



# Complex Child E-Magazine

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## Claiming Your Holiday Cheer

by Shannon Gonsalves

For many people, the thought of the holidays approaching provides another source of anxiety. This can be especially true for families with children who have complex needs. How will my child handle the chaos of a family gathering? Will he eat some of the holiday dinner? Please, God, let him have one day without pain. Will I be able to find a toy that will be appropriate and work for my child's needs? How can I afford my child's medical bills and presents, too?

These thoughts, questions, and prayers are common ones for families with children who have complex needs. It adds another layer of difficulty to an already stressful time of the year. Sometimes, just watching other kids who are typically developing can be a bitter pill to swallow.

Can anything be done? Some of this stress can't be avoided, but how we handle it can make a huge difference in how much enjoyment we get out of the holidays.

### **Set Realistic Goals**

Every year, I hope that my son will partake in the family meals lovingly prepared on Thanksgiving and Christmas days. However, most years, I am disappointed. For the first few years, I let my disappointment of his lack of interest in these special meals overshadow my joy for the precious time that I was spending with our family. I still found enjoyment, but disappointment lingered in the back of my mind like a dark rain cloud looming over a beach party.

Last year, I decided to just accept that he probably wasn't going to eat dinner and, depending on how he greeted mealtime, I might not be enjoying yet another family meal. I set up his tube feeding supplies ahead of time, so I could casually get him going on his feed if he didn't eat. When it was time, I just did it as if it were any other meal. I sat next to him to keep him as entertained as possible. When he was clearly done, I excused him from the table to play instead of both of us leaving the room.

My goals have changed from worrying about whether he'll eat or not to instead helping him find enjoyment in the time we're spending together. It has to be just another meal for us. It can't have that much significance that I let it ruin the time with family. If that means playing in his food, playing with toys, talking with family or even eating, so be it.

Decide what goals are really important for you to find enjoyment in your celebrations and don't set them too high. Often times, our kids develop at different rates and we celebrate their "inchstones" instead of milestones. The same can be true for holidays as well. Keep your holiday hopes and goals to inches instead of miles, and let your family know why your child might not be treated the same as others.

### **Recognizing Limits for You and Your Child**

I know that my son doesn't do well in busy, crowded, loud situations. For this reason, I avoid going to our church's harvest party each year. We can have just as much fun dressing up at home and sitting in Nana's living room watching all the costumed kids come to the door.

If you know that your child just won't respond well to a situation, don't go. I know it gets harder when there are siblings involved. We've gotten around our daughter being disappointed by being willing to divide up and go in different directions. I might take my daughter to a party while dad does something fun with my son. When we went to a water park recently, my son stayed in the room while I took my daughter to the story hour. We knew he wasn't going to handle it in that moment.

If you just can't see fitting in at that neighborhood party, don't go. If your child isn't going to be successful in a certain environment, change it to make it work for you. Know when you have too much on your plate and let something go. Going beyond your limits will just increase your stress levels and decrease your enjoyment.

Too often, moms in particular burn the candle at both ends, causing it to burn out quickly. Add to that holiday celebrations, shopping, wrapping, decorating, and dealing with family, and you have a recipe for disaster.

### **Continue Normal Routines**

Your child's medical needs aren't going to take a break because of a holiday. Last Christmas, my son's stomach pain issues were at their worst. One of our holiday celebrations had him running a Go-Lytely clean out through his feeding tube for 28 hours. He was miserable and we ended up inpatient a few short days later. His body didn't get the memo that it was supposed to take a day off from its usual routine.

Take your child's medications and supplies with you. Stick with your child's routines and don't skip medications or treatments. Put your children to bed at their normal times.

You will still need to take care of you, and that includes not stretching yourself too thin. Try not to schedule in activities or preparing gifts that will keep you up later at night than you usually are. The machines will still alarm in the middle of the night, your child will

still wake up at night, and then you will be too exhausted to enjoy your best laid plans. I have found that I just can't be Supermom anymore and need to just settle for Mom. I haven't had a great night of sleep in a very long time, and my son is showing no signs of letting us sleep anytime soon.

### **Stick to Your Budget When Buying Gifts**

Many of the kids that I know today have huge holiday celebrations with more presents than they know what to do with. Not only does it put a dent into the budget, or add to debt, but it also teaches children to expect a grandiose experience each and every time. The focus becomes the gifts they receive instead of time spent together.

One of my favorite holiday traditions came from a friend named Sue. When I first got to know her, her boys were young teenagers, so I'm not sure when they started their tradition. However, her kids don't expect gifts. Instead, they give them. They adopt a family and shower them with loving attention in the form of gifts, food, or other needs they can provide. In place of gifts, they go away together and read letters that they write to each other. Their focus is on time, sharing kind words with each other, and helping others. I've known Sue for over 10 years and they are still continuing this tradition.

Another mom that I talk with online shared that she is doing a "want, need, wear, read" gift idea this year. Her kids will each get four gifts total from their parents. They will get something they want off their lists, something they really need, something to wear and something to read. That is it.

My son's main gifts all have totaled \$73, including the one that his sister helps pay for. I'm not done with my daughter's gifts, but her end number is heading in the same direction. I have walked away from some things that I wanted to buy for her--like a digital camera--because they were outside my budget. Stockings have one higher cost item in the toe and the rest are dollar type items such as lip balms, stickers, hair bows, or matchbox cars.

My kids have never cursed Santa for his cheap gifts, and neither have I. I am continuing this tradition from my childhood. I will enjoy Christmas more knowing that while it was hard to come up with the extra money for my children's presents, I will not go into debt over a holiday.

If your family cannot afford to buy adult presents then don't do it. Talk ahead of time to your extended family and tell them that you won't be buying adult presents this year. A few years ago, my siblings and I decided that we weren't going to do adult presents any more.

Kids can make crafty gifts for adults so they aren't just receiving presents. These crafts can be as inexpensive and simple as a homemade card or as elaborate as home crafted soaps. Your children will get the message that giving is important and the adults will

appreciate the heart that went into the gift-making. Oriental Trading Company has great crafts kits for low prices. This year, my kids are making travel coffee mugs for their grandpas. They are inexpensive, but the cups are high quality and will look great when done.

Keep in mind that what you do today, your kids might try to live up to as parents themselves. I don't want my children thinking that the reason for holidays is the gifts you receive, no matter what the cost. You will enjoy the holidays much more if you don't have debt to look forward to after the festivities are over.

### **Family Time is Precious**

Focus your energy, time, money, and passion on finding ways to spend quality time together in a manner that will work for your whole family. For us, that tends to be crafts at home. My son doesn't do much of it, but he enjoys dabbling and it's quiet at home. When I take him out in public, I spend most of my time fighting with his sensory issues and it can be too overwhelming for him. At home, however, we are all comfortable.

Load your kids in the car and go look at lights. Take a walk in the snow. Watch a Disney DVD together with hot cocoa and peppermint stir sticks. Whatever it is your family enjoys, schedule it in. If you wait for a day to open up, it won't. Add it to your calendar. This is the same advice some marriage experts make about sex. Sometimes, we just have to schedule recreation into our busy, hectic lives.

### **Practice Stress Reducing Techniques**

Find a way to take a break each day or week. One of my favorite free methods to reduce stress is to do a meditation-type exercise. I have no official experience in true meditation, but this works for me. It is especially helpful when I can't get my mind to shut off enough to fall asleep at night. You can change my method to fit your personal religious beliefs.

Find a quiet place and get comfortable. I like my bathtub, because I can do aromatherapy at the same time with my favorite bath products. Close your eyes and take several deep breaths until your breathing and heart rate slow to a relaxed state. Try to visualize yourself wearing a heavy backpack on a dark forest trail. While you are slowly walking on this path, reach into your backpack and pull out a rock with a word on it. The words on the rocks will be the stresses in your life. Throw them in the woods and keep walking.

As you continue to walk, you begin to feel like your load is lightening and the path is getting more lit. At the end of my walk, my backpack is empty and I am walking into a brightly lit open field. Seated on a throne, is God dressed in a glowing, white robe. Sometimes, I sit at his feet and just feel peace. Other times, I talk to him.

The interesting thing about this process is that I am often surprised by what I see written on the rocks. I don't always realize what is creating stress until I see it written on that rock. It helps for me to identify what I need to eliminate or work on.

In several other articles about taking care of you, I also listed other stress reducing techniques. You can read about these at <http://articles.complexchild.com/nov2009/00168.html> and <http://articles.complexchild.com/Dec2009/00171.html>

Whatever it is, take time for you and find a way to reduce or eliminate stress that can make it hard to enjoy the holidays.

### **Don't Stray Too Far**

If it will stress you out to gain weight, then don't. Treat yourself on occasion, but limit how often and how much. If you know you are going to a party at the end of the week, be good and stay on your diet all week. Eat a healthy snack before going to the party, so you can sample small bits of the food offered instead of gorging on everything.

Gaining weight that will be hard to lose right after can impact your health and stress levels. If you normally exercise, try to continue it on as many days as you can fit in. Follow your normal routines for keeping you healthy, too.

### **Seek Help**

If you are struggling financially with the holidays, look for help. Many churches, schools, fire departments, police departments and local programs adopt families for the holidays. Swallow your pride and ask for help. Our local food banks are planning to provide holiday meal supplies.

Holidays can be emotionally difficult or even depressing for some people. Some churches provide free counseling if you ask. Many insurance companies cover mental health visits with a therapist. Let friends and family know you are having a hard time. Let someone help.

### **Be Prepared for the Unexpected**

My husband and I often joke that if it can go wrong, it will. If it's not supposed to go wrong, it will. When it does go wrong, try to laugh instead of getting upset. We're not pessimistic about life, or looking for the next problem in life, but instead we are preparing for the "what if" situations and are relieved when we don't have to face them.

This has been a joke in our house, but so far it has held true. We've been to the ER many times with our son. When we thought for sure that we were going to be admitted, we would pack a bag. Those are the times we were sent home. When we went just to make the doctor happy or expecting to come home, we didn't pack a bag. Those are the times we've been admitted. Now, we joke that by preparing ahead of time for the unexpected that we are heading off disaster.

One thing we do to plan for the unexpected is to take our son's emergency supplies with us to our events. I pack all of my sons "as needed" medications and extra supplies, even when we are just going to my parents' house for one overnight stay on Christmas. We live 30 minutes away, but the event will be so much more fun if we don't have to spend an hour or more driving back to get something he needs. Plus, it helps me not worry about the "what ifs."

### **It's About Your Family**

The holidays aren't supposed to be about losing yourself and your beliefs in order to make others happy. It shouldn't be something that breaks your family. Take the time this year to decide what it is you want to get from the holidays and stick to it.

It's okay to say no to family. One year, we told all family that we were just going to stay home with no company over for Thanksgiving. Not everyone understood why it was important to us, but we did it anyway and everyone got over it.

You get to choose what messages you want your children to learn about the holidays. Set your limits, make new traditions that work for all your kids, and most importantly, do what helps your family feel connected during the holidays. Take the time to appreciate each other and do for others in whatever ways you can.