

Supporting Families in Bereavement



Learning Objectives

After reviewing this Guide you will be able to:

- Appreciate the impact of child loss on the family unit
- Recognize the positive benefits of clinician outreach to bereaved families
- Consider bereavement support measures that benefit clinicians and families

Introduction

Many families welcome the prospect of holding and respecting a shared history of their child's life with their clinicians, while clinicians often underestimate the importance and meaning of outreach to families. Supporting families following the death of their child can be healing, and also a rewarding continuation of your relationship with the family.

Educating Yourself

Why Reach Out?

Clinician contact with a family after their child's death is of paramount value. The family longs to know that their child made a difference in the lives of clinicians and will be remembered. Although hospice is mandated to provide bereavement services, often a child is enrolled for only a short time and the trust relationships may not have been established. Clinicians who were involved in the child's care prior to death can be instrumental in supporting the family, and in ultimately helping them bridge to community support.

In practice, clinicians may encounter—and feel—powerful emotions. Of course, child loss is out of the natural order of things. It seems unfair that an innocent child has been deprived of a long life, and the parents of seeing their beloved child to adulthood.

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Some parents feel guilt at not having “saved” their child. They may question or regret decisions they made. In sum, parent bereavement is highly traumatic, with specific ramifications that include the intensity of the grief, the time to process it, and the particular isolation parents may feel.

For parents with other children, there is the additional hardship of needing to grieve while caring for siblings who, too, are experiencing pain and loss. As with parental loss, the family structure changes. The sense of bereavement lasts a lifetime, and milestones like birthdays, graduation days, holidays and even seemingly random events commonly trigger new waves of grief. Strong feelings can be provoked by memories of the child’s presence in the home (their sleeping space, photographs, mementos); rituals (marking anniversaries, how to celebrate holidays); the unexpected—a song, place, piece of clothing, smell. And different family members will react, behave and grieve differently.

Helping the family know that these struggles and feelings are part of normal grieving, that all families experience them, will provide validation and perhaps lessen the isolation.

Helping the Family to Understand Grief

Many families are likely to relate to the principles of Margaret Stroebe and Henk Schut’s Dual Process Model (figure1), which explained that grief work is not a linear process or to be experienced as a series of stages. In this model grief is better understood as oscillating between loss-oriented coping and restoration-oriented coping.

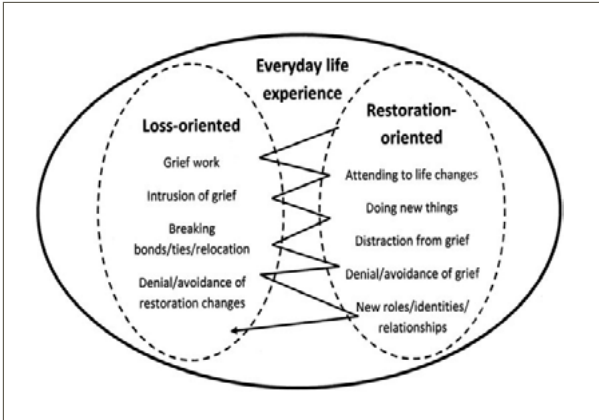


figure1

Although the family may have worked through a good deal of anticipatory grief, the actual physical loss is an entirely new experience. The model suggests that individuals are bound to navigate the two forms of coping—sometimes within the space of an hour, day or week. So, parents and siblings may be struggling at one moment, and then be able to smile or play the next. With the understanding that this can be expected, the family learns how to accept and live with all their feelings.

Important to note and share, as appropriate:

- Bereaved parents are not at increased risk for separation or divorce
- Bereaved parents are at increased risk for physical and psychological morbidity

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Parents' Identity and Support

Here are a few more key things to be aware of.

- **Parents' identities are challenged when their child dies.** In the case of an only child's death, the parent may have questions about whether they are still a parent. They may struggle to answer the question of how many children they have.
- **Parents are better able to support their other children if they are receiving support themselves.** Timing is different for every family, and it may take months for a family to determine what kind of support is a good fit for them, together and/or individually. Culture, spiritual beliefs, religion, and involvement in community activities can influence the kind of support that families reach for.

Clinicians are well-positioned to recommend formal support, especially if there are bereaved siblings whose grief may be invisible unless they are showing clear warning signs (e.g., drastic change in their typical behavior, school avoidance, acting out, or withdrawal from friends or previously enjoyed activities).

Sustaining Yourself/The Clinician

As it is throughout the care of a child who dies, attending to one's own physical, emotional and spiritual self is a critical consideration for the clinician. Knowing what sustains you and incorporating it into your workflow is essential. Encouraging team members to do the same is important.

Some available strategies are:

- Pause, offer a prayer, write, give yourself time to acknowledge your feelings
- Send a card to the family, sharing a memory
- Make a call and leave a message
- Attend a celebration of life or memorial service
- Do something physical you enjoy: run, walk, yoga, bike, exercise
- Debrief with a colleague

[The American Academy of Pediatrics Resilience Curriculum](#) "Resilience in the face of grief and loss" is designed primarily for medical residents and fellows, but is an excellent (and free) resource for all learners.

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Scripts

Personal Outreach from You

You may have mixed emotions about continued contact with a bereaved family. You may be reluctant to remind a family of their child's end of life experience and/or fear of a family's anger at the outcome, co-existing with a need to find some way to communicate that acknowledges your own sadness and the meaning of the relationship with the family.

As noted, parents long to know that their child has had an impact on others. Simply leaving a voicemail message that says "I am thinking about you and (child's name)"; sending a card on a special day, saying, "I am think of you on this meaningful day" or "I remember (child's name)'s smile, laugh or favorite music" is unforgettable for a parent.

You might also acknowledge the ways in which the parents cared for their child, as a way of reassuring them that they did their very best no matter the circumstance. These gestures are deeply meaningful and healing in their own way.

Outreach from the Team

It can be particularly helpful for the clinician team to schedule a post-death or bereavement visit at the clinic, the hospital, or a more neutral place. This meeting offers the family and clinicians a chance to share their anecdotes about the child, and explore any regrets, concerns or lingering questions that the family may have about their decisions or how things unfolded.

You may feel at a loss for words as you prepare for a meeting with a bereaved family. Here are some suggested prompts::

"I want to convey how sorry I am for your loss." "I was so sad after (child's name)'s death and I have thought of her/him/them and you many times since then."

"It was really special for me to get to know (child's name)."

"How are her/his/their siblings doing?"

"I wish I could have attended her/his/their memorial service. Would you tell me about it?"

"I am wondering how you are staying connected to your child."

"It would help us to know how you felt about our care at your child's end of life. Was there anything that felt particularly helpful or not?"

"I wonder if you are second-guessing any of your decisions, or have any regrets or questions you would want to talk about. If not now, perhaps at a later time?"

"Thank you for the privilege of caring for your child."

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Bereavement Support Resources

While everyone makes choices that are specific to their needs and circumstances, finding others who are also grieving can be enormously helpful. Siblings especially may find support by meeting peers in a summer camp or ongoing group setting. The [National Alliance for Grieving Children](#) has a robust list of support groups and resources for grieving families.

With continued outreach from the primary team, families may be gently led toward local counselors, bereavement groups and/ or memorial events sometimes held by hospices in their community.

Most community bereavement support services presume adult, not child, loss. There are few trained clinicians in childhood loss and parent bereavement. In other words, it is difficult for grieving parents to find good support. However, more and more pediatric hospitals are learning how and what services to offer bereaved parents.

Many pediatric hospitals will have a mailing program and reach out to parents at certain intervals. Some hold yearly memorial services which offer clinicians an opportunity to reconnect with bereaved families in a supported context. Families that choose to attend tell Courageous Parents Network that they are thankful for the chance to remember and celebrate the life of their deceased child with other families and clinicians. The service also provides an opportunity for clinicians to learn how the family is coping and living with their grief.

Some hospitals may offer time-limited parent bereavement support groups or one-day family workshops. Occasionally there are community groups offering parent and/or sibling support groups.

Conclusion

Families caring for children with serious illness encounter countless highly-charged moments in which they are asked to make critical decisions. Creating an atmosphere of mutual trust and respect, giving and receiving information, goes a long way toward helping parents feel confident that they are valued members of a team doing the best they can for the child.

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Resources for Clinicians



Videos



“Should providers go to a child’s funeral?”

Patient advocate and chaplain discuss the considerations and other opportunities for connecting with family members.

<https://courageousparentsnetwork.org/guides/a-framework-for-the-difficult-decisions>



“Self-care for providers”

Pediatric palliative social worker emphasizes the importance of making self-care a regular practice.

<https://courageousparentsnetwork.org/videos/a-pediatric-palliative-care-social-worker-on-self-care-for-providers>



“Self-care is important for providers too!”

Pediatric hospital chaplain speaks to the difficulty of the work and the need to care for oneself in order to give families the best possible care.

<https://courageousparentsnetwork.org/videos/for-providers-self-care-is-important-for-providers-too>



Blog

“A Death Smile: A Doctor’s Poem to a Patient”

A second-year resident’s tribute to a young patient who teaches and inspires him with her courage. <https://courageousparentsnetwork.org/blog/a-death-smile-a-doctors-poem-to-a-patient>

Resources for Families



Unit

Courageous Parents Network Unit “Bereavement”

Videos, downloadable guides and other information designed to help patient families understand and cope with child loss, supporting siblings, and tending to the marriage/parenting relationship. <https://courageousparentsnetwork.org/topics/bereavement-2>

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Videos



“Pediatric life-limiting illness & bereavement: A father speaks”

A bereaved father shares that he doesn't feel he is spending enough time “with” his son who has died.

<https://youtu.be/bv65g5iDUc4>



“Support groups can help”

The mom of a daughter who died at age 9 from cancer talks about a support group can help: knowing you're not the only one going through the grief makes a big difference.

<https://youtu.be/8qXWSp-2oZo>

Downloadable Guides

Supporting the Surviving Siblings

This guide explores how to support surviving children, including talking with them about death and loss. <https://courageousparentsnetwork.org/guides/parenting-after-child-loss>

Bereavement Bibliography

CPN maintains a list of books that may help as you support your family in grief.

<https://courageousparentsnetwork.org/guides/bereavement-bibliography-2>

Bereavement Websites and Camps

https://api.courageousparentsnetwork.org/app/uploads/2020/12/Bereavement-Websites-and-Camps-EDIT-2_18_21-PDF.pdf