WINTER NEWSLETTER

Boston Children's Bereavement Program Hospital

November 2024

Dear BCH Families.

Winter is upon us again, and with it, the holiday season arrives. It is never easy to celebrate holidays following the loss of a child, whether this is your first holiday season without your loved one, or even when it has been many years. When facing loss, one's sense of happiness or gratitude often feels further away than it ever has before—the depth of which can feel immeasurable. Some families have shared their disinterest in celebrating at all, while others have expressed the importance and desire to stay connected to their child by trying to create new holiday traditions that help them maintain their bond with their loved one. However you may choose to observe the upcoming holidays, remember that:

"Grief uniquely permits us to evaluate what parts of the holidays we enjoy and don't."

-David Kessler

You are not obligated to do things as you have in the past, and new traditions are often a work in progress that can take many iterations before families settle on what feels right. Perhaps this year, a tradition may begin simply by cooking your child's favorite meal, or setting their place at the Thanksgiving table; hanging a special holiday decoration in their honor, or lighting a memorial candle for them to last through the Hanukkah or Christmas season. However small it may seem, perhaps simply trying something new and seeing what feels right is a place to begin, knowing there is no right or wrong way of doing it, and that you can still try something different next time.

Above all else, we encourage you to focus on what you and your family need to get through this holiday season, granting yourselves grace and gentleness as you continue to navigate the difficult world of grief during this particularly challenging time of year.

We wish you gentle holidays,

SoYun, Ellie, and Fiona The BCH Bereavement Program Team

Articles

<u>Honoring Our Persons Who Died:</u>
<u>Creative Ideas for Families During the</u>
<u>Holidays - The Children's Room</u>

<u>The Longest Night: Grief and the Winter</u> Solstice - What's Your Grief

<u>Sending Holiday Cards After a Death -</u> What's Your Grief

<u>Coping with the Holidays while Grieving</u>
- Jeff's Place

<u>Surviving the winter of grief - Care for</u> the Family

November Recognized as Children's and Teen's Grief Awareness Month



Keeping Connections 2024 Recap

On November 2nd, the Boston Children's Hospital Bereavement Program hosted our annual Keeping Connections Family Conference. This year we welcomed 24 families, with 13 traveling from out-of-state to be in attendance. The conference featured a bereaved parent panel, activities for siblings and families, group discussions, and a few new offerings, including grief-informed journaling, art, and movement workshops. We are honored to have shared this day with the BCH bereaved parent community, to remember your beloved children, and to help foster and support connections between families.

This year, Meggie and James, parents of Finn, attended Keeping Connections and spoke on the parent panel. Meggie also shared copies of a book she wrote after Finn's death, entitled, "Feeling Love." Their story is highlighted below in the Family Spotlight/Book Corner section of this season's newsletter.







"...An opportunity to take off the mask and be with other people who get it."

"We met wonderful people and felt very cared for and comfortable in the group...We were so happy to be able to talk about [our son] and our continuous journey with him. Such a beautiful thing to have for a group of people that really need support from people who have experienced it."

"It's a place to explore with other families who share a familiar pain."

To ensure you will receive a mailed invitation to next year's Keeping Connections Conference, or to update your mailing address, please fill out <u>this form.</u>

How to Honor Your Grief in Winter

- Warmth The harsh weather of winter often leads to more time indoors and can sometimes feel dreary. Add extra warmth and coziness to your space during this time. Leave out extra throw blankets, light candles, or add twinkle lights to make the space warm and cozy. Some people like to keep out something soft from their loved one, such as a clothing item or blanket.
- Introspection The quiet of winter, when some of the deeper feelings of grief might emerge, can be a time for deeper introspection. You may want explore your grief emotions through one-on-one counseling, groups, or journaling. Allow yourself to express some of the more difficult feelings in grief.
- Newness Winter is often characterized as a lack of growth or newness, but you may want to take time to create newness in your own life. As parties, events, and time with family slow down following the holidays, this can create more free time. This can be a great time to do something new. Sign up for a new class, attend a grief workshop, or visit somewhere
 - **Time** Allow yourself time to grieve and heal, knowing that the grief process takes time and cannot be rushed. In this slower season, give yourself extra time to do and accomplish things. Slow your pace.
- **Empathy** Be extra gentle with yourself, acknowledging that grief impacts many aspects of the self. Know that it's OK to not "keep up the same pace" as you did before.
- **Rest** Embrace the slower pace of winter. Give yourself time to rest, allowing your body and mind to heal from the stress that grief can bring. Perhaps sleep in a little longer than usual, get a massage, or watch a funny movie in your pajamas.

Family Activity: Family Recipe Book

Cooking and baking can be powerful rituals to bring family together, engage in mindfulness practice, and remember a loved one through their favorite foods. It may be that particular recipe that reminds you of your child, or you may want to create new tradition in their memory. The Dougy Center has a printable family recipe book help-create.

"If food is medicine, cooking and baking as grief rituals truly are balm to the mourning soul."

~Cooking through Grief



Valentine's Day 2025 Special Edition Newsletter - Call for Submissions



Last year, we shared <u>this podcast</u> from the Dougy Center, featuring a compilation of love stories from listeners, and invited families to join in the conversation by answering the questions: *How did your person love you? How did you love your person?* through written letters, drawings, or other creative expressions.

Once again, this year we invite submissions of your Valentine's, love letters, or artwork for your loved one to be published in our special edition Valentine's Day newsletter in February. Please send any submissions to bereavement.program@childrens.harvard.edu by Feb. 1st. Last names will be removed for privacy, or you can choose to write anonymously.

Children's and Teens' Grief Awareness

Since 2008, the third Thursday in November has been recognized as Children's and Teens' Grief Awareness Day—a day created by the Highmark Caring Place to honor the unique experiences of children and teens who are grieving. We are excited to announce that this year in Massachusetts, Governor Maura Healey has officially proclaimed November as Children's and Teens' Grief Awareness Month!

To mark this important event, the BCH Bereavement Program joined fellow leaders from New England's child bereavement organizations, including Wildflower, Jeff's Place, and HeartPlay, at an intimate event hosted at The Children's Room in Arlington, which featured heartfelt reflections and meaningful conversations. State Senator Cindy Friedman read Governor Maura Healey's proclamation, while State Representatives Sean Garballey and Paul Donato lent their support by attending the event. Massachusetts state legislators and community leaders discussed how we can foster greater awareness and deepen connections for young people who are grieving, underscoring the power of community in creating hope and support for those navigating loss.

Group Photo: MA Child Bereavement Programs
Photo courtesy of the Children's Room

Worldwide Candle Lighting Day

On Dec. 8th at 7 pm. we invite you to light a candle on Worldwide Candle Lighting Day, a day designed to honor all children who have died too soon. Find an in-person candle lighting event with a local chapter of the Compassionate Friends here.



Virtual Support Groups and Programs

Care Dimensions' Coping with the Holidays Workshop

Wednesday, December 4th, 3-5 pm via Zoom A workshop to discuss helpful ways to cope with the holiday season. Participants will have time to ask questions and find mutual support. RSVP required to <u>Grief@CareDimensions.org</u> by Wednesday November 27th.

Family Nights - The Children's Room

The Children's Room hosts a monthly arts-based service currently offered via Zoom, that provides families the opportunity to gather together, centered around a creative arts activity focused on memories and meaning-making. Extended family encouraged to participate! Materials are mailed to all participants prior to this expressive arts evening.

*To stay up-to-date with the BCH Bereavement Program offerings, including groups and workshops held in early 2025, join our Facebook group and fill out this form to indicate interest in our programs. *

In-Person Remembrance Events

Care Dimensions' Service of Remembrance and Tree of Lights

These events offer the community the opportunity to remember and honor loved ones. This year, the four services will be:

- Danvers, on Tuesday, December 3rd at 5pm
- Swampscott, on Tuesday, December 10th at 5pm
- Gloucester, on December 4th at 5pm
- and Waltham, on Thursday, December 12th at 6pm

Angel of Hope Candlelight Vigil - Sturbridge, MA

December 6th at 7 pm St. Anne and St. Patrick Shrine 16 Church Street Sturbridge, MA

Angel of Hope Candlelight Vigil - Woburn, MA

December 6th at 7pm Horn Pond on Arlington Road Woburn, MA

This vigil is held annually for families grieving the loss of a child. Candles will be provided.



Featured Blog

<u>GoodGriefCook.com</u> is a food and grief blog from bereaved mom and award-winning cook Lisa Keys. In memory of her son William, she shares her recipes and "public grief journey." She writes "If I can help just one grieving parent celebrate their child's life then my mission is accomplished." <u>Click here</u> to read more about her story (and find a recipe for chocolate chip cookies).





Family Spotlight and Book Corner Q&A



Meggie, James, and Finn

For this edition's Family Spotlight and Book Corner, we are honored to share an interview with Meggie, mom of Finn and author of <u>Feeling Love</u>. Read on to learn about Finn's story, reflections on Meggie's grief journey, and her experience writing the book.



All proceeds of Feeling Love go towards supporting a child undergoing medical treatments and their families. Learn more at HeartFinnFoundation.org

Can you share a little about Finn and your story?

After years of fertility treatments and a challenging start to my pregnancy with Finn, we were so grateful and excited when we felt some smooth sailing in our pregnancy journey. Finn had already seemed to overcome so much in question about the initial success of the pregnancy, that I named him our "little fighter" in my pregnancy journal. The easy pregnancy journey didn't last long when at about 16 weeks I experienced some bleeding in pregnancy and learned that I had placenta previa and eventually was also diagnosed with vasa previa. The bleeding was worrisome and we knew it could lead to an early arrival of our little guy. I was admitted to the hospital multiple times for the bleeding and during one hospital stay learned that our "little fighter" also has a congenital heart defect called tetralogy of fallot. We were somewhat familiar with this diagnosis because both my cousin and nephew have the same heart condition. I was soon admitted to the hospital for what would be the duration of my pregnancy due to more bleeding and remained in-patient at Brigham and Women's for 2 months, before an emergency c-section at 34 weeks.

We learned that Finn's heart condition was a little more complicated than typical tetralogy and that he would need to have open heart surgery immediately. After spending a day reading books to Finn and holding him as much as we could, he underwent his first open heart surgery with great success. After two more successful open heart surgeries, the team soon learned that Finn's body was shutting down due to sepsis. We held Finn for the last time the morning of July 13, 2023 as we played music and sang to him and embraced as a family of three.

What has been most challenging for you in your grief journey?

Socializing in groups and in public has been a very challenging part of our grief journey. Initially, it was very hard seeing other babies in public or seeing families. It would bring up a lot of anger; that should be us, so happy with our Finn. Grief can be so isolating, even with an amazing support system like we have. Decisions about who to be vulnerable with and share Finn's story with can still be hard, but in some instances it can create a beautiful moment that is so real and raw to the human experience of understanding grief is something most of us experience. It was also hard to feel like you could or should be having any joy. How could you have joy if your baby isn't there to share it with you and be the source of all of your joy.

There is so much guilt and anger mixed up in grief, and working through those feelings and allowing yourself some grace is such a challenge. But it also felt so important to move those feelings aside to be able to continue to feel close to Finn and see the signs from him each day letting us know he would always be part of our lives.



Our "little fighter" was perfect, and we named him Finn. I will never forget the sound of his voice when he first cried out.

How have you been tending to your grief and what do you hope your grief will feel like in the future?

Soon after Finn passed away, books and podcasts on grief and long walks were the most helpful way to work through my emotions and feel less alone. We have an area in our room where we keep Finn's urn and photos and a box of small things that remind us of him. I love just being with him there, kissing his photo as I am walking by or staring at him as I am falling asleep. I was able to take some time to myself to feel that I could turn into my grief instead of running from it, and I have been seeing a therapist to help me do that. I feel like being able to embrace all that we experienced, trauma, heartbreak, and so much love, was the only way to make it a comfortable new part of me.

I can feel my grief changing. I know it will always be with me, but it was so hard to imagine it taking any different shape early on. Sometimes it feels like Finn is putting joy in front of us and wanting us to have it, and we try to lean into that when we can. I feel the more we talk about Finn and tell his story, the more easily we move aside harder parts of the grief, and the love can be what is felt and shared.

What was the inspiration for your book and what is it about?

I wrote, Feeling Love, soon after Finn passed away when I couldn't sleep one night. At the time it felt like a way for me to believe that Finn was able to feel all the love from us and everyone and that he could understand it, how to feel it and share it. It gave me this chance to experience him as a little boy learning and growing, and maybe that was happening just not physically with us.

I was never thinking I would print the book or do anything more with it, but it definitely felt like Finn was pushing me. He led me to an amazing illustrator, Siski Kalla, who was about to undergo cancer treatment and shared with me the comfort and love that drawing Finn (as his little bunny character in the book) brought to her as she would sit in the hospital. The journey of creating the book was a beautiful part of my healing and grief journey that made me feel so close to Finn. The story follows Finn along his journey to learn what love is out in the world. He learns what love means to others and how showing others love can bring more love to oneself. Some prompts at the end of the story ask the reader to share what makes them feel love and how they try to show others love.



What was your experience attending Keeping Connections this year?

Keeping connections was an amazing event. We felt so comforted by being with others that could relate to our experiences. It was wonderful to be able to talk about Finn and share his story and learn about other families' beautiful children that had passed. To be in a group like that, where you are all connected by an experience that a majority of people in the world have not had, was really indescribable. You know you are not just being heard, but really understood on a deep emotional level.

Socializing has been so hard for me, and being able to feel so comfortable in a group was something I had been missing. The staff that helped facilitate were so caring and thoughtful and created opportunities for open supportive discussions and creative ways to work through emotions of grief.

We hope this newsletter provides a space to help connect you with grief resources and programs, and to support shared experiences and connections between BCH families who have experienced child loss. If you would like to contribute to our newsletter by sharing a recommendation for a book, podcast, article, or resource that you believe will be helpful to other families, please click this link to let us know about it, and we will try to include it in an upcoming edition. If you would like to send a letter or poem to share, or to be featured in our family spotlight, please email us at: bereavement.program@childrens.harvard.edu

<u>Connect with the BCH Bereavement</u> <u>Program on Facebook</u>

Please reach out for further resources or recommendations

SoYun Kwan has been a clinical social worker at Boston Children's Hospital since 2005. She has worked in the Medical/Surgical Intensive Care Unit, and in the Liver, Intestine, and Multivisceral Transplant Program, supporting families facing serious illness. She currently runs the BCH Bereavement Program, where she is dedicated to offering bereavement support and programming to BCH families.

SoYun Kwan, LICSW Bereavement Program Social Worker bereavement.program@childrens.harvard.edu



Ellie Frechette is one of the clinical social workers on the Pediatric Advanced Care Team (PACT), who specializes in supporting bereaved parents/caregivers and siblings. Ellie currently runs many of the programs offered through the bereavement program, including support groups, educational sessions, and expressive arts workshops.

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