

Winter 2023

# Pass it On

Information to use and share with families and professionals caring for children with special healthcare and education needs from birth to 26



**DOING THE HOLIDAYS  
YOUR WAY**

New Hampshire  
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PARENT INFORMATION  
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### About this edition: Why a holiday issue?

As the holiday season approaches, we are reminded of the magical moments that make this time of year so enchanting. It's a time of celebration, gratitude, and reflection. However, it's important to recognize that for families of children with special needs and chronic health conditions, the holidays can also be a time of unique challenges and complexities.



The joy of the holiday season is often accompanied by the need to navigate routine disruptions, the consideration of medical needs, and the awareness of sensory sensitivities that can affect our children. Social interactions can be both a source of joy and stress as we seek to balance our children's comfort with the expectations of gatherings and celebrations. Moreover, we understand the significant challenges of limited respite care and the emotional and physical demands this time of year can place on parents and caregivers.

It is our hope that this edition of *Pass it On* will serve as a source of support, awareness, and empowerment for our incredible community. We believe that building awareness and fostering understanding among those who interact with and support families of children with special needs is essential. This understanding can lead to more inclusive and considerate holiday experiences for all children.

In this edition, we have gathered tips and resources to provide families and those that support them with information that will make holiday celebrations more enjoyable and less stressful during this festive season. We have also tried to be inclusive regarding all holidays occurring in December and January -- if we missed one, just let us know!

Remember, you are not alone on this journey. PIC and NHFV are literally just a phone call away and are here to offer support all year long. We wish you and your loved ones a peaceful and joyous holiday season.

Warm regards,

Michelle Lewis,  
Executive Director, Parent Information Center (PIC)

Terry Ohlson-Martin  
Director, NH Family Voices (NHFV)

### A Farewell Message from Terry Ohlson-Martin, Director of NH Family Voices since 1987

36 years! A lifetime for some of the people I work with, but for me, it's the amount of time I've been lucky enough to work with NH families, children, and youth. As of December 31, 2023, I am leaving my position as Director at NH Family Voices to spend time with my family and friends, read, relax, and make quilts. This is an exciting time for me and also a reflective time.

In cleaning out my office, I've found notes from families that I'll never forget. We shared lots of personal information, we laughed, we swore, and we avoided crying - I'd rather swear. It has always been a privilege to share the highlights and the struggles of a life that hasn't gone as expected. In many ways, it's been a better life, but it's also been a lot tougher. I've come to realize that's what life is for most people.

I also find myself reflecting on the changes in the system. There have been so many!! The "Early Intervention" (now Birth to 3 system) that my son received was not free to us; it was available to a narrowly defined group of children, and he was "entitled" to none of it! We were asked to pay a nominal fee to participate. The system of services for children from birth to 3 years old has vastly improved. And it's my hope it will continue to change and improve for families and with families.

Thirty-six years ago, there also wasn't formal "family support." My support came from the wonderful women who were my friends and neighbors. I was lucky to have them, but I quickly realized not everyone was so lucky. And they really didn't understand this new life I was living. I didn't know anyone else with a child like mine. Fortunately, I got a job at PIC, and became part of the movement that systemized financial assistance for families who have a child within the area agency system. That meant a lot of testifying before legislators (I was petrified), working with state staff (I was intimidated), and sometimes embracing other families who had different experiences and beliefs (I struggled). It was an amazing experience, and we have a phenomenal system in NH. I hope families continue to work with professionals in NH to improve it.

Years later, when it became clear that many families had kids with illnesses who didn't qualify for any support, we were able to set up a system and have funds for kids not part of NH's area agency. An accomplishment that I hope families don't allow to slip away. Speak up and make an impact.

It's been a privilege, a challenge, and an experience that I recognize was brought on by my son's "unexpected" diagnosis. You just never know what's going to come out of an unexpected twist in the road. Thank you for being part of my journey, and know that I believe in my very soul that each of you can have a positive impact on our system -- speak up, be heard, and support one another.

Thank you to all the professionals I've worked with over the years. Especially to those who were not offended when I blurted out in a very undiplomatic way exactly what I thought. Thank you for listening and hearing my intent, even if the words could have been better. I have improved my delivery -- somewhat.

Thank you to all the families who have shared this road with me. Allowing me to walk beside you as we impacted, and sometimes created, services. We laughed, and we cried (okay, we also swore - well, I did anyway), and we learned. There was so much to learn!!! You have helped me to provide a better life for my son and for the sons and daughters of so many others.

It's been a privilege,

Terry Ohlson-Martin







## Reduce stress and truly experience the joy of the holidays

Tips from REAL families



The holiday season often brings get-togethers, shopping trips, crowds, music, and lights. It's loud and colorful and can sometimes be a little tricky for kiddos with autism, anxiety, sensory issues, and other special needs. Planning ahead and communicating openly can go a long way!

Speak with friends and family members that you plan on hosting or visiting with. Share your child's particular behaviors, quirks, or sensitivities so that everyone is on the same page and understands your child's needs and expectations.

For children who experience anxiety, the anticipation leading up to festivities can be a significant trigger. To prevent anxiety overload and possible meltdowns, consider ways to keep the holidays low-key. For some children, piles of presents that cannot be opened can be stressful. Keeping these gifts out of sight can help take the focus off waiting or opening gifts too early.

Various sensory stimuli, such as lights, music, bells, smells, tastes, and crowds, can be overwhelming for some individuals. Talk with your child to identify the most stressful elements and create a strategy together. For instance, if certain smells upset your child, consider using an artificial tree and battery-operated candles. If lights are a trigger, try using ones that don't blink. When planning visits to the mall, choose less-crowded times when your child is well-rested and not hungry.

Prepare your child for hosting or visiting family and friends in advance by discussing who will be involved or where you will be going. Explain that it's okay if they

don't want to hug or shake hands. Make a comfort kit together with noise-canceling headphones, a weighted blanket, a stuffed animal, a tablet, or books -- whatever soothes your child, either in your home or in a backpack packed for the day.

Let your child know it is okay to feel a bit 'off' during the hectic, crowded time of the holidays and that their routine will return after the dinner/visit/outing. Work with your child to be sure to get positioned in a place (a corner of someone's living room, a separate quiet room, a seat in a house of worship such as an aisle near the exit) that offers some comfort and an exit strategy.

As parents and caregivers, we often overlook our level of stress. If you feel out of sorts and overwhelmed, your child may react. It is essential to check in with yourself and take stock of where you are. Take a break, ground yourself, and you'll find your child will be more relaxed, too.

The bottom line is that families celebrate holidays in many ways. By communicating and planning, it can truly be a magical time of year.

### School Holiday Celebrations

Communication is key! Ask your child's education team what changes will happen so you can prepare them for assemblies, early dismissals, outdoor activities, whatever it may be. Ask your child's teacher to include a "one sheet" about your child in their sub-folder. The folder should include what a substitute teacher needs to know about your child and what may cause them distress. If your child has special dietary restrictions or preferences, plan ahead and send some treats into the classroom that your child will enjoy.

Some families have daily family briefings at breakfast and dinner. It sounds formal, but it doesn't have to be. Just talk about what will happen that day and explain what will be different. Consider contacting your child's therapists or support staff and ask if they will help frontload new experiences by incorporating role-playing, scripting, or social stories related to holiday festivities.

Be flexible and resilient, and understand that things won't go as planned, and that's okay! Celebrate small wins and focus on what brings you and your child joy.

# The Joy Of Rest

Saundra Dalton-Smith, a physician and author, introduced the concept of "seven types of rest". According to her, these types of rest are crucial for maintaining overall well-being and go beyond just getting enough sleep. They address different aspects of our lives and help us take better care of ourselves, which in turn helps us care for those we love. By recognizing our individual needs through these seven types of rest, we can navigate the holiday season with more resilience and joy, while also enhancing the well-being of those we love.





# Holiday Gift Shopping for Kids with Differences



I remember, over the years, the struggles of purchasing gifts for my son. He has significant differences – both physically and cognitively – from his siblings. But like them, he loves to open a present!

I would search for something I thought he would like or be able to “do”. Truth be told, it often wasn’t as easy or as much fun as buying for my other kids. “Special” toys were expensive. Clothes can also be hard to purchase for those who have sensitivities or need easy access in and out of them. When my child was young, I didn’t worry about “age-appropriate,” but that soon changed, and others were saying I should be aware and make choices based on his age. But at a much older age than most, I had to worry about small parts and things going into the mouth. Age-appropriate meant different things to me than others. This also added to the difficulty.

Fortunately, things have gotten

a little easier, and companies are better about developing and selling inclusive toys – Barbie in a wheelchair, baby dolls with g-tubes, or amputated limbs and crutches. I applaud those efforts. There is even a remote-controlled Hot Wheels Wheelie Chair with Motocross champion Aaron “Wheelz” Fotheringham’s figurine included -- probably not age-appropriate, but I might enjoy it. There are special needs clothing lines for kids -- not cheap, but they are available through well-known entities. We are becoming recognized as a consumer group with a need and means to pay for these reasonably priced items.

These are significant changes to the world of gift-giving, but they don’t always make the emotional tug that we experience during celebrations go away. Nor should they – we get to feel what we feel! I hope these toys and clothes help our kids to feel more confident in who they are and that it helps make other kids and families aware that they aren’t alone. Other family members are also shopping for their kids with a tug in their hearts. We do our best and hold one another up as we move through these days.

That’s something to be celebrated! You got this!! Happy shopping!

## Suggestions when shopping for someone with differences

1. Don’t be afraid to get creative. The definition of a “toy” should be adapted to what your child’s enjoys. Whether anyone else thinks it’s a good gift or not!
2. Ask others what they have found that their child enjoyed. I found it was important to talk to people whose children had similar capabilities rather than just the same diagnosis.
3. Google is your friend! I have found clothing made by companies I routinely shop at, so it felt very inclusive – especially for kids.
4. Shop when you’re feeling positive about your child’s abilities. I could never follow up a doctor’s appointment or a team meeting with shopping for my son. It was too hard.
5. Make sure you know what your child does and doesn’t want! If possible, get some ideas from them.
6. Start early – this can be time-consuming.

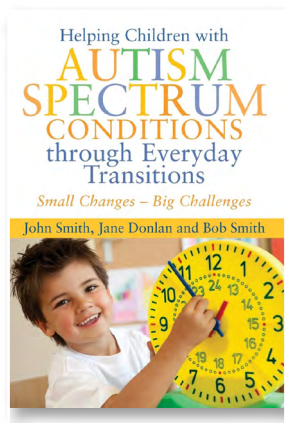


## PIC & NHFV STAFF TIPS FOR THE HOLIDAYS

We asked PIC and NHFV staff to reflect on their families’ holiday season experiences and share what they felt really mattered and what they want other families of children with disabilities and special healthcare to know as they head into the holiday season. Here is what they had to say!

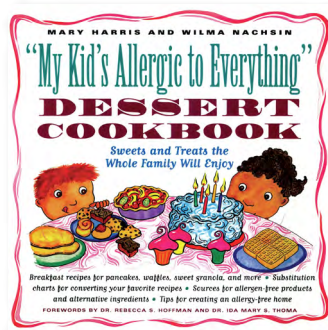
FOCUS ON MAKING MEMORIES	DO WHAT YOU CAN AND REMEMBER THAT IS ENOUGH		IT'S OKAY TO HAVE "ALL THE FEELS"
NAPS ARE NOT JUST FOR CHILDREN		WHATEVER YOU DO OR DON'T DO IS FINE. CREATE YOUR OWN TRADITIONS	
	THE GREATEST GIFT IS YOUR PRESENCE JUST FULLY BE WITH YOUR LOVED ONES		DON'T WORRY ABOUT TRYING TO CREATE A HALLMARK CHRISTMAS
DON'T GO TO THINGS THAT YOU OR YOUR FAMILY WON'T ENJOY		LIVE FOR THE LAUGHS, UNEXPECTED MOMENTS, AND MISHAPS	





***Helping Children with Autism Spectrum Conditions through Everyday Transitions***  
by John Smith, Jane Donlan, and Bob Smith

This guidebook is a wealth of information for helping your child cope with daily and seasonal changes throughout the year. This book contains scripts and examples for various situations, such as preparing your child for more visitors in the home, bedtime disruptions, and sensory overload. The last chapter is handy to parents and caregivers who feel the strain of the holidays (and everyday life) because it addresses the topic of burnout and how to avoid or minimize the effects. I recommend this book to anyone with a child who doesn't handle change well. There is a lot of helpful information for many types of children and their challenges around routine disruptions.

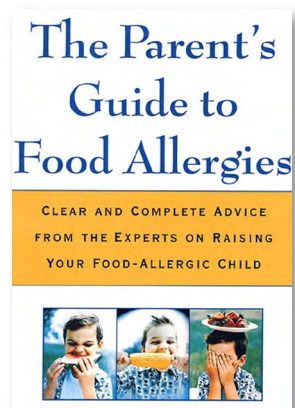


***"My Kid's Allergic to Everything" Dessert Cookbook Sweets and Treats the Whole Family Will Enjoy***  
by Mary Harris and Wilma Nachsin

Grab your bowls and spoons, and get ready to find your new favorite allergy-friendly treat for the next family gathering!

This cookbook contains tasty treats and helpful conversion charts for substitutions to keep your desserts safe. You'll also find lists of substitutions to try in place of common allergens like eggs and milk.

This is an excellent cookbook for families looking to try new ideas or for parents who have their student's class parties coming up and know of a child with food allergies in the class.



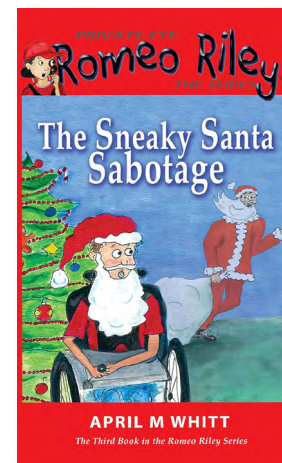
***The Parent's Guide to Food Allergies: Advice from the Experts***  
by Marianne S. Barber, Maryanne Bartoszek Scott, M.D., and Elinor Greenberg, Ph.D.

This in-depth guide is a "must read" for families and caregivers learning how to prepare food safely for someone with food allergies.

This book covers various topics, from recipes and substitutions to navigating a school-aged child's mental well-being when coping with an allergy that may make them feel out of place among their peers.

Through this book, you can feel supported through the experience of experts who understand the ins and outs of food allergies and the complications they present in everyday life.

***Private Eye, Romeo Riley The Series: The Sneaky Santa Sabotage***  
by April M. Whitt



With Christmas on the horizon, Romeo Riley's school is excited about their upcoming Christmas party because Santa will be there. However, the holiday spirit is in trouble when strange things happen, and things start to go missing. Private Eye Romeo Riley is on the case when a strange man appears at school! Romeo is a young boy who is in a wheelchair and cannot speak, but that doesn't stop him from cracking this mystery wide open. This short chapter book would be an excellent read for a 2nd – 4th grader who enjoys the combination of Christmas and action!

***Let's Go to a Party: Preparing Your Child with Autism for Social Situations***  
by Deborah Woo-Ming

Let's Go to a Party is an illustrated book you can read with your school-aged child who may need some help with social queues, like what kind of questions are appropriate, how do we talk inside, and other situations kids can face in new social situations. This book does focus on a birthday party, but it can be put in the perspective of any event.



Hi! I'm Sam Collyar, a Resource Specialist at NH Family Voices.



Outside of work, I'm a wife, mom, and pet mom to 3 dogs, a cat, and 21 chickens. I keep busy in my garden and love books. My passion for books really kicked off when my then-eight-year-old was diagnosed with cancer, and we saw just how much hope could hide in the pages of a book. We turned to books for knowledge and stories from others in our shoes a lot, and I'm so excited to be in a position to connect people with books from our FREE Lending Library that could provide that same level of knowledge and comfort.

If you are looking for a specific book or resource on a particular topic, email me at [snc@nhfv.org](mailto:snc@nhfv.org)!

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## Holiday Resources for Families

**Sensory-friendly holiday shopping at Walmart** from 8 a.m. to 10 a.m. every day at all Walmart U.S. and Puerto Rico stores, beginning Nov. 10.

**Toy Like Me** offers a wide range of dolls and toys with disabilities. Learn more at [www.toylikeme.org](http://www.toylikeme.org)

**Santas Village Sensory Guide** offers accessibility and amenities to help guests with cognitive disabilities, including those on the Autism Spectrum. Read more at [www.santasvillage.com/wp-content/uploads/2021/04/Sensory-Guide\\_2021\\_small.pdf](http://www.santasvillage.com/wp-content/uploads/2021/04/Sensory-Guide_2021_small.pdf)

**Community Action Programs (CAP)** operate programs that assist with food, paying the bills, finding housing, and more for N.H. families. Find your local CAP at [capnh.org](http://capnh.org)

**Family Resource Centers (FRCs)** offer different supports to families over the holidays. Find out how they can help your family by visiting <https://bit.ly/3G04Pnt> or calling [1-866-444-4211](tel:1-866-444-4211).

**NAMI NH** provides support, education, and advocacy for people affected by mental illness and suicide. Visit [naminh.org](http://naminh.org) or call [1-800-242-6264](tel:1-800-242-6264).

**Military OneSource** helps military families manage the care and services for family members with special needs. Learn more at [militaryonesource.mil/special-needs/efmp/](http://militaryonesource.mil/special-needs/efmp/)

**Addiction Support:** Talk to someone who has been there and find other free resources this season at <https://bit.ly/3ubhqkV>

## Subscribe to Our Newsletter!

The Parent Information Center and NH Family Voices are committed to delivering valuable information and resources to families of children with disabilities and the professionals that work with them.

The *Pass It On* newsletter is among our most valued resources and appears in many doctors' offices, schools, and community organizations across New Hampshire.

If you would like hard copies for your place of work or community space, please email [rda@nhfv.org](mailto:rda@nhfv.org).

If you are interested in receiving the electronic or print version of our newsletter, follow these steps:

1. Go to [www.nhfv.org](http://www.nhfv.org) and click on Membership.
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This FREE resource is intended for sharing, so please "Pass It On" to friends, family, and professionals you think might find it helpful.

## Notes from Youth Voices on the Holidays

Written by Ansley Peacock, Transition Initiatives Coordinator for PIC & NHFV



If you live with a chronic health condition or have a disability, this opening from the [Tips For Surviving The Holiday Season Chronic Illness Edition](#) video may be relatable. If you don't have a disability, it may also resonate, as the holidays, even with all of their wonder and joy, can exhaust everyone!

Here are some tips and tricks from youth videos to help stave off feeling like Scrooge and have less bah humbug!

### Simplify celebrations

This doesn't mean we can't celebrate! Maybe it means simpler gifts, less shopping, a cozy movie night with a watch party instead of going out, making things together as a family, and having a few beautiful decorations instead of many. What really matters to you for the holiday? Check out this [video](#) (URL provided at the end of the article).

### Plan, pace, prioritize

Asking about gatherings, food, and timing ahead of time can let you know how long you'll be "on" for or what you might need to bring. It's also nice to know if there is a quiet space you can rest in while away from home. Pacing and prioritizing can mean you choose the most important or treasured holiday activity and kindly say "no thank you" to others. It's not always easy to find this balance, and it may take some practice, both for you and the family/friends around you.

### Take regular breaks

We all can get swept up in the hustle and bustle of the holidays, but saying yes to everything and everyone EXCEPT our body/energy level when it asks for rest can lead to burnout. Often, with a disability, we need to take breaks, or our body will take the break for us. Be honest about where you are at with yourself and those around you.

### Celebrations and self care may look different to you, and that's ok.

Self-care may mean saying "No" to things you wish you could say yes to, but your top need is rest. It doesn't mean you have to be disengaged. Are there ways to adapt

holiday activities so you can participate (sitting, having a friend help)? [Check out this video on adapting holiday activities](#) (URL provided at the end of the article). Can you go to gatherings and visit for a shorter amount of time? Are there friends or family members you trust and can let them know ahead of time what would be helpful? Reach out. They care about you and would likely appreciate a chance to have you enjoy your time with them instead of being in pain.

### Give love

When you're young, you may not have a lot of funds to buy gifts with. This can also be true when you have a disability, as medical expenses add up. Give love. Write, type or voice record a letter to someone to tell them how much you care about them. Create a piece of art, music, or something from nature (pretty rocks, photos) that made you think of them, tell them a story about a memory you cherish of them, or sit with them and give them your time. These gifts are precious in a way that isn't created at a factory or from a store. They're the kind we see on mantles, refrigerator doors, work desks, and bookcases...sometimes years after it was given.

### We acknowledge and thank the content creators for the videos referenced in this article:

- Victoria @ChroniclesKV on youtube for her video Tips For Surviving The Holiday Season: Chronic Illness Edition at <https://bit.ly/3MNaq4f>
- Youth Disability Advocacy Service @YDASVic on Youtube for their video Disabled Young People Answer: What is self care? at <https://bit.ly/49B3kcl>
- Uniting @UnitingCareNSWACTSydney on Youtube for their video, Inclusion Makes the World More Vibrant at <https://bit.ly/47Bpjid>

### A note on language:

We recognize that the families and communities we serve are rich in their experience and diversity. With that comes different ways to talk about disability and chronic health. For simplicity, we use the terms found in our newsletter. We also respect the choices of authors, families, and individuals whose viewpoints we reference. This is not an endorsement of any one way to talk about this vast topic! Read more about language and disability from the Disability Rights Center of NH at <https://bit.ly/40BShMC>

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☐ physical disability ☐ learning disability ☐ developmental disability ☐ behavioral challenges

☐ I am interested in materials relating to: \_\_\_\_\_

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