

Connections

A Newsletter from the Family Guidance and Bereavement Program at LPCH

The Family Guidance and Bereavement Program supports LPCH families and their communities who are facing the death of a child. Our services are offered at no cost in English and Spanish. All are welcome to participate.

Dear families,

We know that the experience of grief is unique for each person, and there are a multitude of factors that affect how grief is felt internally and expressed externally. Grief also shifts over time for each person, gaining more nuance within the emotional landscape of the individual with each passing year.



This issue of *Connections* focuses on the changing nature of grief in time. First, we present the parent talk from the 16th annual LPCH Day of Remembrance & Rededication ceremony by a young couple sharing their journey with grief over the past five years. You'll also find an article written by a grieving mother reflecting on how her grief has evolved over the past fifteen years. Finally, we've included links to helpful child grief resources in honor of Children's Grief Awareness Day to help readers understand loss from a child's perspective - and how that perspective changes as children grow.

We are attuned to the difficulties of grieving during this lengthy pandemic, and we hope that you continue to find ways to stay connected to the people, animals, places, and activities that nourish you the most. We are here for you, too, and encourage you to contact us for grief support when needed no matter how many years of grief you carry.

Warm Regards, The Family Guidance & Bereavement team

Family Perspectives

Parent Reflection

This speech by Will and Jen Townsend was presented at the LPCH Day of Remembrance ceremony on October 3rd, 2021, online.

Jen: We are honored to be speaking with you today during Day of Remembrance. This day has always been a special one for us and we would like to tell you about our son, Cole.

Cole was born on December 18, 2015 at 30 weeks, after a complicated pregnancy that included 14 weeks of bedrest. After he was born, he was immediately taken to the NICU due to

underdeveloped lungs. For the next three months we were at the Lucile Packard Children's Hospital, spending every available moment with our son. Despite his incredible strength and fight, Cole passed away at 99 days old. During those 99 days, we were able to do arts and crafts, read with him, hold him as much as possible and try to enjoy life with him. Of course, that can be difficult to do in a hospital setting, but we made the most of it. Our care team at the hospital was phenomenal and they helped us to create a life with Cole while we were there.

The Family Guidance and Bereavement Program

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Family Perspectives (continued)

Will: Every day Cole fought to get better. However, Cole's lungs just never made the progress they needed and his body was failing him. When we could tell his time was getting short, we spoke with the Palliative care team about what our next steps were. It was comforting when they asked what they could do for Jen and I as well as Cole. The team wanted to know what kinds of experiences had we looked forward to enjoying with our son. For me, I had always dreamed of taking my kids to a San Francisco Giants game, so Cole and I dressed up in our Giants gear and had a "Giants Day" in the NICU. We still celebrate Giants day every year. As an ocean lover, Jen wanted to have a beach day with Cole. We brought in sand and salt water for Cole to put his feet into, while he was sporting swim trunks and cool shades. The lengths the entire hospital went to in order to help us create these special moments was nothing short of amazing. Throughout our journey we had both sad and happy times, but we always try to remember the positive, beautiful moments we experienced.



Our "Giants Day" baseball, complete with Cole's handprint.

Jen: From the time I was pregnant until Cole's passing, we went through many changes in our journey. Changes from the initial excitement of being pregnant. New changes during the 14 weeks of bedrest. Changes in our everyday life from living in a hospital. And now the most difficult changes after our son passed away. While everyone deals with grief differently, it hit me like a



Ocean waves remind us of our beach day with Cole.

ton of bricks. That first year was especially rough. I found triggers everywhere. A sound, a place, a smell, or even the way a light turned on would remind me of Cole and bring me back to feelings of despair. Even if it wasn't remotely related to Cole, it was astonishing the random things that could make me cry at the drop of a hat. There is a saying that grief is like the ocean - sometimes it's calm and seems to be lapping at your feet and then all of a sudden - bam - a huge wave of it hits you. There were many large waves in the beginning of our journey. Will and I have each learned how to best weather those moments of deep emotion. Years later, we were able to take some time to reflect on our experiences with grief. What has this journey been like for us?

Will: Soon after Cole passed on, Jen and I sought some additional support. We had both been grieving in our own ways and it was reassuring to hear that this is normal. We learned to embrace our individual ways of grieving while continuing to be supportive of one another. Jen needed times of quiet reflection and many tearful moments. I, on the other hand, needed to keep busy, doing projects around the house and tried to stay active. Our mantra was "be kind to yourself." It was helpful to repeat this and then try to live by it after Cole passed. Even now, all these years later, it's been a great go-to motto. Learning that grief is an individual process really helped me in moving forward.

Jen: My journey with grief was like being a flower. Right after Cole's passing, I was just a little seed. I had become a new person and just like a seed, was planted in a new place. That first year was especially difficult. Birthdays, family gatherings, holidays and missed milestones were all hard and I did not look

forward to any of those things like I had in the past. But, I worked through my grief and I had support systems to help. These support systems included going to see a therapist and touching base with the Bereavement team. Going to our first Day of Remembrance was helpful, too. I also realized how important self care was. I allowed myself space to feel every emotion I was having. In addition, I tried to check in with myself to see what I needed on any given day. Being aware of my needs was beneficial. It allowed me the space to know what I had the capacity for. For example, some days I wanted to be around others and be more sociable, but other days, I knew that I just needed to be by myself and conserve my energy. It was important to know that every day was different for me and that there is no set time table for when I had to feel any certain way. Even today, I have my good and bad days. I continue to check in with my emotions. And that's my new reality. Between the support I received and my self care, my roots took hold and gave me more strength every day. All of this lead me to the tools I needed to help myself during my most difficult moments. Days turned into months and that seed continued to grow and my roots gave me some stability as I settled into this new life. As the years went on, I slowly grew taller and stronger. Eventually, my petals began to bud and I grew into the new me. I am not the person I once was and that's ok. I've found my own way to keep Cole in my heart and live this new life. I still have hard days but with my root system in place I know I can weather any storm. Eventually the good days outnumber the bad. There are still times where the big waves come in, but I feel fortunate that I can look back at our experiences and time with Cole and smile, thinking about the memories we had with him.



Elephants were a theme for Cole's nursery.

Will: As the years have gone on, I'm really happy with how strong my relationship with Jen has become. I've heard that losing a child can be a big struggle for a couple, but I think we've come out even stronger on the other side. We still use strategies we learned going through the initial grief even today, when dealing with the litany of challenges life throws at you. During darker times, I sometimes wonder what life would have been like if we hadn't gone through the unbearable loss we experienced. But every time I start to think about that, I immediately can't imagine our lives without Cole, even just for those 99 days. And I will continue to keep Cole's memory alive for the next 99 years as I try to live my life to the fullest for him.

Jen: Cole would have turned 6 this upcoming December. He should have begun kindergarten this school year. It's still difficult reaching these milestones without our son, wishing we could be taking him to his first day of class or coaching his t-ball team. I hang onto the positives and fun times that we had with Cole all those years ago. There isn't a day that goes by where I don't think of him or miss him. Those memories with him will always be with me. I try to be the best flower I can for him and, in turn, the best person I can be for my family. And I know that makes Cole proud.

Thank you, Will and Jen, for sharing the story of your family and your sweet baby, Cole, at this year's Day of Remembrance ceremony.



Fifteen Years Later

Aly Yisrael

Our daughter, Micah Mei, died on May 3, 2006 from complications of a seizure disorder. While there were some concerns about her health, her death was sudden and unexpected. She was 17 months (and one week) old.

Before Micah died, I remember thinking, "I don't think I could live if something happened to my child." Surviving a child's death was inconceivable. In the years after Micah's death, I remember the horror of realizing that I would live without one of my children. I would survive. And fifteen years later, I not only survive, I am living a joyful yet complicated life.

It is an understatement to say that grief is complicated. It is both different for every person and every loss, and yet we find so many similarities among our emotions and experiences. In the first few years after Micah's death, I was convinced that I would not heal. I read stories by and met other bereaved parents who eventually found happiness again, beside their grief, but I felt different. They were like me but not like me. I don't believe I thought I loved my daughter more, grieved more than anyone; but I could not imagine a world where I would be anything but deeply sad and despairing. I knew that grieving took time, but I was not hopeful that any amount of time would help me.

Thinking back, I cannot think of anything that someone could have said or done to convince me otherwise. That was my own journey of grief - that I could not trust or believe that it would ever ease. If you are in that space now, do my words and experience help? Perhaps. Or perhaps, like me, nothing but working through my grief* AND time (a lot of it) would show me that I would, indeed, begin to heal at some point (*individual therapy, couples therapy, a child loss group, eventually volunteering with Kara, etc.).

I am wary of sharing the timeline of my grief transitions because, again, we are all different. But as you can likely guess, we are talking years and not months. At a certain point, I did notice some relief. The grief was all still right there, but the pain wasn't as sharp; and the time that I could sustain thoughts outside of grief grew. My mind could tolerate the future more, and I sometimes felt joy. This realization, however, was complicated. I so wanted to experience those moments of relief, but they were uncomfortable. I hated it because I feared what it meant. Did I love Micah less? Miss her less? Was I forgetting her? Was I less committed to her?



It took some time, but I realized that a change in my grief was not a reflection of my love or ability to remember Micah. It was human. Humans adapt. And when we don't, things don't go so well. I was beginning to adapt to a world without Micah here, and that was OK. (If it helps, you can insert your child's name and repeat that sentence a few hundred times. Because it is true. And so important for us to know and believe.)

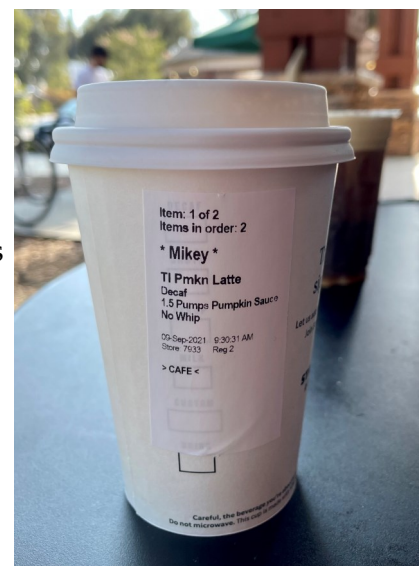
And so while I had and continue to have years of grieving in front of me - though changing, it will always be with me - I was at the very beginning of grieving my grief. What an odd concept, but it was so neces-

sary. In my acute grief, I felt deeply connected to Micah. The pain was searing but it also made me feel closer to her. It became familiar and, at the time, was my connection to her. Over time, pain was not the only way to be with Micah; but it was hard to trust this and let some of that acute grief ebb. Of course, what I wanted most in the world was to have Micah here, but if that wasn't possible, I at least wanted what had made me feel her the most. How was I missing moments of agony? Rather than question this turn in my grief (as I had learned, logic and grief are often at odds), I slowly began to grieve that acute grief. Grieving it became a way for me to respect it and to acknowledge how it had served me. The moments of relief were ok - and hard earned. I was moving forward (not moving on). And I was bringing Micah with me.

How do we bring our children forward with us? I am sure we all do this in different ways. In the years following Micah's death, I put my "mothering energy" for Micah into my work. It helped me to be very intentional about this, to have a physical and emotional space for some of this energy to go. I also started giving blood regularly in her memory, again directing my energy in a way to honor her life. Our family remembers Micah in special ways together throughout the year. These rituals have changed over time, but they are always meaningful. It may sound odd to someone who hasn't had a child die, but I really like when the four of us (me, my husband and Micah's big sister and little sister) go to the cemetery. For one, because it is a time when I feel like the five of us are together. My husband spends time cleaning Micah's stone and then all of the other stones in the baby section where she is buried. Micah's big sister and I are usually lying down on a blanket at the foot of Micah's stone, either wrapped in blankets on cold days or creating makeshift shade out of our clothes when the sun is blaring. Micah's little sister used to wander through the markers, reading names and collecting rocks. We always share chocolate or a treat while we are there, to bring some sweetness to Micah and our loss. It is peaceful and comfortable and one of my favorite places to be. By choice? No, but given my reality? Yes.

I'd love to share three other ways that I keep Micah with me that may seem silly, but I continue to get a lot out of them. One is getting the stickers that represent your family on the back window of our car. I may have rolled my eyes at those stickers in the past, but I love having a concrete way to see my family of five (including my three girls) in front of me every day. The other is using Micah's name for my drink when I get coffee. As time goes on, you hear the name of your child who died less, and fifteen years later, I note every time a barista calls her name. It is always special. Finally, only English teachers may catch this, but when referring to our children, my husband and I use oldest and youngest vs. older and younger, so Micah is always there.

And because Micah is not just someone who died, but a sweet girl who lived, I want to share a little of her with you. Micah had shiny black hair and saved her biggest smiles for her big sister. She loved cats and was indignant if one ran away from her little hands. Micah loved the water, especially splashing her sister in the bath, and would shimmy shoulders when she heard music. She was a sweet and goofy bundle of love.



*Micah's beloved nickname,
Mikey*

Family Perspectives (continued)

This August we took Micah's big sister to college. If I was missing my acute grief, I got to have it again, right there. It felt complicated because this is what is supposed to happen, what Micah wasn't able to do: to grow up. I know that for many having your child leave for college or move out is bittersweet, but I could only taste the bitter; it was heavy and deep. When we said our final goodbyes near the campus center, she walked back towards her dorm and we began to walk to our car. I made it a few steps before starting to sob. My husband quickly found a bench for us to sit for me to ride the wave of grief. I thought about leaving the hospital without Micah after she died, walking to the car with an empty car seat to drive home. And now here

I was walking to the car without my daughter, again. My brain knew the circumstances were different, but my heart felt deep pain. I was grateful to have my loving husband with me to acknowledge that pain. As Micah's big sister settled in and I got a few days from the emotional drop off, I began to feel some of the sweet part of the bittersweet: seeing my daughter working hard meeting new people and trying new things, beginning to blossom as a young adult apart from us. It is difficult but it is beautiful.

Grief, too, is difficult and (I can't believe I - of all people! - am going to say this) sometimes beautiful. It is beautiful because it is a manifestation of our love. Deep, deep, unending love. I will grieve for Micah always, because I will love her always, fiercely and deeply. I am not in as much pain as I was when she died, but I love her just as much and I miss her every day. She is a part of me and my family forever. She is pure love.



Our three daughters

Summer Scamper Fundraising Update

Wednesday, June 30, 2021



The Family Guidance and Bereavement Program team was the top LPCH Summer Scamper fundraiser for the 8th year in a row receiving \$74,057 in donations towards grief support services for LPCH families. We especially thank the Caulfield family and the Thompson family for supporting our program as our Patient Hero Families this year. Also, we are especially grateful to Katy Orr, who raised the most funds ever (over \$70,000!) The donations received from the Summer Scamper are used to pay for the program's grief support services such as memorial events, grief literature sent to newly bereaved families, support groups, and individual grief counseling. We extend a big thank you to everyone who participated in the Scamper this year.





This national day of awareness was created to send love and hope to all children who have had someone they love die. And on this day, we want children to know that we care about them and acknowledge their grief.

Whether this important person in a child's life passed away a few months ago or many years ago, the grief is always inside of them. Children and teens may want to spend special time with family on this day to make a loved one's favorite meals or desserts, watch their favorite movie, create a new tradition, or hold a small ceremony with family by lighting a candle, saying a prayer, playing a song, or having a moment of silence. It's also okay if children want some time for themselves, maybe to journal or write a letter to a loved one, look through photos, read a comforting book, or listen to music that the child wants to hear. Ask what your child or teen would like to do, and know that it may change over the years.

Here are a few online spaces to find more information, resources, community, and comfort on this day and in those to come:

Childrensgriefawarenessday.org

The official website for Children's Grief Awareness Day has many resources and ideas on how to participate as a family or in your community.

Annie's Hope Read Aloud

A YouTube channel by Annie's Center for Grieving Kids, where staff read aloud books about grief for kids.

Dougy.org

A hub of resources and information for grieving children and those who love and support them.

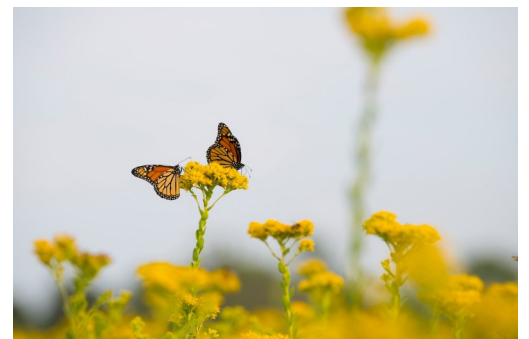
Grief Out Loud Podcast

Produced by the Dougy Center for Grieving Children, this podcast opens up conversations on the avoided topic that grief can be, with a mix of personal stories, interviews, and tips for coping. Check out these teen-friendly episodes:

Episode 158 | Growing (Up) with Grief: One Teen's Story

Episode 152 | Teenage Grief Sucks: Natalie Adams

Episode 96 | Dear Me: A Mini Episode



Community Events

Interfaith Memorial Service and Candle Lighting (in-person or online), Hospice of Santa Cruz— November 17 at 6:30 pm - 7:30 pm

<https://www.hospicesantacruz.org/event/fall-interfaith-21/>

The Interfaith Memorial Service and Candle Lighting is an invitation to pause during the busy holiday season and tune into what counts: remembering a beloved family member, or dear friend, who has died. The community gathers for words of support, candle lighting, and a remembrance table, for which attendees are welcome to bring a photograph or object of your loved one. Children and families are welcome.



Child Grief Awareness Day— Thursday, November 18th: <https://www.childrensgriefawarenessday.org/cgad2/index.shtml>

Grief Awareness Day is observed in November every year, as this time of year is a particularly important time to support grieving children. This event provides an opportunity for all of us to raise awareness about the painful impact that the death of a loved one has on the life of a child or teen and to make sure that grieving children receive the support they need. (See page 7 for additional information.)

Kara, Candlelight Service of Remembrance (online)— Thursday, December 2nd: <https://kara-grief.org/events/2021-candlelight-service-of-remembrance/>

A meaningful evening of remembrance where personal sharing on the themes of Love, Hope, Memory, Courage and Community come together with live music and culminate in a special candle lighting ceremony to honor loved ones who have died. This non-denominational service is open to all.

Would you like to receive the *Connections* newsletter by email?
If so, please send your name and email to bereavement@stanfordchildrens.org.
Thank you!

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Child Life: (650) 497-8336

Palliative Care: (650) 497-8963 or (650) 723-7288, pager #19474