

Bereavement

ISSUE #67 | MAY 2022



Pediatric E-Journal

PEDIATRIC ADVISORY COUNCIL

Released in collaboration with the National Hospice and Palliative Care Organization



NHPCO
National Hospice and Palliative
Care Organization

Grief Magic

Alysha Lacey, LPC, ATR, FT

Director of Program Services

Dougy Center: The National Grief Center for Children and Families

alysha@dougy.org

"I don't really know what it was, but tonight in group I just felt some of that Dougy Center 'magic' happening."

I've heard this statement many times in the five years I've coordinated peer grief support groups for children and families. It comes up most often in our "post-meeting," which is a time for Dougy Center staff and volunteers to debrief after the families leave for the night. Volunteers who talk about this "magic" usually have a distant, satisfied, almost stunned, gaze. There's a shared sense that the group time had a special quality, that the sharing and caring was, well, magical.

While I love a good fairy tale, I also know that the "magic" they're experiencing results from the intentional environment we create for children and families to openly express their grief. Creating a safe space and everything involved to make that happen is an important aspect of *The Dougy Center Model* for peer grief support. For over 40 years, the children and families we have served in peer support groups have taught us what helps them as they traverse all the changes in their lives following the illness and death of a family member.

One part of the "magic" is our fundamental understanding that grief is a natural and normal response to a death in our lives. Children and teens who are grieving want to know that how they feel, what they think or wonder about, how they act, and what they experience each day doesn't make them broken or a problem to be fixed. They want to know they're not alone in their grief, and that someone else understands what they're going through. One dad who brought his daughter to Dougy Center for their first groups wrote to us after the group: "I have to tell you that she had a fantastic time! She's asked me almost every day since we were there, 'Dad, when do we go back to Dougy Center?' On our way there, she was apprehensive, and shared with me, for the first time, she doesn't like to tell people about her Mommy because she's afraid they'll laugh. After our group, she chit-chatted the entire way home telling me about the people she met, and that lots of people had someone die in their life, and she doesn't feel scared to talk about it. Obviously, this was the reaction I'd hoped for, but I was shocked at how, in one visit, it opened the door for more conversation about her mom than I've ever heard her initiate, and it's been two years since her mom's passing."

Another part of the "magic" is the skills we use to listen and invite more conversation. In a group for young adults ages 18-24, one of the participants shared a dream they had involving their mother, and but also mentioned that their dog was in the dream. The coordinator asked about the relationship between their mother and their dog, and they smiled for the first time since joining group. The participant then talked about how their mother had a real love/hate relationship with the dog. After group, this participant emailed to say, "I wanted to say how much joy your question about my mom's and my dog's relationship has brought me. I haven't felt a lot of joy for a long time, but it truly brought the biggest smile to my face. Thank you!" Had the facilitator shifted to ask others about their dreams, or possibly reflected a different detail, that participant would have missed the opportunity to think about how their mother lived and not just that she died.

The combination of skillful listening and the perspective that grief is natural and normal creates an atmosphere where participants are willing to risk sharing their experiences. This is especially true in our groups for children and teens. When asked, "How would you explain Dougy Center to a friend," a teen group member said, "We talk about stuff. Stuff I haven't thought about. Processing different parts that I didn't know I needed to process. That's why I come to group. The activity was helpful because I started remembering little things I hadn't thought of. Remembering things about my brother....this stuff after he died and thinking back on this stuff is kinda healing I guess."

A participant in our groups for 11 to 14-year-olds described the safety she experienced being around others of a similar age who were also grieving, "I felt like if I talked in the open about this people would say 'OK, weirdo,' but everyone here is just so nice, and I can speak my mind, people understand here." Another member of the group added, "I don't really talk about my grief with my friends or anyone outside of Dougy Center...here I feel included, understood, and like people just 'get it.'" A younger participant summed it up saying, "It's like we're all one big grief family! I just love it here!"

Another important part of the "magic" is the connections made between participants. They often relate to each other through even the simplest of statements, saying things like, "I have totally felt that way before!" when listening to a peer bravely offer their experience of jealousy over the attention their sister who died still receives. This was shared during a particularly quiet virtual group, one where most of the participants had their cameras off and the screen was full of small black boxes with just names. In this situation, the "magic" was rooted in choice, another important element in *The Dougy Center Model*. Each of these participants knew they had a choice about how to engage—some by speaking and others by intently listening to one another. They don't always have the same experiences, emotions, or responses, but they respect the differences as well.

The administrator side of my role as Program Director knows the "magic" we create in our peer grief support groups is the result of intention and hard work by our staff and volunteers. But I too often feel dumbstruck at the end of a group. I sit back and feel honored to bear witness to stories shared by trusting children and teens, who may have never told anyone what they're experiencing. As one volunteer stated it, "There is something about these groups. It's so magical to see the dynamic that's created among the participants. People can talk candidly, and no one rushes in to judge, 'correct,' or disagree. Everyone is respected for their experience, even if it's different from someone else's. As one participant said, "I could have survived without Dougy Center, but with it I learned to live." For me, that's the ultimate compliment for how *The Dougy Center Model* works. How can you not call that "magical?"

For information on Dougy Center, our model of grief support, and access to our Grief Out Loud Podcast, free downloadable Tip Sheets, and many more resources, visit our website at www.dougy.org.

Family Pathways: Coping with an Advanced Serious Illness of a Family Member

Alysha Lacey, LPC, ATR, FT

Director of Program Services

Dougy Center: The National Grief Center for Children and Families

alysha@dougy.org

When someone in your family receives a life-limiting medical diagnosis, you might feel a range of responses: sad, afraid, angry, overwhelmed, confused, shocked. This news may raise concerns, questions, and anxiety about the future. When children and teens are involved, these reactions may be amplified as adults try to balance tending to their own needs with supporting their children. This mix can strain communication in the family, between individuals, and for the entire system. For 32 years, Dougy Center's support programs for families served them following the death of a family member or someone close to their family. In 2014, in recognition of the need for services when a family member has been diagnosed with an advanced serious illness, we started the *Pathways Program* which provides peer support groups for family members, including the person diagnosed with the illness. Over the years, *Pathways Program* participants have shared deep insight into what helps them when they are navigating the changes and uncertainties which accompany this new reality.

One common hurdle is figuring out how to share the hard news with a child or teen. While there will never be a perfect scenario, it is helpful to put some intention into the timing and location that will work best for the family. Use open, honest, and clear language and try to follow the cues that a child or teens gives. They may ask questions, they may be quiet, they may get angry, or they may initially need some space and return to the subject later. Some reactions are expected, while others may surprise a parent or caregiver. Eight-year-old Marcus shared, "I just came home from school and saw that my mom made me cookies. She told me that my dad had glioblastoma and I didn't really know what that meant so I just said 'OK'. Then she said it meant he was really, really sick and would be in the hospital a lot. Then I didn't really feel like eating the cookies, but I did give my dog a big hug."

Individual family members may need different information, which can also pose a challenge. In addition to thinking about a child's age and developmental level, consider their personality, needs, and way of processing as you decide what to say. Each child may need to be told differently and given more or less information based on these factors. Mari, a mother whose wife was living with advanced ALS, said "Sometimes I feel guilty because my 14-year-old daughter usually hears things right away, while my 12-year-old learns them gradually. I'm not trying to hide anything, but I know my older child does better with concepts that are concrete and thorough and asks a lot of questions while my younger child gets easily overwhelmed and needs to take things in on her own timeline." Giving children choices about how much information they receive, as well as how and when, can help them feel they have some sense of agency in a situation that feels very much out of their control.

In addition to choices, validating emotions and listening without interrupting are excellent ways to improve communication within the family. It is reassuring for people of all ages to know it's okay to feel how they feel and that they have someone to share those feelings with that will truly be present with them. When asked what adults should know about talking with their teens, 16-year-old Robert whose brother has leukemia offered, "My Uncle Joe and I have what we call 'car talks' where we just drive around together, and I can say what's on my mind. He's good at just being

quiet and listening and when I will bring up a problem, he usually says 'Well what do you want to do about that?' If I ask him what he thinks I should do, he will offer suggestions but mostly he just lets me talk it out." Bianca, 11, participated in a group activity where participants could make a card for someone in their family and write what they would like to tell them on one side and what they would like to hear from them on the other. She said, "I want to tell my mom how much she hurt me. I want to hear that she gets it, is sorry, and that she loves me as I am."

On an average day it can be difficult for family members to connect between juggling work schedules, school, homework, sports, and other extra-curricular activities, meals, and home upkeep, but when you add medical appointments, keeping extended family and friends informed, and the general lack of predictability that comes with an advanced serious illness, it can feel impossible. One solution is to create a Family Question Jar where each family member is invited to write a question and put it in the jar as needed. Roberta, whose partner has colon cancer, shared how her family uses this idea. She said, "Sometimes there are questions in there, like 'will I get cancer too?' and that showed me that it was something the kids were worried about, and we needed to talk about it with them. Other times there are comments like, 'I like when we got ice cream together today' or just 'I love you'. I sometimes try to add memories in there too to remind the kids of days where things weren't so complicated, or compliments that let them know how proud I am for enduring all of this."

One technical tip related to a Family Questions Jar: We suggest you use a clear container placed in a highly visible area, so it doesn't go unnoticed. You can also assign a child to keep a close eye on the jar and alert family members when there's something new inside or to call a family meeting.

With frequent communication, there is also more opportunity for kids or teens to ask questions where the answer is unknown. Sometimes, you can defer to medical professionals or others who are helping your family for assistance, but even then, some questions don't have clear answers. It's okay to model that adults don't always know the answer, which can sometimes feel scary and confusing. However, this normalizes these feelings and can lead to conversations about how to cope with those emotions. You may say, "When I'm nervous about something I can't control, it helps me to talk to someone and to take a long walk. What do you think helps you when you're nervous about something big?"

Finally, remember each family member is doing their best to make it through an impossibly difficult time. Communication won't always look perfect. Everybody will make mistakes as stress is high and emotions run deep. Carlos, whose wife Gloria died of breast cancer when their children were 8 and 12, spoke of the time between her diagnosis and death. He said, "I wouldn't wish it on anyone. It was hard and I felt like I never knew the right thing to say or do. I know I wasn't always well-spoken, but I just tried to be honest and remind the kids that they were loved, and we would make it through day by day. Sometimes I didn't believe it, but by telling the kids, I also kind of convinced myself. And you know what, we did make it. We all miss Gloria constantly, but I think talking through all the hard things during that time made us better at doing it now."

For more information from Dougy Center, including resources for supporting children and teens who are grieving, visit our website at www.dougy.org.