

Sensing Connections: Peer-to-Peer Grief Support for Families of Children with Deaf-Blindness

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What we have once enjoyed we can never lose. All that we love deeply becomes a part of us. – Helen Keller

How an individual's grief manifests itself is very personal, yet studies indicate that people's experiences of grieving can be quite similar. While this may seem odd, it is exactly what a group of women who participated in the first National Deaf-Blind Family-to-Family Grief Support Group, sponsored by the National Center on Deaf-Blindness (NCDB) and state deaf-blind project personnel came to realize. Many of the group's discussions ended with feelings of validation and connectedness, yet there were still variances.

Data from the National Deaf-Blind Child Count indicates that over the past 7 years there have been an average of 91 children with deaf-blindness, aged birth through 21, who die annually. These families must deal not only with the loss of their child, but also the secondary loss of no longer belonging to or identifying with the group defined by their child's disability. Connecting to a support group is one way of coping and maintaining a sense of normalcy. It provides an opportunity to connect with other parents and family members who are traveling a unique, but similar, path. It provides an opportunity to share, care, and learn coping skills.

Beginning in May 2017, seven mothers began meeting virtually via web-based video conference calls twice a month for 90 minutes to receive emotional support and death education, and experience normalization of the grief process in a shared, supportive community led by trained facilitators. The calls spanned three time zones in the United States.

Prior to the first meeting, a Grief Kit that included a homemade blanket, candle, and journal was mailed to each participant. Upon receiving the kit, one mom reported that it made her feel welcome and special and that she knew immediately that caring for the participants was the core purpose of the group. She felt connected before the meetings even started.

Each session had a defined theme related to a curriculum provided to the participants. Before each session, they were encouraged to look through the section relevant to the selected theme and reflect on their own personal feelings and experiences.

After completing the 10 sessions over 5 months, the group found themselves yearning for additional time together and determined that meeting once a month for an

additional 6 months would be helpful. As a result, Phase 2 of the grief support group was born. It commenced in October 2017 and is comprised of 1-hour conversations with guest speakers on topics chosen by the group members themselves. It provides an opportunity for group members to do a "deeper dive" into topics they feel need further exploration.

So, as a group, what have we learned so far?

1. Losing a child with complex healthcare needs does not lessen the shock of death, even when the possibility is present or expected. Ironically enough, we often think of our children with complex healthcare needs, as resilient! As Jennifer Smith Stepanek wrote in *The Experiences and Needs of Parents Whose Children Died Due to Degenerative Disabilities*, "They have often beaten the odds."
2. The curriculum served as a guide for conversations that brought up feelings participants had previously pushed away. "It helped to have a structured way to think and reflect on my grief," said one participant.
3. To talk about our children and be truly understood is a way to celebrate them. When asked how helpful it was to have the opportunity to talk about her situation with other parents, an honest participant replied "You feel like you live on a different planet, so it is helpful to connect with other aliens."
4. Our children continue to impact our everyday thoughts. The emotions attached to those thoughts can be sad and depressing and/or happy and hopeful all at the same time.
5. It is a reality that our grief will continue for a lifetime, although at differing levels throughout our lives.

The participants in this initial group were honest, brave and supportive. In no time flat they created a safe community for healing and reflection that was not hindered by the need to meet virtually. What's in store for them next? Continuing with Phase 2 and presenting about their experiences with the group and healing at the upcoming Deafblind International Network of the Americas Conference in Cape Cod, MA in April 2018. If you are planning to attend, put their presentation at the top of your list. They have incredible insights to share.

A second grief support group will begin in January 2018. If you are aware of a family member who might benefit, please contact Megan Cote, megan.cote@hknc.org or Molly Black at mblack@pattan.net.

[Read more about the grief groups and resources available to support families](https://nationaldb.org/wiki/page/10/753)
(<https://nationaldb.org/wiki/page/10/753>).



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