Published in final edited form as:

Pediatr Blood Cancer. 2019 February ; 66(2): e27489. doi:10.1002/pbc.27489.

How I approach expressing condolences and longitudinal remembering to a family after the death of a child

Meaghann S. Weaver¹, Wendy G. Lichtenthal², Kara Larson³, Lori Wiener⁴

¹Division of Palliative Care, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, Nebraska

²Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York

³Division of Spiritual Ministry and Chaplaincy, Department of Pediatrics, Children's Hospital and Medical Center, Omaha, Nebraska

⁴Pediatric Oncology Branch, National Cancer Institute, National Institutes of Health, Bethesda, Maryland

Abstract

Bereaved families fear their child being forgotten by those who knew their loved child, including their child's oncology team. Thoughtfully timed, family-centric condolences shared by pediatric oncology team members have the potential to extend our compassion and kindness toward a family during the darkness of grief. Well-intended medical teams sometimes feel "at a loss" in terms of what to say to a grieving family and how or when to say it. This paper provides a tangible overview of written or verbal condolence communication in a format that can be personalized to the provider and the patient's family.

Background

The origins of the word *condolence* come from two Latin roots: *com*, meaning 'together,' and *dolere*, meaning "to grieve". The majority of parents who are mourning the death of their child benefit from the condoling words and actions of those around them. Words of condolence need to take into account how irreversibly changed the family's life has become as the world as they knew it is unrecognizable to them. They have lost more than a child; for many, they have lost their bearings, their direction, and no longer recognize the road before them. They are often desperate for their grief to be recognized and for their child to be remembered; and letters, calls, or memorial visits can provide that (1). Each communication of condolence offers opportunity to serve as a message of sympathy, compassion, and affirmation (2). Yet when confronted by the anguish of another's grief, words often feel inadequate. Meaningful, tailored offerings of condolence are both a tribute to the child who died and a source of comfort to the parents. Words that are perceived as impersonal or not sincere risk further pain or emotional distance. Condolences should be intensely personal.

Conflicts of Interest

The authors have no known conflicts of interest to declare.

A recent survey of 500 pediatric oncologists revealed that nearly all (98%) believed that bereavement care (such as condolence contact) is part of good clinical care (3). And yet, approximately two-thirds of centers delivering pediatric cancer care do not have a policy or standard for delivering bereavement care (4). Bereavement care is often disparate based on local practice and personal or professional comfort of the care teams. Time, resources, perceived lack of knowledge of what to say, and the complexities of emotion are cited by pediatric oncologists as realistic barriers to personalized condolences (3). To neglect bereavement outreach is to miss an opportunity for extending a caring connection. Condolence messages have the potential to foster connection for a family by messaging that their child was known, was appreciated, and is remembered. Bereaved families depict a sense of displacement from their “medical home” and even a sense of losing the human connection of a caring medical team (some bereaved families remember their child’s health care team as a medical family). Condolence messages serve the important reminder that a loved child and a grieving family are remembered (5).

Bereaved parents identify the profound impact of receiving correspondence from a familiar care team member who personally knew their child (5). In 2015, 15 evidence-based standards for the psychosocial care of children with cancer were published (6). One of the standards is specific to the health care team contacting a family after a child’s death (7). The standard states that bereaved families “want follow-up and benefit from continued connection with their child’s healthcare providers” (7). Yet, approximately one-third of pediatric cancer centers that do engage in bereavement contact report that the person initiating contact did not know the child (4). In fact, offerings that appear impersonal can leave the family feeling unseen and unknown, and run the risk of causing the family more pain.

This paper shares ideas for expressing condolences both in written and verbal format. Pediatric oncology teams are welcomed to apply or adapt these ideas in a way that is personalized for the provider and the patient’s family.

Considerations for Expressing Written Condolences

- Don’t rush to send out a card. Your words are very important to the family. The family may go back and read your note many times over the years so it is better to take your time. A hand-written note will be more meaningful than an email, text, or social media (e.g., Facebook or Twitter) post/message. You may consider selecting a generic sympathy card, although this is less preferable to a personalized card. You may opt for a personalized card that reflects a remembrance of the child’s favorite items or a picture symbolic of the child’s preferences. For example, an airplane card for a child who loved planes or a lamb card for a child who carried a stuffed animal sheep to clinic each week.
- It is hard to find the way to start a condolence note. It is helpful to start by expressing something personal about the impact of the loss (e.g., “I was so saddened to learn about Tommy’s death.”) followed by an expression of genuine sympathy (e.g., “There are no good words, but please know how very sorry I am.”).

- Parents want their child to be remembered for who they were in life. Share a story, memory, accomplishment, or experience with the child. A personalized note that speaks of the child that has died (e.g., “I will always remember her silly sense of humor in teasing me about my matching socks in clinic and how she approached so many challenges with a smile on her face.”) is much more meaningful than clichés. Parents find reading about their child’s special qualities and the impact their child had on you and others comforting. Feel free to include pictures you may have of the child and always try to use the child’s name when communicating.
- Praise or compliment the family for how they supported or parented their child and, if appropriate, their other children as well. (e.g., “I witnessed what wonderful parents you were to Amelia and how you supported each other. I hope you continue to take such good care of each other.”)
- If there are siblings and/or grandparents, a personalized note to them will be tremendously appreciated. For younger siblings, such letters will mean a lot to them when they get older.
- Within a letter or conversations of condolence, it is best to avoid words that express the provider’s own belief system (e.g., “I know he is in a better place,” or, “God doesn’t give you more than you can handle.”) if this is different than the family’s belief system. Families may find your efforts to make sense of the loss or to minimize their pain with platitudes very hurtful (e.g., “Everything happens for a reason,” “You have other children,” or “Time will make it better.”). Even if the writer has lost a significant person in his/her life, if the writer has not lost a child, words such as, “I know how you feel,” can make the person feel even more alone and lead to more suffering.

Table 1 offers suggestions for sharing written condolences. In selecting between the format of contact such as a telephone call versus a written message, oncology teams may consider whether the bereaved family has initiated contact; the timing of contact; and the content of contact. If a bereaved parent initiates contact with the oncology care provider with a personal message or an invitation to the child’s memorial service, this initiation by a parent during a time of grief may kindly be reciprocated in the personalized format of spoken voice. If the timing of death is near a holiday in which the bereaved family may be traveling or a time when the family is experiencing a particularly busy season, a written message may be a comforting greeting while not imposing on the family’s schedule. If the oncology team is concerned about prolonged grief or mental health outcomes for the bereaved, a phone call would allow for screening and would foster opportunity to offer additional support referrals. If the bereaved family made frequent phone calls to the care team during the child’s treatment, a phone call from the care team may offer the sense of familiarity and proactive remembrance in a memorable way. One particular bereaved mom called our oncology clinic every other Wednesday afternoon for lab counts and so our oncology nurse found that calling this mom on those same Wednesday afternoons in her initial bereavement was a form of personalized remembering. Format of contact may be personalized to the bereaved family member’s personality and baseline communication style.

Considerations for Conversational Condolences

A unique consideration in verbal condolences is the necessity of family-centered timing. Any phone call should open with a gentle inquiry as to whether the timing and setting of the call is acceptable for the receiver. Seeing the children's hospital number on a family member's phone caller ID may trigger memories of the child. Hearing a health care provider's familiar voice may also invoke emotive memories for the family member. The caller should graciously offer the family an option to decline ongoing telephone communication upfront (8). The provider should offer for the family to designate if and when they may wish to receive a follow-up call if the timing of the first call is not preferred by the family.

In addition to providing support and connection with someone who knew their child well, the phone call should be "to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement" as has been recognized as a Standard of Care in pediatric oncology (7). Each conversation should thus open with a statement of phone call intent and a gentle offering of content rather than imposed conversation. This opening can be simple, such as "I wanted to check in and let you know how much I am thinking about you and to see how you and your family are doing." This phrasing may be shared on a voice mail with an accompanying contact phone number, should the family wish to return the call or should the family request to opt-out from future contact. Personalized to the family, if a family has not expressed a desire to opt-out of further contact, the provider may elect to call the family a second time a week after leaving an initial voice mail, to offer another attempt to connecting or to invite the family to share if they prefer not to receive contact.

A standard of bereavement care in pediatric oncology is to "assess grief and provide the family with appropriate resources" (7). Assessment of the family's bereavement experience on the telephone can be through gentle inquiries (e.g., "Do you feel you have support right now?" "How have you been coping with difficult moments?"). The need for resources can be approached with a question like, "Can I try to find out about any support resources that might be helpful for you, like groups, counselors, books, or websites?" The call ideally would be concluded in a way that allows for future contact and determines the family members' preferences about future contact (e.g., how and when). If the risk for bereavement-related mental health challenges or distress is noted to be high (Table 2), referral to an external counseling or support agency may be warranted (9). Some other important details to consider include:

- The person placing the communication should, ideally, have known the child and family.
- Phone calls should be made in a distraction-free, quiet environment. Providers should contact the family in a timeframe when they will not be interrupted. The phone call should allow time for the family to describe what life has been like for them and to reminisce in a non-rushed format.
- The person placing the phone call should have access to mental health referral services and bereavement support resources in the event that the communication

reveals the need for further psychosocial care for the family. Identification of symptoms of prolonged grief or a mental health crisis warrant close interval follow-up and timely referral to additional resources (e.g., mental health providers, counselors, etc).

- Important or challenging days identified by the family member on phone calls should be noted as times when future supportive contacts would be appreciated (e.g. birthdays, anniversaries, Mother's Day, and Father's Day.
- If one parent is the primary point of contact on the telephone, consider offering for both parents to be together on the phone or for a separate supportive phone call for the child's co-parent.

An example of one pediatric oncology center's phone call timing and content protocol is shared as Table 3. The content of these three phone calls are initiated by the palliative care team in partnership with the oncology team with call content then reviewed in an interdisciplinary care team setting. Universal domains of bereavement that may be relevant to telephone call conversations are provided as Table 4.

Longitudinal Remembering

While not always possible, many parents benefit from having their grief recognized across time. Bereaved families have identified meaningful days of their child being remembered via a letter or card such as on the child's birthday, the anniversary of the child's death, and on certain holidays such as Mother's and Father's Day, the first day of school, Halloween and Winter Holidays. Parents especially appreciate when something is done in honor of, or in the child's memory, on one of these difficult days. An example may be planting wild flowers in a hospital's healing garden in honor of bereaved mothers on Mother's Day or donating school supplies in honor of bereaved families on the first day of school. Condolence outreach should include inquiring from bereaved family members their permission for longitudinal remembering. Bereavement research has shown that families perceive a greater need for support in the second year following death than even the first year and that the grief trajectory continues for many, many years to come (10). Centers may thus consider a a longitudinal bereavement care plan based on programmatic feasibility and family preference. Some centers chose to continue to send memorial cards on the anniversary of the child's death or the child's birthday for a minimum of five years. The process of remembering dates each month, gathering appropriate cards, and hand-addressing envelopes requires time and attentiveness; some oncology programs include volunteer coordinators or administrative assistants in the tangible bereavement tasks of gathering stationary and organizing the mailings. Realizing their child is remembered can help the family return to and sustain function (11).

Memorial Services

Attendance at a child's funeral or memorial service is a personal decision for healthcare professionals. Some healthcare professionals elect not to attend services, as they strive to separate what seems a personal ceremony from a professional role. Others find a sense of closure and comfort in attending services. For oncology team members who do attend a

memorial service, opportunities for debriefing and discussing with colleagues may be a meaningful form of self-care and team-care (12). If an annual bereavement service will be held at your medical center that will acknowledge the child's death, it is appropriate to let families know about this early on so that they are prepared for the invitation. Families have appreciated personalized contact from staff in the days following hospital memorial services to check-in and assess coping.

Legacy

Many parents search for meaning after their child's death, though for some, this is a long and painful process (2,13,14). Creating a legacy, something that positively represents the child who died, can be one way for the family to help provide meaning. If future correspondence occurs, supporting discussion about legacy can be helpful. Examples parents may mention include creating an award in the child's name at his/her school or sports club, a special fund to support something that was helpful to the child during cancer treatment (e.g., art therapy supplies or music therapy instruments), and avenues to encourage scientists to conduct research in childhood cancer therapies.

Potential Resources

Pediatric oncology teams may consider partnering with palliative care teams, social work, behavioral health, child life, grief community groups, and bereaved parents (14) to further define pediatric oncology condolence outreach appropriate to their local setting.

Final Comments

Condoling actions are often deeply appreciated by families who have lost a child as they attempt to adapt to the physical absence of their child. It is common for the profound pain that bereaved parents face to persist, and all members of the family will need ongoing support for a very long time. A recommendation would be to continue bereavement care in the form of letters or cards for five years while allowing the family to designate opting-in to such longitudinal care approach. Bereavement is without a timeline. The grief trajectory is highly individualized to each family member, each family approach, and each culture. Families are comforted when people take the time to write personal letters, listen to them, and talk with them, especially about their child and their grief. Writing about and talking about the child shows families that their child has not been forgotten, which is extremely meaningful and critically important for bereaved parents.

References

1. Denhup C Grief. In: Pediatric Palliative Care. Hoffman R& Smith S (Eds), The American Childhood Cancer Organization (ACCO), Kensington, Maryland, 2015, pp205–215.
2. Zunin LM, Zunin HS. The Art of Condolence. Harper Collins, New York, New York, 1991.
3. Jensen J, Weng C, Spraker-Perlman HL. A provider-based survey to assess bereavement care knowledge, attitudes, and practices in pediatric oncologists. J Palliat Med 2017;20:266–272. [PubMed: 28072917]
4. Wiener L, Rosenberg AR, Lichtenthal WG, et al. Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings. Palliat Support Care 2018 2 1: 1–6. doi: 10.1017/S1478951517001249.

5. Snaman JM, Kaye EC, Torres C, et al. Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys. *Cancer* 2016;122:2757–2765. [PubMed: 27244654]
6. Wiener L, Kazak AE, Noll RB, Patenaude AF, and Kupst MJ. Standards for the psychosocial care of children with cancer and their families: An introduction to the Special Issue. *Pediatr Blood Cancer*; 2015 12; 62 Suppl S:S419–424. [PubMed: 26397836]
7. Lichtenthal WG, Sweeney CR, Roberts KE, et al. Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatr Blood Cancer* 2015;62 Suppl 5:S834–869. [PubMed: 26700929]
8. Darbyshire P, Cleghorn A, Downes M, Elford J, Gannoni A, McCullagh C, Shute R. Supporting bereaved parents: a phenomenological study of a telephone intervention programme in a paediatric oncology unit. *Journal of clinical nursing*. 2013;22(3–4):540–549. [PubMed: 23083428]
9. Hudson P, Hall C, Boughey A, and Roulson A. Bereavement support standards and bereavement care pathway for quality palliative care. *Palliative and Supportive Care* 2017;July 13:1–13
10. Lichtenthal WG, Corner GW, Sweeney CR, Wiener L, et al. Mental health services for parents who lost a child to cancer: If we build them, will they come? *J Clin Oncol* 2015 7 10; 33(20):2246–53. [PubMed: 26033819]
11. Kreicbergs UC, Lannen P, Onelov E, Wolfe J. Parental grief after losing a child to cancer: impact of professional and social support on long-term outcomes. *Journal of Clinical Oncology*. 2007;25(22):3307–3312. [PubMed: 17664479]
12. Finlay FMacCallam J Supporting best practice for attending a child's funeral as part of our professional role: Guidelines for developing service policy. *J Palliat Med* 2017;20:801. [PubMed: 28661719]
13. Kelly-Langen C, Carst N, Friebert S The child's legacy In: *Pediatric Palliative Care*. Hoffman R & Smith S (Eds), The American Childhood Cancer Organization (ACCO), Kensington, Maryland, 2015, pp221–235.
14. Snaman JM, Kaye EC, Torres C, et al. Parental grief following the death of a child from cancer: The ongoing odyssey. *Pediatr Blood Cancer* 2016;63:1594–1602. [PubMed: 27187020]

TABLE 1.

Suggestions for Written Condolences

Format	Recommendation
Envelope	<ul style="list-style-type: none"> Utilize a hand-written address instead of typed or computer generated font Utilize the professional mailing address as the return address (not the provider's home address)
Stationary	<ul style="list-style-type: none"> Consider selecting a card personalized to the child For longitudinal winter or birthday holiday mailings, centers might purchase cards in bulk for the clinic so that the stationary is not accidentally duplicated between years for an individual child
Content	<ul style="list-style-type: none"> May include a photograph of or with the child May include a personalized message to siblings or grandparents May consider including a brochure or print-out for local grief support group or grief resource library
Introduction	<ul style="list-style-type: none"> Include the child's name May name your own emotion such as sadness or grief Refrain from religious platitudes that may not be shared by the family's worldview, false reassurance, or minimization of family sadness
Body	<ul style="list-style-type: none"> Share a personalized memory of the child Depict impact of the child's legacy on your work or life Consider recognizing the positive aspects of the family's relationships
Conclusion	<ul style="list-style-type: none"> Mention a commitment to continue to care for children with the same disease Remind the family that their child is remembered and will always be remembered

TABLE 2.**Risk Factors for Bereavement-Related Mental Health Challenges ***

Medical treatment-related factors	<ul style="list-style-type: none"> • Unclear or ambivalent goals of care • Invasive measures witnessed by family such as chest compressions or failed respiratory resuscitation efforts • Child's physical and total pain during treatment and in final phase of life • Family conflict during treatment such as continuation of hospitalizations or aggressive therapy despite pediatric patient's desire to be home or one co-parent's preference less aggressive therapies • Intense treatment-related side effects • Family caregiver burden or family relocation/separation for treatment • Economic impact of treatment on family
Death-related factors	<ul style="list-style-type: none"> • Unexpected death • Cumulative grief in the form of multiple recent losses (death of family pet, loss of aging grandparents, etc.) • Low acceptance of or delayed recognition of impending death • Inability to say goodbye to the child prior to death or to express love/affirmation prior to the time of death • Death in a setting not preferred by child or family (such as intensive care unit setting for a child who voiced preferring to be home) • Perception of insensitive or depersonalized communication regarding death notification
Psychosocial-related factors	<ul style="list-style-type: none"> • Alienation from support network or social isolation • Insecure attachment style • Traumatic past personal life experiences • Past or current history of post-traumatic stress disorder, anxiety, or depression • Substance abuse disorder or dependence • Pre-loss communication discordance • Perception of guilt or blame regarding underlying diagnosis or prognosis • Relational co-dependence with medical team • Marital tension or strife • Existential distress or faith crisis surrounding diagnosis or grief • Close or dependent relationship to the deceased person • Concurrent major life stressors such as financial hardships

* Table 1 **References:** Roberts K, Holland J, Prigerson HG, Sweeney C, Corner G, Breitbart W, Lichtenthal WG. Development of the Bereavement Risk Inventory and Screening Questionnaire: Item generation and expert panel feedback. *Palliative and Supportive Care* 2017; 15(1):57–66.; Aoun S, Breen LJ, Howting D, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. *PLOS One*. 2015;10(3); Burke LA, Neimeyer RA, editors. *Prospective risk factors for complicated grief*. New York: Routledge; 2012.; Ellifritt J, Nelson KA, Walsh D. Complicated bereavement: A national survey of potential risk factors. *American Journal of Hospice and Palliative Medicine*. 2003;20:114–120.; Thomas K, Hudson P, Trauer T, Remedios C, Clarke D. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a longitudinal study. *Journal of Pain and Symptom Management*. 2014;47(3): 531–541.

TABLE 3.

An Example of the Timing and Content of Phone Call Offerings for Families *

Timing	Call Intention	Potential Conversational Content
Week 1–2 As the family concludes memorial events; timed for a few days after the child's memorial service	Your Child is Remembered	<ul style="list-style-type: none"> • Share personal memories of the child • Share staff memories of the child • Inquire about the family's experience with the memorial service • Address needs and supports of family members (parents, siblings, grandparents, etc) • Answer medical questions raised by the family, if asked by family • Gently listen for physical, cognitive, spiritual, emotional, behavioral and social domains of bereavement to help guide conversations for the second follow-up phone call (note: this content could guide offering referrals within the interdisciplinary team such as chaplain or social work or external support resources) • Ask about receptivity to access support for expressed needs and resources
Week 3–4 As the family transitions into their "new normal"	Support for Grieving Families and Family Functioning	<ul style="list-style-type: none"> • Touch base with ultimate concerns from the previous conversation • Allow the conversation to unfold with ease by offering active listening • Normalize grief symptoms and bereavement responses • Ask the family if they are open to talking about how they are doing in terms of physical, cognitive, social, etc. domains of wellness <ul style="list-style-type: none"> • If the family is part of a close-knit community, inquire on how the community has been responding to the child's death • Ask the family if they are finding the resources they are needing for emotional and practical support • Ask the family if they would feel supported by another follow-up conversation and empower their selection of timing
Usually Around 2 Months As the family continues to remember and perhaps worries the community may forget	Honoring Legacy	<ul style="list-style-type: none"> • Focusing on ultimate concerns addressed from the previous conversation • Inquire about favorite memories • Ask how the family thinks their child would have liked to be remembered • Ask how the family would like their child to be remembered • Inquire if and how the family would like the medical care team to continue to engage in communication

* One example from a pediatric oncology center bereavement program – can be personalized to provider and patient family

TABLE 4.

Domains to be Explored When Contacting Bereaved Family Members in the Weeks and Months After Loss

Domain	Grief Experience	Potential Care Inquiries
Physical	Changes in eating and sleeping	-Have you been able to sustain sleep and rest well for restored energy in the day? -What are you doing to help you fall asleep and stay asleep? -Are you experiencing fatigue? -How have you been feeling physically? -How has your appetite been -(Consider assessing for substance use based on responses)
Cognitive	Experiencing difficulties with concentration, fogginess, shifts in memory, and a sense of unreal living (“is this a dream?”) without child	-How have your thoughts about the past and future been? -How has your concentration been? -Are you remembering events in a way that is helpful?
Behavioral	Slowly but steadily returning to family and life routines	-We recognize that we never “get over” a death. What do you think “future living” might look like for you/your family? -Are there routines or family traditions you are finding helpful?
Emotional	Recognizing the roller-coaster of emotions	-What has the past few weeks been like for you in terms of your emotions? -Have you noticed any significant changes in mood/emotions of your family members?
Spiritual	Focusing on hope and meaning making; if available and important, acknowledging specific religious and spiritual traditions	-How have you found strength on these harder days? -What has helped you stay connected to your faith even in grief? -Have you had a sense of peace?
Social	Listening for places of connection and acknowledging how sometimes the people closest to the bereaved do not know how to offer support	-Who has been present or offering support this past month? -Have you found someone to talk to who you trust?