



NTSAD Lifeline



From the NTSAD staff and board to the NTSAD community - we hold each and every one of you in our hearts and in our thoughts this holiday season.

May your holidays be filled with reasons to be thankful.

Having loved and having been loved is perhaps the most wondrous reason of all.

Thanks for the little while.

~ Darcie Sims

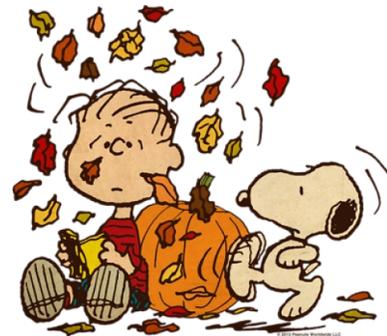
Read the full poem by Darcie Sims [here](#).

Darcie spent two conferences with NTSAD sharing her laughter and her wisdom.

A New Normal

The holidays this year may not be what you planned. They can already be a challenging time but then with a new diagnosis or a first holiday without your loved one, it can be all the more overwhelming. Borrowing a message from several years ago, we're sharing a few thoughts as we head into the season -

- Discuss, as a family, what traditions, celebrations, decorations and activities mean the most to your family and focus on those.
- If going to the neighborhood holiday party isn't meaningful and uplifting - send your regrets! And if home is where you need to be, ask family and friends to come to you for a visit.
- Brainstorm new traditions that honor this chapter in your family's life. Put turkey feathers on the suction machine, hang Christmas tree ornaments off the feeding pole or put dreidel stickers on the stroller.
- Make feeding tube meals festive by pureeing a small plate of your holiday favorites and put that through the feeding tube!



- A dash of nutmeg or cinnamon isn't just for lattes! Add to formula for a special holiday treat!
- And remember to take time for yourself! Rest, eat right, exercise (a little bit!) and savor the joy of sharing the holidays with your family!

If there is something that helps you through the holidays, feel free to post to the NTSAD Family Support Group page here. #NTSADHolidays

Be Kind to Yourself

Remember it's OK to celebrate, laugh and enjoy the holidays! It is also OK to cry and not feel joyous.

Invite family to share their favorite memory. Everyone will be missing your loved one and this will show it is OK to talk about him or her. There will be tears but more smiles and hugs.

Take a moment to gather as a family to light a special candle in loving memory of your loved one.

Take care of yourself! Plenty of rest, healthy snacks and light exercise will make the heartache easier to carry. So will hot chocolate or your favorite indulgent treat!

Worldwide Candle Lighting Ceremony

We invite you to join the [Compassionate Friends Worldwide Candle Lighting](#) from the comfort of your home on Sunday, December 8th at 7pm to honor and remember all the sweet angels gone too soon. As candles are lit around the globe at 7pm local time for one hour it creates a 24-hour wave of light and remembrance.



With love in our hearts and tears in our eyes we will light a candle for far too many angels lost to Tay-Sachs, Sandhoff, Canavan, GM1 and related diseases. In their honor, NTSAD will work vigorously to continue to support families wherever they are.

PRE-HOLIDAY CHECK-IN

- 😊 I'm excited.
- 😐 I think it will be OK.
- 😬 I'm nervous.
- 😓 I'm feeling overwhelmed.
- 😕 I don't really know.
- 😞 I'm not feeling great about it.
- ❤️ I could use some support.

#MightyMinute

The Mighty Check-in

Would you make a holiday pledge to be there for another person this year? If you're in the space to be there for someone else, post #Here4U to let others know that you're there.

And if you are having a tough time, feel free to post your emoji to the NTSAD Family Support Group page or on Instagram.



Sue Kahn, Executive Director

Becky Benson, Conference Coordinator
Diana Pagonis, Director, Family Services
Oxana Surugiu, Development Associate
Patrick Woods, Director, Development

NTSAD
 2001 Beacon Street
 Suite 204
 Boston, MA 02135

www.NTSAD.org