



Everyone Knows What Grief Is, Now

Five Ways Hospice-Based Grief Experts Can Support Patients and Families in the COVID-19 Era

Complex Grief, Bereavement Support—COVID-19 Sheds Light on a New Era of Complex Grief and What Hospices Can Do to Support Their Communities.

As COVID-19 has forced rapid and unprecedented changes in nearly every aspect of our daily lives, it has created one constant: “Everyone knows what grief is, now,” says Patti Anewalt, Ph.D., LPC, FT, director of the Pathways Center for Grief & Loss in Mount Joy, Pennsylvania. “Grief is the emotion we feel when we lose something we care deeply about. In the age of COVID-19, all of us have lost someone or something important to us—a family member or a friend, a job, financial stability, and our sense of safety. Some of us have experienced all these losses in a very short period of time.”

Unfortunately, this is just “the tip of the iceberg,” explains Diane Snyder Cowan, director of Grief Services for Hospice of the Western Reserve in Cleveland, Ohio. “We are experiencing the perfect storm for a society-wide complex grief reaction. We have only just begun to see how these extensive—and extended—losses will affect all of us.” said Snyder Cowan.

Lisa Balster, director of Patient & Family Support Services and director of Patient Care at Ohio’s Hospice of Dayton, is particularly concerned about how the crisis will affect four distinct groups: grieving children and teens; people who are isolated, particularly the elderly; those for whom grief leads to depression; and healthcare providers who are shouldering unprecedented burdens during this pandemic—in caring for patients, their own families, and themselves.

Balster believes that with their expertise in grief and bereavement, many hospices are well positioned to help families, communities, and healthcare providers navigate this uncharted territory. The original not-for-profit hospice movement, founded in England in the 1950s by Cicely Saunders, MD, was committed to patient- and family-centered care that included bereavement support. Grief and bereavement services offered for families is an integral part of the hospice experience as defined by the Medicare hospice benefit. However, not all hospices provide the same level of services as Dr. Saunders envisioned.

There are challenges. Hospice grief experts want to be supportive, says Snyder Cowan, but resources were limited even pre-COVID-19. The Centers for Medicare and Medicaid Services (CMS) requires hospices to provide bereavement services as a condition of participation in Medicare. But CMS does not reimburse for this care and does not clearly define what these services should include.¹ Larger not-for-profit hospices are more likely to have comprehensive grief and bereavement programs, often reaching far beyond the patients and families they care for to serve the needs of the entire community regardless of whether the death occurred under hospice care. Smaller not-for-profit hospices, on the other hand, offer bereavement support, but often through professionals who may wear many hats, including social workers and spiritual care providers.²

This white paper was created to offer guidance to hospice professionals from a wide range of backgrounds who are being called upon during these difficult times to provide a unique level of grief and bereavement support to families, communities, and their own provider teams. The paper provides an overview of the kinds of grief we are experiencing as individuals and as a society.

Recommendations to help hospices provide grief and bereavement services during this crisis, including information and resources for:

- Caring for children and teens,
- Supporting the isolated elderly,
- Recognizing when grief becomes depression,
- Encouraging advance care planning,
- Having difficult conversations,
- Creating virtual memorials,
- Offering virtual support groups, and
- Ensuring self-care.

This paper describes available resources and provides links at the end for more in-depth descriptions and guidance.

The Grief We Feel: COVID-19’s Impact on Families, Communities, and Healthcare Providers

“We have lost the world we knew—our assumptive world,” says Balster. “We have lost many of our traditions, rituals, and expectations—a million little griefs. People say they just want their lives back. While this is a very human emotion, it is irrational, and we are all struggling with it.”



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“We have lost our sense of predictability for the future, and experiences that bring us joy, like commencement, prom, starting college, visiting with friends, and hugging our grandchildren,” explains Snyder Cowan. “We have even lost the ability to grieve in a traditional way after a death, with delayed funerals and memorial services. Under normal circumstances, grief is difficult. When it is compounded like this, it can create a complex grief reaction, characterized by greater anxiety, fear, stress, and depression.”

The authors of the article, “Grief During the COVID-19 Pandemic,” describe three types of grief and their relationship with COVID-19: anticipatory, disenfranchised, and complicated.³

Anticipatory Grief: Under normal circumstances, anticipatory grief is the mourning we feel when death is expected, such as after a prolonged illness. During this pandemic, anticipatory grief is magnified by the growing uncertainty about who will be affected by COVID-19, the unknowns about the progression of the disease, and whether policies will keep family members apart from a loved one who becomes seriously ill.⁴

Disenfranchised Grief: Kenneth J. Doka, Ph.D., first used the phrase “disenfranchised grief” 20 years ago to describe grief that cannot be openly acknowledged or publicly mourned.⁵ In the COVID-19 era, this applies to individuals and families who cannot have a traditional funeral or memorial service because of social distancing rules. It also may apply to anyone who feels guilty if he or she could have exposed a loved one to COVID-19, which resulted in death. This can create feelings of shame and anger in addition to sadness over the loss.⁶

Complicated Grief: The heightened sense of anticipatory grief, the disenfranchisement created when families cannot say good-bye to a loved one or grieve together, and the prolonged nature of the COVID-19 crisis have combined to create greater opportunities for complicated grief. Pre-COVID-19, complicated grief meant that someone was struggling to adjust to his or her loss and experiencing anxiety or depression. During COVID-19, the potential for individuals to experience complicated grief is higher than usual.

Complicated grief may become a particular problem for healthcare providers as the crisis continues. If the patient’s death was difficult and no family member could be present, a provider serving as a surrogate may feel the loss but not have the time or a proper setting to grieve. In addition, some providers may experience the added burden of moral distress if they have had any constraints placed on them in providing care, such as more patients than they could handle

or a lack of needed equipment.⁷

Key Practices for Managing the Impact of Grief

Anewalt, Snyder Cowan, Balster, and other grief professionals offer a range of recommendations for helping families, communities, and healthcare providers effectively manage their grief and bereavement during this unprecedented crisis—from online funeral services and virtual support groups to journaling and art therapy to express emotions. In addition, the authors of the article, “Grief During the COVID-19 Pandemic,” recommend comprehensive resources for three key grief mitigation practices: advance care planning, empathetic and effective communication with families after a COVID-19-related death, and professional self-care.⁸

Key Practice 1: Encourage Advance Care Planning

Advance care planning conversations ideally happen far ahead of illness. Organizations such as the National Institute on Aging have long offered guidelines for advanced care discussions⁹, and the Funeral Service Foundation provides resources for how to “Have the Talk of a Lifetime” to pre-plan a memorial service that best honors someone after death.¹⁰ The rapid decline of some patients with COVID-19 can make these goal discussions urgent if they have not been held before, particularly if the patient is older and/or has a chronic disease.¹¹

Respecting Choices[®], a not-for-profit organization dedicated to helping individuals identify their care goals, has developed a valuable discussion guide for clinicians that is specific to COVID-19.¹² The overarching theme is: “What matters most to you matters to us.” The guide offers step-by-step suggestions for inviting the discussion, exploring care goals, and summarizing the decisions. Respecting Choices also offers COVID-19-specific guides for family members who want to lead care-goal conversations prior to or immediately after a diagnosis.¹³

Key Practice 2: Conduct Effective Communication with Families Upon Death

The COVID-19 crisis has led to restrictions on families who want to be at the bedside of a dying relative, placing unprecedented pressures on clinicians who serve as family-patient liaisons during this difficult, emotional time. To guide clinicians through these post-



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death discussions, VitalTalk has created a comprehensive COVID-19 “playbook.” VitalTalk is a communications-focused not-for-profit that provides research-based guidance to clinicians for effective, empathic, and honest conversations with patients and families. The organization created the playbook in rapid response to the worldwide impact of COVID-19 and the need clinicians expressed for communications support.¹⁴

Key Practice 3: Adopt New Grief and Bereavement Tactics for the COVID-19 Era

After a patient dies, it is nearly impossible for family and friends to physically gather together during the pandemic. The risk of spreading the virus, social-distancing rules, and travel restrictions are major hurdles. Snyder Cowan, however, recommends that families not postpone funeral services, but instead plan a virtual gathering immediately to avoid delaying a vital component of their grief journey.

“Families can always hold another service in person when this crisis is over, but delaying grief increases the likelihood of a complex response,” she explains.

She recommends that hospices guide families toward streaming a funeral service using Zoom, FaceTime, Skype, or other online tools. Funeral homes are rapidly becoming more familiar with this approach and can help facilitate a virtual memorial, says Snyder Cowan. Online resources in your area can be found by searching “virtual or streaming funeral services” and adding your location to the search terms.

Anewalt says that in her experience, all age groups are becoming comfortable with online services, especially given the urgency of the need. She also suggests that families create new rituals to replace old ones and, encourages them to use photos and mementos, for example, to create designated places in their homes to honor their loved one.

In the longer term, many hospices are offering virtual grief support groups. The Hospice Foundation of America has developed a comprehensive guide to creating and managing these kinds of virtual programs.¹⁵

Anewalt also recommends that grief professionals encourage individuals to find the coping method that works best for them.

“Mourning is what you do with your grief reaction, and everyone needs to feel safe to mourn in their own way,” Anewalt explains. “In

addition to support groups, I have recommended journaling, music, art, and mindfulness activities to help people express their emotions. And during this COVID crisis, many of these kinds of activities are supported online through social media, if family members are interested in group-based programs.”

Snyder Cowan also has suggestions for family members and friends who want to help and are accustomed to being supportive in person.

“Even if you cannot visit someone in the traditional way, you can still send a thoughtful card, offer to pick up groceries or run errands, and even ask if you can visit from a safe distance,” she says. “As a result of COVID, we have lost some of our traditions, like sitting Shiva (Jewish traditional act of mourning), but we can still find ways to help friends and families through the bereavement process.”

Key Practice 4: Support Special Populations

Children, teens, people living alone—particularly the isolated elderly—and those for whom grief becomes depression are all specialized groups that may need additional support and attention as they cope with grief during the COVID-19 pandemic.

Children and Teens: “Grief work isn’t classic therapy,” says Balster. “People who are experiencing grief are just sad, tired, and worried. What we offer as counselors is that we show up. We are present. The time we set aside is just for that person, no one else. In today’s world, though, how do we ‘show up’ when we can’t be physically present?”

While online counseling sessions are an option in some cases, they are not ideal for children and teens experiencing grief, Balster says. “Small children are not going to get on the phone and just talk. We find that parallel play and working in tandem often help children and teens open up when we are together with them in the same room. It’s much harder to engage younger people this way remotely.”

She says that one of her art therapists is developing activities she can do with children online, and another counselor took an unusual approach to connect with children who had lost their father. It was the father’s custom to take them to the opening day of an amusement park. The counselor found roller coaster rides online, and together, she and the children virtually rode the rides during their session.

Balster and her team are suggesting to parents and guardians that they make sure to create a time for their children to talk with them and encourage them to share their feelings by writing or drawing, and then discuss what their work means. She also suggests offering



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ongoing reassurance and listening carefully when their children talk.

“Again, it’s about being present—recognizing that time is the gift we can give right now,” she says.

Those Who Are Isolated: To support those living alone, particularly the elderly, Balster emphasizes the importance of making a connection, whether the individual is grieving a loved one or the loss of family visits.

“Get that note in the mail, send a text, reach out on Facebook, or make a phone call. A simple message that says ‘I’m thinking of you’ makes a huge difference. And if the person has lost a loved one, share the story you might have shared if a memorial had been held. When we are grieving someone, we need to know that the person mattered. When we are grieving our assumptive world, we need to know that we matter.”

Those Who Become Depressed: Finally, it is important to watch for signs that grief may be turning into depression, particularly as people cope with multiple losses during COVID-19, both through the death of a loved one or through the loss of a job, sense of stability, or physical connections with family and friends. This may be triggered by the death of a loved one, through the loss of a job, losing the sense of stability, or the disruption of physical connections with family and friends.

In an article on grief and depression, Anewalt is quoted, “In grief, you may have a bad day or a bad moment, but it eventually passes. Clinical depression, on the other hand, is not intermittent. It is persistent, ongoing, never changing ... While deep sadness is usually more focused on feelings surrounding the loss, clinical depression often has a negative self-focus which can become distorted with feelings of worthlessness and guilt.”¹⁶

As always, grief counselors should be watching for the signs that someone may be moving from grief to depression, Balster says. They are then ethically bound either to refer the individual to a mental health professional if there is an existing connection or to provide a list of resources. The counselor also can seek client consent to share information with a mental health clinician to allow collaboration and ensure the best possible care.

Key Practice 5: Ensure Your Own Well-Being—Provider Self-Care

Healthcare providers traditionally are trained to put aside their own

feelings and emotions and to put patients first. During this crisis, however, with limited time and resources and the pressures of caring for larger numbers of critically ill and dying patients, providers put self-care even lower on the priority list, says Snyder Cowan.

“COVID has put a heavy weight on the shoulders of providers,” says Anewalt. “Hospice providers are the link between the patient and family at the time of death, which is a very meaningful role. But it is also a highly stressful one, especially during a prolonged crisis like this pandemic. We do not know when this will end.”

According to the authors of “Grief During the COVID-19 Pandemic,” providers must take time to recognize their own emotions and process them for their own physical and mental well-being. “Self-care is of utmost importance to minimize the potential for long-term outcome effects so that providers are able to continue caring for patients during this unprecedented strain on the health care system.”¹⁷

Snyder Cowan says she has heard more people than ever say they are deeply tired, and she encourages providers to find a “moment of calm” every day. “We must protect ourselves,” she reminds us. “Mindfulness activities, which can take just a few minutes, can rejuvenate us to continue to provide support to others.” A link to Snyder Cowan’s five-minute guided imagery page called “Mindfulness Moments” is provided at the end of this article.¹⁸

In addition, Anewalt recommends that hospice providers take a day off if at all possible, to help keep immune systems healthy. And leading or participating in daily huddles with colleagues can be a valuable “check-in time” for everyone involved in providing COVID-related care.

What the Future Will Bring

“We grow through grief,” says Snyder Cowan. “Some of us will be markedly different after this intense experience, seeing joy in simple things, being kind and more altruistic, and having a greater appetite for life and new possibilities. This will not happen for everyone, but in my experience, grief can be a catalyst for personal growth.”

Anewalt says many people she has talked to are asking existential questions: What really matters? What are our priorities? Why are some people dying while I am still here? “It is very important to pay attention to what we are feeling and to take time to reflect on these questions and our emotions,” Anewalt says. “The world is changing, and how will we change? I am hopeful that we will all become more mindful, more attuned to the world around us, as we continue



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through and emerge from this devastating crisis.”

“We know that this experience will test us,” says Balster. “We are coming face to face with the fact that life doesn’t last forever. It is finite. But I try to remember that I don’t have to ‘do tomorrow,’ today. I can ‘do today,’ today, and take each moment as it comes. I want to feel peaceful about what I’ve done, for myself and others, during this crisis.”

Resources for Hospices in Supporting Grief and Bereavement and Ensuring Self Care

Advanced Care Planning from the National Institute on Aging, Respecting Choices® and the National Funeral Directors Association

NIA: <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>

Respecting Choices: <https://respectingchoices.org/covid-19-resources/>

National Funeral Directors Association: <https://nfda.org/consumer-resources/why-a-funeral/have-the-talk-of-a-lifetime>

Decide to Be Heard: <http://www.decidetobeheard.org>

COVID Conversation Playbook from VitalTalk

<https://www.vitaltalk.org/guides/covid-19-communication-skills/>

Planning a Remote Funeral from CNET Health and Wellness

Note: Many funeral homes offer step-by-step guides on their websites for setting up and managing a virtual memorial service. Search Virtual or Streaming Funeral Services and your location.

<https://www.cnet.com/health/how-to-plan-a-remote-funeral-or-memorial-and-grieve-during-the-coronavirus-pandemic/>

Developing and Managing Virtual Grief Support Groups from the Hospice Foundation of America

<https://hospicefoundation.org/Education/How-to-Develop-and-Manage-Virtual-Grief-Support-Gr>

Supporting Grieving Children

<https://childrengrieve.org/about-us/news/208-covid-19>

Mindfulness Moments for Self-Care from the Hospice of the Western Reserve

<https://www.hospicewr.org/western-reserve-carelink/Pages/Mindful-Moments-.aspx>

General COVID-Related Information and Guides from the National Hospice and Palliative Care Organization

<https://www.nhpco.org/coronavirus>

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- 17 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7153515/pdf/main.pdf>
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About National Hospice Cooperative

Our mission is to provide world-class, business support services, maximizing financial and process efficiencies to empower community-based, not-for-profit hospice providers to focus their resources on the delivery of quality care.



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