help you. If you're spending the holidays with people who love you and want to help you have a good experience, give them a fighting chance. Tell them what to expect - and be honest. Tell them what works, and what doesn't. For example, says Dr. Barkin, "Don't be afraid to say, 'My child drools. Here's how we deal with that. Are you going to be cool with that?'"

Keep your kids in the loop. "We don't tell kids what will be happening often enough," says McLean. "The bigs decide things, and then never fill the kids in on the plans." She recommends explaining to kids what will happen as frequently as possible, for example: "Tomorrow will be different. No school. We're going to Nana's after breakfast. You'll see Nana, Papa, Aunt Judy, and cousins. If you need help, you can come and tell me."

Stand up for your family. It's not easy to feel like you're on the defensive all the time, but it's important to let people understand your reality. "Behavior that might be considered bratty can be more understandable if folks understand there's a reason for it," says McLean. "Stay simple, though: 'He's afraid of loud noises, and I think that's why our singing bothered him. That's why he covered his ears and shouted.'"

Say no when you need to. That picture-perfect holiday? It only exists in pictures. Figure out which events and activities are the must-dos, and let go of the rest. "A polite 'That won't work for us,' might be the most honest and accepted way to decline an invitation. Folks tend to read into it what they'd like," says McLean.

With some smart preparation, your family should survive the season - and maybe even spread some cheer.