

Happy Holidays?

By Al Freedman, Ph.D.

"It's just not fair!" exclaimed my sister-in-law as we arrived for a family holiday gathering in the winter of 1995.

Only a few weeks had passed since our son, Jack, had been diagnosed with SMA and given a year to live by doctors. Looking back, we were all still reeling from the shock of the news. It was a very difficult and awkward time for everyone in our family. Certainly, for Anne and me, life didn't feel fair at all. We had just been taken from the life of a typical couple with a 6-month-old baby and thrown into what felt like an incomprehensible situation.

But I also realized we needed to take care of Jack despite our sense of shock and deep despair. As we arrived that evening in December, my mind was on other things...Were any of Jack's young cousins sick?... If one of the other kids had a cold, would we need to leave and go back home?.....Did we remember to bring all of the right supplies, activities, and equipment?..... What kinds of questions might Jack's young cousins have about his condition?.....Would Jack be able to get to sleep with all of the noise and excitement of the extended family?... How could we possibly "act happy" when we were feeling anything but happy?.....

That first holiday season with our families was very hard for many reasons. Being with Jack's young cousins, who are healthy, reminded me of all the things Jack would not be able to do and all the milestones we would miss out on as parents. And for our relatives, spending time with us could not have been easy, either.

Somehow, we managed to get through that weekend with our family, and, as always, Jack enjoyed himself. In the five years since, our family gatherings have become larger and in some ways more challenging. As a result, we are very careful when planning for the season. Making decisions about the Thanksgiving, Hanukkah, Christmas, and New Year's holidays is no simple matter for families with SMA-affected children.

Stress and the Holiday Season

Families with healthy children often experience significant stress during the holiday season. For families with children affected by a neuromuscular disease, every season presents its challenges, and the holiday season can be especially difficult. Traveling, wintertime illnesses, and family dynamics can make for a difficult combination of hurdles.

When people experience stress -- from exhaustion, conflict, personal difficulties, or any other source -- our bodies respond by producing adrenaline and other stress hormones to protect us. These hormones are produced when our bodies perceive danger of any kind. However, if these hormones signal the body to react to the threats produced by stress, we are less protected from other types of threats such as bacteria and viruses. In short, our immune systems can be weakened if our hormonal 'attention' is diverted.

For our children affected by a neuromuscular disease, the holidays are an inopportune time to have a compromised immune system. But the risks are obviously greater during this time of year. Holiday events and travel expose your child to more people carrying viruses. The pace and intensity of the season is markedly different than the leisurely summer and the rhythms and routines of the fall. And research has repeatedly demonstrated an association between negative emotions such as anger or worry, and a weakened immune system. If you plan to spend your holidays with extended family or friends, considering a number of issues in advance may help you and your family have more fun, less stress, and keep healthy during your "vacation."

Traveling with your Child

Until we are away from home, we may take for granted the unique accommodations, equipment, and routines we have established to support our SMA-affected children. There is nothing more stressful than traveling away from home and not having what you need to properly take care of your child. If this occurs, your vacation will likely not feel like a vacation. Creating, keeping, and updating a list of necessary equipment and supplies can be helpful as you plan and pack for your trip.

Before committing to a trip away from home, Anne and I first ask ourselves three questions. First, do the advantages of a change of scenery outweigh the challenges associated with packing, moving, and unpacking all of Jack's medical equipment, supplies, clothes, and activities? Second, is the home or hotel sufficiently accessible for Jack's wheelchair? And finally, to make the trip worth all of the work involved, what is the minimum number of nights we should stay?

Prior to leaving on your holiday trip with your family, be sure to inquire about handicapped access at local malls, museums, and parks, as well as where you will be staying. Ask where the nearest hospital is located. If your child uses a bipap machine, ventilator, feeding pump, or other medical equipment, don't be shy about asking your host, hotel manager, or the local fire company about the availability of a generator in case of a power outage. Equipping your car or van with the medical equipment your child may need, along with an electrical source, may give you some additional peace of mind.

Family Issues

Whether hosting holiday events at your home or traveling, gatherings of extended family can be stressful. For medically fragile children, there is a higher than usual risk for serious illness during the winter season. Unless you are very clear with your relatives about the seriousness of the risks to your SMA-affected child, you may find yourself in the uncomfortable position of needing to separate your child from others who are ill, or leaving the family gathering altogether. By contacting your relatives prior to your visit, you can plan together to avoid awkward tension when children are ill in the presence of your medically

fragile child. In our family, we have "taken turns" in these situations. Sometimes we have offered to not come to a family event when another child is ill, while on other occasions our brothers and sisters-in-law have taken the initiative to keep their children at home when they know Jack will be joining a family gathering.

When together with your relatives, you may sense some discomfort from family members who have not spent much time with your SMA-affected child. This is natural, as well-intentioned relatives may be concerned about saying or doing the wrong thing. Maximize time you spend with family members who respect and support you and your child. Spend less time with those who add to your stress because of their issues or lack of sensitivity to your family's special situation. You can help your relatives by taking the initiative to talk about your child's interests, abilities, and achievements, and by offering to answer their questions. It can also be helpful to take occasional breaks from the large gathering and invite a relative out for a walk so you can talk individually.

Your family may not know what type of holiday gift to bring for your

SMA-affected child. If asked, let others know what your child enjoys.

If you sense others are concerned about choosing an appropriate gift,

feel free to offer some ideas. By modeling a positive attitude and by talking about your child as any other parent does, others will follow your lead.

Including Other Children

Young children in the extended family may initially shy away from interacting with your child because of their discomfort. Other children may get too close to your child too quickly. One way to reduce the anxiety of young relatives is to bring activities in which your child can participate together with them. Because Jack enjoys stories and games on his computer, swimming, children's videos, and listening to books read aloud, we arrive prepared for those activities, and we encourage Jack's young cousins to join him. There's nothing more satisfying to Jack than having the company of one of his cousins while he shows off on his computer or enjoys a story.

As other children become acquainted with your son or daughter, be prepared to receive and answer their questions. Provide an honest and

simple answer when responding to a young child's questions. It is not uncommon for a wide-eyed child to approach us in the local mall, watching in amazement as Jack cruises along in his power wheelchair.

"What happened to him?"

"My little boy's name is Jack. Jack has very weak muscles, so he can't do the same things you can do."

"Will he ever get better?"

"We don't know. There are doctors trying to figure out how to make Jack's muscles stronger, but it's not an easy thing to figure out."

"Can he walk by himself?"

"No, Jack can not walk. But he can drive his wheelchair by himself, he can play games computer by himself, and he loves to go swimming, listen to stories, sing songs, and watch shows on TV."

Giving the simplest answer first and emphasizing the things Jack CAN do is an important aspect of any conversation with someone new to our situation. Remember, too, that your children are listening to every word you say in their presence. Although Jack can't speak clearly, many children with SMA can talk normally and should feel free to speak for themselves in these types of situations.

Children's books also can prepare young children for their first experiences with your SMA-affected child. There are a number of well presented, age-appropriate children's books about disabilities which can help other children understand and be sensitive to your child's situation. You can give these books to your young relatives as gifts, or to have them on hand for family gatherings. Some books worth considering are A Very Special Critter, by Gina & Mercer Mayer; Arabella, by Wendy Orr & Kim Gamble; and The Handstand, by Barry Rudner.

Some Final Thoughts

As you consider the many choices of activities and events for your family during the holidays, plan with realistic expectations about what you can accomplish. Choose a few activities that your child will enjoy, but don't overdo it. Emphasize the things your child CAN do.

Be kind to yourself by paying attention to your needs, and your child's. If your child is unable to enjoy a holiday event or activity, excuse yourselves from it and offer whatever explanation to others you feel is appropriate. Don't pressure yourselves to participate in activities that do not work for you. Be sure to take breaks from the group and go out for a walk or a jog. Take in a movie. Do something fun that you normally don't have the opportunity to do. After all, isn't that what vacations are for?

With careful planning, a positive attitude, and a little help from family and friends, the holidays can be happy. Those of us with SMA-affected children who are alive and relatively healthy are fortunate. The holidays are a time to for us to reflect, give thanks for each day we are together, and to keep hope alive.



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