A conceptual illustration featuring a large, open wooden window. The window looks out onto a bright, vibrant landscape with a green field and a winding path under a blue sky with soft clouds. Sunlight streams through the window, creating a warm, hopeful atmosphere. To the right of the window, a small figure of a person in a white shirt and dark pants stands looking out. The background outside the window is a dark, textured grey. The overall mood is one of hope and looking towards a better future.

# Standardization of Bereavement Care Across Oncology Institutions



**T**raditionally, bereavement services are equated with individual grief counseling and support groups, yet these services do not encompass the universality of the grief experience. The implementation of bereavement services across the oncology social work field will help providers to better support bereaved clients, while also working to disrupt the delusion that health care providers are immune to loss.<sup>1</sup> Implementation of institutional and personal bereavement support will grant permission for professionals to tend to their own bereavement needs within the professional space. This practice is in contrast with the current notion that professionals must practice self-care on personal time. Established bereavement programs and protocols in oncology settings have been shown to support better psychosocial outcomes for clients.<sup>2</sup> Documented outcomes include a reduction in grief, depression, and anxiety.<sup>3</sup> Despite being identified as a central component of high-quality end-of-life care, bereavement services tend to fall behind other components of palliative care and lack standardization across practice.<sup>4</sup> Standardization of bereavement care across oncology institutions has the potential to increase positive connections between staff and bereaved families and promote emotional support and healing among bereaved clients and professionals alike.<sup>1,2,5</sup>

The Dempsey Center, a nonprofit organization serving individuals impacted by cancer, has implemented a bereavement standard work process that informs, connects, and supports clients and staff. Elements of the framework include, but are not limited to:

- Individual grief counseling
- Legacy and life review
- Expressive arts workshops
- Grief after cancer loss support groups
- Intentional space made for staff members to process client deaths.

This article is designed to be a call to action for the ongoing provision of bereavement services in oncology social work. With barriers in mind, we describe in detail the key elements of the Dempsey Center's bereavement programming for practical considerations of implementation in other oncology settings.

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The literature focuses heavily on bereavement care within pediatric oncology or palliative care settings, yet the delivery of comprehensive cancer care supports the provision of established programs or protocols in all oncology settings.<sup>2</sup>

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### The Dempsey Center as a Model

The Dempsey Center is a nonprofit organization that was founded in 2008 by the actor and Maine native Patrick Dempsey. Dempsey's mother was diagnosed with cancer and through his journey alongside her, he was inspired to create a space where the whole person would be treated, not just their illness. Through that experience, the Dempsey Center was born with the goal of providing personalized and comprehensive care at no cost to anyone impacted by cancer, at any point in their cancer experience. Populations served are those with a cancer diagnosis as well as care partners, family, and friends. Currently, most services are primarily available to those who live in Maine, but it is the active goal of the organization to expand the reach of services outside of the state in the coming years.

Service offerings for clients include individual and family counseling, support groups, nutrition-focused consultation and programming, youth-focused programming, life and legacy work, movement and fitness, massage therapy, acupuncture, and psychoeducational workshops. The program encompasses 2 physical office locations, an online platform for virtual programming, and a hospitality house, which provides lodging for clients who must travel a long distance for cancer treatment.



Remembrance flags created at the 2022 Dempsey Challenge.

### Making the Case for Bereavement Care

Grief is a central component of the entire cancer experience, from the time that the diagnosis is received, throughout the course of treatment, and at any point in between and after—whatever that after may look like. Grief is most often associated with death, yet numerous nondeath losses occur throughout a cancer journey, for the person receiving the cancer diagnosis and their loved ones. The ripple effect of secondary losses may include concrete losses (eg, shifts in finances), relational losses (eg, losing friends who cannot be supportive), belief system losses (eg, questioning of faith, reimagining hopes and dreams for the future), and identity losses (eg, career termination or changes of physical abilities) (Figure 1).<sup>6</sup> Oncology social workers are attuned to the vastness of grief that accompanies a cancer diagnosis and are uniquely prepared to identify those losses and respond to the bereaved.<sup>7</sup>

While not always absent, bereavement care is highly variable across settings. Studies of oncologists have demonstrated that bereavement care varies significantly based on factors including specialty, resource availability, and individual opinions.<sup>9</sup> Some institutions have designated bereavement follow-up practices, yet there is a question of what the “right” kind of follow-up should be.<sup>5</sup> The literature focuses heavily on bereavement care within pediatric oncology or palliative care settings,

yet the delivery of comprehensive cancer care supports the provision of established programs or protocols in all oncology settings.<sup>2</sup>

Barriers to implementing bereavement care may include financial, lack of systems for identifying and tracking the bereaved, and competing work demands.<sup>4,9</sup> In medical oncology settings, caring for patients is, of course, the first priority, yet as one palliative care physician states, “Following people through bereavement is very important...[yet] bereavement care always ends up on the bottom of the list of things to do. It can always be put off until tomorrow.”<sup>5</sup> Many oncology providers do not receive formal training on how to navigate the personal impact of client deaths and may grapple with how to be present for bereaved loved ones while also tending to their own emotional landscape and risk of burnout.<sup>4</sup> Without a designated process and designated staff responsible for that process, bereavement services may easily continue to be a component of care that is seen as a desirable “bonus” as opposed to a necessity.

Bereavement services are often associated with grief counseling or support groups, but there is a wide spectrum of meaningful procedures and practices that can have a powerful impact without requiring an abundance of resources. What’s more, counseling and support groups do not encompass the provider’s grief experience. The reality is that the implementation of bereavement services is

important for any professionals working within oncology, considering the high frequency in which they are encountering death and holding other people's grief.<sup>1</sup> Not only are oncology social workers pivotal in addressing the bereavement needs of clients served, but also in highlighting the tendency for professionals to neglect their own mental, physical, and spiritual well-being.<sup>9</sup> Establishing a standard practice for bereavement care that includes professionals who confront death in their working lives can destigmatize grief in the workplace and highlight the inevitability and universality of loss.

**What Research Shows**

It is estimated that 609,820 cancer deaths will occur in the United States in the year 2023.<sup>10</sup> Extrapolating these data, it is clear that the number of bereaved individuals will surpass this number. The death of a central person from cancer can be distinguished from other types of bereavement, due in part to the reality that the bereaved are exposed to numerous sources of psychological distress throughout the cancer experience. These include observing physical and emotional changes in their loved one, witnessing traumatic events (eg, watching a loved one experience cachexia or be subject to falls), and experiencing uncertainty surrounding a loved one's prognosis.<sup>11</sup> With the number of cancer-related deaths remaining steady, it is imperative that oncology social workers recognize their position in being able to provide support and education to the bereaved as they move through grief.

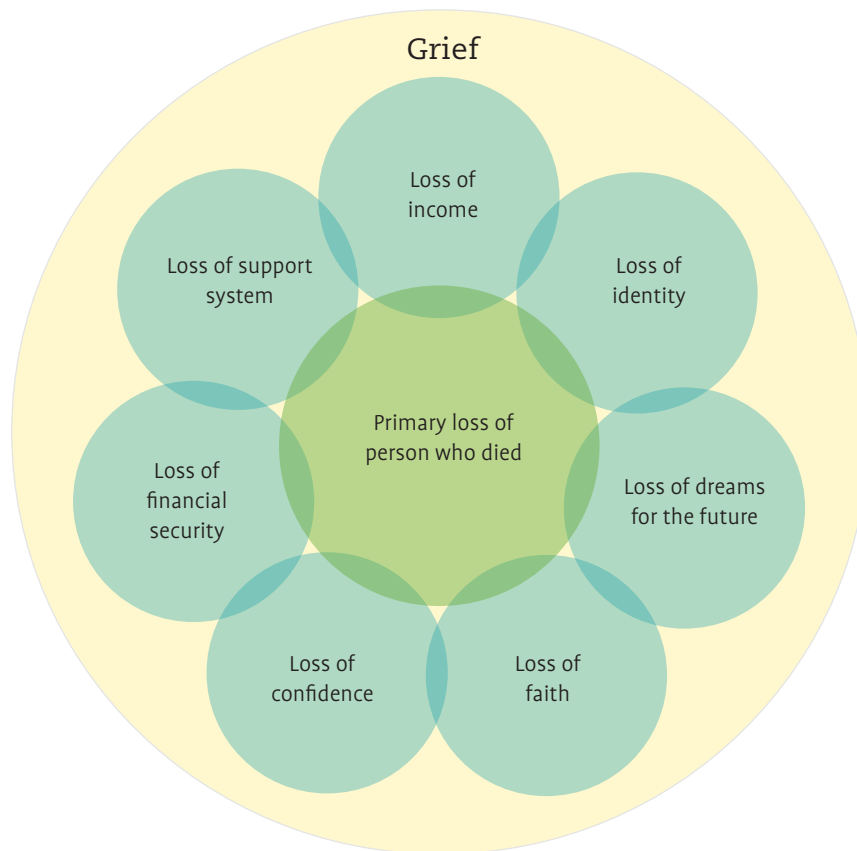
Grief does not begin at the time of death, but rather during periods of change.<sup>12</sup> A cancer diagnosis is marked by chaos, uncertainty, and unpredictability. Thus, individuals grieve the anticipated loss in addition to the ongoing secondary losses throughout the course of illness.<sup>13</sup> With the awareness that grief is not reserved only for those whose illness ends in death, it is crucial for oncology social workers to name the experience of anticipatory grief and provide support around these feelings to anyone navigating a cancer impact.

The adolescent and young adult (AYA) population experiences unique challenges in bereavement, specifically the increased experience of loss of future with their deceased loved one. While grief is universal, the challenges that arise for younger adults (18 to 40) are different from those that can present for bereaved adults in their 50s and 60s. No person's grief can be deemed more or less intense, but the experiences are different, which highlights why grief support for the AYA population is so crucial. The death of a parent, for example, can be one of the most stressful life events a young person moves through, and the terminal phases of a parent's illness are a period of psychological vulnerability.<sup>14</sup>

**Client Care**

The Dempsey Center's team of oncology social workers are responsible for most of the bereavement services, all of which are offered in-person and virtually. Bereaved clients are offered 10 individual grief counseling

**Figure 1. Secondary Losses Associated with Cancer<sup>8</sup>**







Collages created from an expressive arts workshop.

sessions as well as grief after cancer loss support groups. Most Dempsey Center bereavement groups are general, meaning they are open to anyone who has experienced the death of a loved one to cancer. Others are tailored to a topic, such as navigating grief during the holidays. Given the special considerations for the AYA population, several age-specific groups are offered in rotation: general grief after cancer loss, loss of partner, and loss of parent. Support groups have been shown to encourage members to share their experience while working towards restoration of their current lives. To grieve with others normalizes the grief experience and promotes healing in community.<sup>6</sup>

Expressive arts healing workshops are another option for bereaved clients. Often the experience of grief goes beyond what words can describe and therefore processing it through other media such as writing, drawing, or collage can be powerful and healing. As social creatures, humans possess an innate drive to express themselves outwardly. The inability to do so has been shown to promote poor physical health.<sup>15</sup> Meanwhile, engaging in expressive acts, even solitary activities such

as writing, has been shown to promote well-being.<sup>16</sup> Human existence is full of uncertainties, and it is a natural inclination to want to understand the world and all that it encompasses. To create is a natural response to wanting to make sense of the sensory stimuli people receive daily. Art allows for the nonverbal aspects of an experience to be displayed, to step in and translate when words are not enough.<sup>16</sup> Workshops at the Dempsey Center have included curricula featuring writing, collage, and drawing. These groups are limited to 10 participants and have a mix of solitary work and community discussion.

The psychosocial team also offers legacy and life review filming, a process in which an oncology social worker and a client who has been given a terminal prognosis work together to come up with questions and answers that reviews the client's life, takeaways, and sentiments they would like to express. The results are compiled into a professionally edited film for the individual to share as they wish. This interview process allows for a meaning-making opportunity for the client, validating their personal experience, taking control over what they want to leave behind, and how they want their life to "end."<sup>17</sup> The film is a meaningful keepsake for loved ones after the client dies, serving as a way to maintain an enduring bond with their person, which we know to be a healthy, productive, and normal part of the grieving process.<sup>18</sup>

Beyond the psychosocial team at the Dempsey Center, massage, reiki, fitness classes, and nutrition support are all open to bereaved clients. All are reminded and encouraged to use these offerings to promote self-care and tend to the physical responses to grief. Bereaved clients often express feeling surprised or even frightened by the ways that grief manifests physically, but studies in neurobiology have proven how losing a loved one can literally change biochemistry, impacting our respiration, heart rate, and nervous system responses.<sup>19</sup> Viewed in that light, these integrative services are yet another way to validate and normalize the entirety of the grief experience.

### Staff Care

While the impact grief has on clients is clear, grief also impacts oncology social workers and other oncology providers. To support staff members, the Dempsey Center psychosocial team regularly discusses individual practices that clinicians can engage in after a client's death, whether it be lighting a flameless candle, reciting a poem or blessing, or spending time in quiet contemplation.

On a larger scale, the Dempsey Center staff members have found that sharing the names of recently deceased clients at monthly all-staff meetings provides the opportunity to reflect on and honor clients who have died. Speaking to her experience as a member of the Advancement team, a staff member states, "As a staff member...with limited interaction with clients, I am often shielded from the grief that many of our counselors and providers see daily. Incorporating the reading of names into staff meetings has been a powerful way to be reminded of the mission of the organization and the gravity of loss happening to our clients and care partners. I'm grateful this process was introduced as a way for us to honor those that have passed and as a collective group to virtually wrap our arms around one another in show of support." This ritual encourages all employees, regardless of role, to recognize and appreciate the magnitude of the work and the impact on those served.

Having a designated team to track and report client deaths allows the Dempsey Center to be efficient and mindful. Upon learning of a client’s death, staff members who have regularly seen that individual are contacted, which can allow for emotional processing, but also helps to ensure the bereaved are not receiving any potentially now-unnecessary communications from the center. A group of Dempsey Center volunteers is then responsible for sending a sympathy card to the bereaved, offering condolences and a reminder that the center continues to be a place of support. The Dempsey Center also heavily prioritizes the well-being of psychosocial team members. For example, individual and group supervision is provided on a biweekly basis, with additional individual opportunities readily available. The support group model includes scheduled time for group facilitators to center together prior to group and to debrief afterwards.

### What the Dempsey Center Is Doing for Clients and Staff

The Dempsey Challenge is an annual run/walk/ride event; bereavement activities are intentionally incorporated into the fundraiser. These events are always open to clients, registered participants, and staff. Prior to the Dempsey Challenge, families and individuals are invited to design “Signs of Hope and Healing,” memorial road signs to go along the racecourse. These signs offer a profound race experience, encouraging participants to acknowledge those who have died and those who continue to be impacted by cancer. During the 2022 Dempsey Challenge, a remembrance flag activity was introduced. A special tent was designated for anyone to gather and take time to decorate and then hang a flag in honor of someone who had died of cancer or someone who was amid their cancer journey.

### Meaning-Making and Creative Rituals

Rituals are acts committed with intention and often represent far more than the act itself. Rituals can come from families, culture, higher power beliefs, and personal reasoning. Individuals engage in rituals daily: removing shoes before entering a home, prayer at mealtimes, wearing specific jewelry for special occasions, wearing the same jersey at certain sporting events, and/or a bedtime or wake time routine, just to name a few. Big or small, these rituals can be grounding and give people a sense of safety and direction.<sup>20</sup>

Mourning rituals have occurred for centuries—decorated burial grounds, community gatherings, wearing black, lighting candles, sharing a meal with the dead, burying the deceased with items they loved, and so on. The urge to create symbolic ways to continue bonds with the deceased has existed beyond what recorded history shows. Grief rituals have historically been highly organized social gatherings intent on encouraging the bereaved to be present with the intensity of their feelings. This path is still true for many, but it is not the only way grief rituals can be carried out.<sup>21</sup>

While large gatherings are still practiced mourning rituals, the understanding of such practices has expanded, with recognition of *meaning-making* being a pivotal part of the experience. Authors and grief professionals Rando, Laird, Schnell, and Neimeyer have all contributed to this understanding of grief rituals, “a specific series of actions, grounded in meaning about death and mourning, that gives symbolic expression to thoughts and feelings about a particular loss.” Personal grief rituals, in turn, are essential when satisfactory opportunity has not been provided by the culture.<sup>21</sup>

Figure 2. Creative Rituals<sup>22</sup>


<p><b>MEDIATIVE ART PROCESS</b></p> <ul style="list-style-type: none"> <li>• Select a focus of intention for a drawing and explore it</li> <li>• Identify a thought, feeling, or experience and express it through color, shape (abstract or imagery), and/or form (visual art, poetry, music, movement, etc)</li> </ul> 	<p><b>JOURNALING</b></p> <ul style="list-style-type: none"> <li>• Write or draw the sensations, thoughts, concerns, etc, to get relief and receive internal guidance and support</li> <li>• Follow loss-specific writing prompts</li> <li>• Letter writing</li> </ul> 	<p><b>TALISMAN OR COMFORTING OBJECT</b></p> <ul style="list-style-type: none"> <li>• Like a smooth stone that can be rubbed, something that represents being present at this moment</li> </ul> 
<p><b>MEMORY OR EXPERIENCE REPROCESSING</b></p> <ul style="list-style-type: none"> <li>• Explore something that has happened to oneself, followed by asking what is needed</li> </ul> 	<p><b>STRUCTURED ART MAKING</b></p> <ul style="list-style-type: none"> <li>• Adult coloring books, craft making, collage, knitting, etc, to refocus the brain and promote feelings of grounding and safety</li> </ul> 	<p><b>INTENTIONAL GROUP GATHERING</b></p> <ul style="list-style-type: none"> <li>• Sharing names, thoughts, feeling about the person who has died</li> <li>• General and loss-specific support groups</li> </ul> 

Personal grief rituals can be rooted in creativity, incorporating practices of meditation, writing, creating art, intentional gatherings, or performing music (Figure 2). All these activities are relatively low-barrier, cost-effective ways for oncology social workers, and any oncology care provider, to create personalized bereavement rituals. For others, quiet contemplation and remembrance may be all that is needed. The important reminder is that rituals can be as elaborate or as simple as they need to be. When reflecting on her own grief ritual after learning of a client's death, a Dempsey Center staff member shares, "While often I can't remember what I ate for breakfast, it is amazing what comes back to me about individuals—where I met them, who they were connected with, what their struggles and joys were. I guess that *is* my ritual: remembering who they were. We have the privilege of meeting people at their most vulnerable, and that essence stays with me. So: no rocks, candles, thoughtful times of reflection...but they are *always* remembered."

Oncology social workers are in a unique position to forge connections with individuals during a most vulnerable and intense time. The learning of a client's death is absorbed, consciously or unconsciously, and personal grief rituals can provide a way for clinicians to acknowledge and sit in the weight of that honor.

### Concluding Thoughts

The presence of grief and loss throughout the entirety of the cancer experience supports the importance of awareness of this topic. Oncology social workers can help develop a new way of practicing bereavement care through the promotion of healing in community, artistic expression, and an emphasis on the well-being of the physical and emotional body for both clinicians and clients. The Dempsey Center framework serves to offer potential elements of bereavement care that individual providers and institutions might use to enhance or establish their own bereavement protocols.

It is the authors' hope that other cancer programs and practices will consider conducting more research on understanding and helping to establish standardization of bereavement care services across the oncology social work field. 

*Erin King, LCSW, APHSW-C, OSW-C, is an oncology counselor and Kristen Breault, LCSW, is a young adult oncology counselor at the Dempsey Center in Maine.*

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