

Grief & Bereavement Literacy Series

Session 11: “You are Missing from Me: The Lifelong Grief of Bereaved Parents”

Presenter: **Mary Coleman, MSW, RSW**

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July 10th, 2024: 12pm-1pm

AGENDA ITEM	DISCUSSION
<p>Introduction</p>	<p>Facilitator: Joshua Black, PhD</p> <p>Presenter: Mary Coleman, MSW, RSW Clinical Practice Lead, Bereavement Canuck Place Children’s Hospice</p> <p><u>Learning Objectives</u> By the end of the session participants will be able to:</p> <ul style="list-style-type: none"> • Understand the complexity, intensity and lifelong process of adapting to the loss of a child. • Explore themes related to the unique grief of bereaved parents. • Identify particular ways bereaved parents may seek informal and formal support.
<p>Presentation points</p>	<p>Presentation slides available here</p> <ul style="list-style-type: none"> • Caregivers can never take the pain away resulting from loss but can help alleviate some of the suffering with support and acceptance of wherever the bereaved are and their grief. <p><u>The story of Mitch and Lily:</u></p> <p><u>Mitchell</u></p> <ul style="list-style-type: none"> ➤ At the age of 3, Mitchell developed cardiomyopathy spending the next 8 years of his life quite heavily medicated in cardiac support until one day during recess in Grade 5, he collapsed on the playground. He had suffered an arrhythmia and was left with a resulting hypoxic brain injury. Mitchell died in 2008. <p><u>Lily</u></p> <ul style="list-style-type: none"> ➤ Lily was diagnosed in 2014 at the age of 13 with an inoperable brain cancer. Described as an energetic and athletic girl who had dreams of being a dancer. She fought for 6 years and through the many highs and lows, she always kept smiling and was always very curious about other people. Lily passed away in 2020, at the age of 19.

	<ul style="list-style-type: none"> • Grief informed care models help us to understand how griever adapt and integrate losses like the continuing bonds, the dual process of stepping in and out, oscillating through restoration of life and feeling the pain of loss. • Cultural values, beliefs, traditions are important factors that plays out when people are grieving. • Things to note when we talk about child loss are: <ul style="list-style-type: none"> ○ the age of the child who died. ○ the circumstances of how they died. ○ other factors before a child dies that really informs how they grieve. ○ the impact- long time social, emotional and spiritual impact.
<p>Discussion</p>	<p>Lived Experience Discussion</p> <p>Q: What would you be willing to speak about how grief has affected you over the years, and how it's changed? (Sarah for 16 years and Hollie for 3 years).</p> <p><u>Sarah</u></p> <ul style="list-style-type: none"> ➤ Mitchell died in May and the first bereavement group started in the fall. Within that time, they were totally numb and just trying to figure out how to get through each day. The group was helpful in them finding a community which had other families that had experienced child loss and it was the one place they could go to and feel safe and protected. ➤ For two years, the group was instrumental in helping them learn their narrative on how Mitchell died and also how to integrate his loss moving forward. ➤ Sarah has had to integrate the loss into the work she does with her nursing background. Having meaningful conversations with Canucks Place and a deeper dive and understanding into death, dying and bereavement. ➤ This loss informs everything she does everyday as the connection is still there. Over time, she has learnt to live with it and build her life around it. <p><u>Hollie</u></p> <ul style="list-style-type: none"> ➤ Hollie touched on the physical impact it had on both her and her husband. She developed painful arthritis, osteoarthritis in her hands and hip, body pain, aches, headaches, chronic fatigue, low immune system, intense moments of crying to the point where she makes herself sick and developed migraines that has eased off over time. <p><u>Uncertainty, Paradox and Hope</u></p> <ul style="list-style-type: none"> • There is a quote from Dr. Hal, the medical director at Canuck Place, that states that when a child is living with a serious illness, the one diagnosis families have is uncertainty. This can be applied in grief as well. It's like stepping into a world where there's no roadmap or direction and a world that no one wants to be in. • Sense of uncertainty is important to remember that it continues from the moment a child has a diagnosis and having to learn what they need along the way which is part of coping with the uncertainty.

- The sense of paradox is like there are many truths at the same time. You hear from bereaved families feeling they want some relief from the pain but at the same time, the grief is the way they connect with their child.

Q: Hollie - Touching on the sense of paradox, what does it mean when you say living in two worlds at the same time?

A:

- Hollie has another daughter; Violet, who's 26. For her, the meaning of living in two different worlds is that she's always wondering where Lily is. Though not physically with her, but she still remembers her and also having to be available for her living daughter who she can see physically and being stuck in-between. All of these has brought her to accepting her relationships for each child and not having to reconcile but just holding it all.

Q: Sarah -Relating Hope with your story?

A:

- It started with hope for survival for Mitch and then hope to survive as a family of 4. Hope is ever changing and just trying to create meaning and integrating the loss of Mitchell into their everyday lives and for their kids to have happy lives and survival of their marriage. Everyday we all wake up with different hopes but what gets us through every day is always having hope.

Recognizing the complex interplay between trauma and the death of a child

- The loss of a child shatters a sense of trust in the world and understanding of the way the world should be. Shattered senses of assumption that one can protect their child, they will grow up and be happy, healthy adults is all gone.
- How a parent sees suffering is different from what the medical team sees. A medical team can think all the symptoms were properly managed and they had a peaceful death but that doesn't always mean that's how the parent sees what happened and so that perception of suffering is really important to ask about how they see and make meaning of their child's medical journey.

Lifelong Attachment

Q: Hollie, tell us about the picture and what that means to you, as far as your connection with Lily and what's important?

A: Hollie feels like she connects with Lily in many different ways and the major way she and her husband both connect with her is through outreaches and telling her story through the light of life campaign for Canuck place. They have been in newspapers, done public speaking events for kids and always willing to share their story and get back to the places that have helped them such as Canuck Place. These are all ways of connecting with her and keeping her legacy alive.

Sarah: Touching on Lifelong attachment

- Sarah's continued attachment with Mitchell was starting a routine as a family to light a candle brought from Canuck Place for the last 16 years. The first person

	<p>who's awake every morning lights it, and the last person who goes to bed blows it out, and that has become their way as a family of keeping Mitchell in their everyday lives,</p> <ul style="list-style-type: none"> ➤ About 6 years after Mitchell died, they built a home and the kids asked if Mitchell would have a bedroom. So, they needed to be able to integrate him as still part of the family into the new space. A time capsule was created which was all about Mitchell with his prayer card that was put into the foundation of the home, so his story can go on and creating a courtyard with a fountain as he was the middle child which they find symbolic for them. • Research work indicated that siblings are forgotten grievers with a double loss: As Hollie shared from her story, siblings all have different needs in this process and their needs were met through the bereavement groups that they attended. They had choices about how they were navigating their grief. <p>Supporting a Grieving Parent.</p> <ul style="list-style-type: none"> ➤ Asking about their child was important to them and as professionals, not trying to fix and being scared of emotions. <p>Q: What would you advise is best in terms of group support for parents and how important is it to have a parent group?</p> <p>A: It is quite complex but also important having a regulated separate support group for parents and siblings experiencing grief. Aligning the experiences by taking lots of considerations when putting these groups together and respecting each one's process.</p>
<p>Resources</p>	<p>Next Grief & Bereavement Literacy ECHO session: <i>Bereavement in the Context of Homelessness</i> Wednesday, Aug 7th 12pm-1:15pm (75min): Registration link</p> <p>All Together Symposium: https://ccevent2024.bc-cpc.ca/registration/</p> <p>Other Links: Joshua's podcast link: https://www.griefdreams.ca/</p> <p>Our ECHO program webpage lists all current sessions open for registration</p>