

Death, Grief and Funerals in the COVID Age

Optimal strategies for helping people develop new rituals to honor those who die during the COVID-19 era.

The Virtual Funeral Collective:

Consisting of a group of over seventy doctors, nurses, scholars, grief therapists, psychologists, funeral home directors, hospice workers, thanatologists, chaplains, hospital administrators and end-of life-practitioners from around the globe, the Virtual Funeral Collective is a group of specialists who work with dying, death, and grief on a daily basis. We are uniquely situated to offer solutions, resources, and training to those dealing with dying, death, and disposition issues stemming from COVID-19.

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Introduction

Grief and death are on everyone's mind. For most of us the scale of the COVID-19 pandemic and the associated death and collective grief is unprecedented. Combined with social distancing protocol, end-of-life issues, death care, and grief have become even more complex.

Navigating these restrictions—and the sheer volume of loss—can feel overwhelming. How do you comfort a patient when their family can't be present? Are you supposed to bring up advanced directives on intake or wait until the person is facing their death? If we can't hold a traditional funeral, how do we mark someone's passing?

The Virtual Funeral Collective banded together as part of a larger initiative called the Global COVID-19 Relief Coalition (<http://gogcrc.org/>). The Global COVID-19 Relief Coalition is a 501c3 project of The Giving Back Fund bringing together world leading labs and organizations to provide solutions for the current COVID-19 pandemic.

This White Paper contains a collection of resources and best practices from our collective to help you support your clients, patients, communities, and yourself during this stressful time.

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Dying Alone: Tools for Keeping in Touch in an Era of Pandemic Dying

Family members are often not allowed at the bedside of a dying loved one during a pandemic. This brings up challenging emotions for both the ill person and their families. Connection is difficult, but not impossible. While this is a very challenging time, here are some suggestions that can help foster connection. (Before implementing any of these suggestions, please check with your hospital or care center regarding their policies and protocols.)

- Friends and family members can send letters, cards, and meaningful mementos to the dying person's room. While they may not be able to be there in person with their loved one, these physical reminders of love and connection can provide tangible comfort.
- Use your smartphone or other device to record a message from your patient to their friends and family. As with any of these suggestions, look for familiar apps first, utilizing the technology you have; don't try to download and learn new apps during a stressful time unless that's the only option.
- Encourage friends and family to record an audio or video message for their loved one. These can be created using a smartphone, iPad, or your laptop to record a video, and can even be sent via text. Hearing is often one of the last senses a dying person loses, so recording an audio message is a great way to let a loved one know you love them.
- If assistance is available, help the patient connect with their loved ones via real-time video such as Zoom, Facetime, or Google Hangout. Physically seeing someone you love—even on a screen—often enhances the sense of connection.
- Smart home speakers offer a way for families to keep in touch without relying on staff or outsiders to orchestrate. Devices such as Amazon's Echo or Alexa, or Google Home, allow family and friends to keep in touch inside palliative care centers, nursing homes, and hospitals—anywhere someone is isolated and ill during the COVID-19 pandemic. These devices are affordable and fairly easy to install. Once set up, these smart speakers have a “drop-in” feature, which would allow friends and family to check in on their loved one anytime. Think of it like a high-tech walkie-talkie: conversations can happen without an intermediary. This could allow people to not—strictly speaking—die alone. These do rely on access to the internet in one's room, so check with your facilities resources.
- *A Sacred Passing: Death Midwifery and Community Education* has a [wonderful resource online](#) for dying in the COVID-19 pandemic era that is helpful for the dying, and especially for the caregiver, along with some valuable healthcare resources.

While nothing replaces human touch and connection, virtual options can create a kinder and more connected end-of-life experience. For more ideas on how to use technology to bring the family to the bedside, check the Helpful Resources section.

COVID-19 Burial, Cremation, and the Pandemic Funeral

Restrictions on visitations and funerals vary and are changing rapidly, depending on state regulations. The inability to gather with loved ones can be difficult on families, as the need for touch and connection is a core part of being human. In addition, many grieving families feel that they can't give their loved one the kind of funeral or memorial they deserved. This can intensify feelings of loss.

The suggestions gathered below may help people connect from a distance as they celebrate and mourn the lives of loved ones.

We share both low-tech and high-tech ways to gather together and honor loved ones. As always, we encourage people to utilize the technology they are already familiar with in their everyday lives so that the stress of trying to adapt or learn new technologies is not an added burden.

- Remind families that there is no single correct way to memorialize a life. It's okay to be creative: talking about ways to note their loved one's passage can be a connective, healing experience.
- Just because a traditional funeral, wake, shiva, or memorial might not be an option right away, doesn't mean they can't gather at a later date to "do it right." If their families are stressed about not giving their loved one the send-off they deserved or requested, they can plan a do-over.
- Depending on available resources, funerals and direct burials can be livestreamed, using tools such as Facebook Live or Instagram Live. This allows funeral directors to livestream the funeral or interment while interacting with viewers in real time. These platforms also allow for the video to be recorded for later viewing. Note that Facebook is a familiar platform for many people, especially in older age ranges—this is helpful when planning services for those whose social circles include older demographics.
- In some cases, friends and family may be able to witness the interment or burial from the safety of their own vehicles. Check with both state regulations and your funeral service professionals.
- Some people might consider asking funeral directors for a handprint of or lock of hair from their loved one as a way to remember the deceased. In this way, they could "touch" the handprint in the absence of a physical touch. A lock of hair can be stored in a keepsake locket, or made into wearable art.
- Encourage families and friends to write notes, send photos or create art, which can be handwritten or sent via email to the funeral home or cremation provider, to be tucked in with the body for burial, or kept with the body during the cremation process. They might also send a special shroud to be included in burial or cremation. This is a way for family and friends to be with their loved one even from a distance.
- Include the children! Children understand more than we think. Have them encourage the children to ask questions and come up with their own creative ideas to bring the family together. Help them to discover familiar tools that can mark the loss in their own ways. For example, popular video games like Minecraft allow users to build virtual spaces which could stand as virtual memorials for the dead.

Share with the families that they can find their own unique ways to acknowledge the loss. These could include such ideas as:

- Setting up an altar. Have them place a picture of the deceased in a part of their home, and adorn it with candles, flowers, and favorite objects of the deceased. Even if they are non-religious, honoring the dead in this way in their home helps them to remember their loved ones in a way that their death is a tangible part of their life.
- If under lockdown, hold a candlelight vigil, and invite individuals to drive by, flash their lights and/or leave or light a candle or flowers on the steps of the home of the deceased. This is a beautiful way to honor the deceased loved one while supporting their family.
- Encourage them to write a letter to their deceased loved one as a way to heal and process grief. You can find one process to doing so [here](#).
- Have them cook food that reminds them of their person. Suggest the idea of organizing a memorial virtual brunch in which other members of their family cook their favorite recipes. Gathering with food is such an important part of memorializing people we love. Zoom, WhatsApp, Facebook Live, and Google Hangouts are all good options for virtual community meals.
- Share the idea of their creating a rolling funeral in which they schedule a series of dates with friends and family to remember together. They don't always have to talk about grief and death (although they can if they want). Connect by phone, video calls, or multiuser platforms like Zoom and Google Hangouts.
- Other virtual memorial activities could include sharing songs that remind them of the person they've lost (e.g., creating a shared playlist) or creating a collective photo album to which everyone contributes their favorite photos.
- Another idea is for them to create a shared calendar (via WhatsApp, Google, or email) that outlines a series of "suggested" memorialization activities everyone can do together. For example, Day 1 could feature using grandma's recipe for cookies and gathering together to eat cookies and chat. Day 2 could feature virtually visiting special places on Google Street view and talking about the memories they made there. While Day 3 could have them watching their favorite film and keeping a running text thread with movie commentary.
- Suggest that they order takeout, meal delivery, or buy gift cards for grieving family and friends so they don't have to worry about food shopping or preparing during a time of grief. [Meal Train](#) and [Lotsa Helping Hands](#) are great websites to help people plan "casserole brigades" and coordinate delivery of meals.
- Encourage story sharing. Have them create a Google document or other page and invite friends and family to share their favorite memories and stories. To help people get started, they can share a simple prompt or question such as, "Tell us about the most embarrassing moment you had with (person's name)?" or "We don't often realize the impact we have on each other. What's one thing you remember about (person's name) that they thought was no big deal?" For more structured story ideas, see the list of resources in Chapter X.

- LifeWeb 360 and New Narrative Memorials have published two valuable free resources for planning funerals—one for families and another for funeral directors. The one for families has all sorts of ideas for families wanting to be involved in planning the service for their loved ones and can be found here: [Planning A Virtual Memorial Event A Free Step-by-Step Guide For Families To Create an Online Ceremony](#)

Additional resources we recommend include:

- *What's Your Grief* maintains a list of ways to honor and remember those who are sick or have died. Among their suggestions are to make and share a playlist that reminds friends and families of their person, or co-creating a list of things that the dying or deceased person has taught them. For more great ideas visit their [website](#).
- Nurture.Co offers a wonderful list of Things to Say and Not Say to those who are grieving [here](#). Among their suggestions are to avoid judging, offering solutions, and making assumptions, and to respect the griever's perspectives, be curious, and to let experts weigh in.
- Sarah Chavez, the director of The Order of the Good Death, has created a guide to end of life and funeral planning in the age of COVID-19. Find the toolkit [here](#).
- Oregon Funeral Resources & Education, a non-commercial website dedicated to making home funeral information easy to find, has created a frequently updated online Pandemic Care Guide. The Pandemic Care Guide assembles articles on death in the time of pandemics and ideas on what to do when a funeral isn't possible, with resources on how to care for the dying, the deceased, and the bereaved in this time; emotional support for grief and trauma; advance directives completion; and FAQs about care for the dead at home and COVID-19. Find it [here](#).

A Special Note

We expect to see a lot of survivor's guilt in the aftermath of COVID-19 deaths. As the virus is spread through close contact, surviving family members may feel responsible for spreading the virus to their loved one, resulting in their death. This is a normal response to a complex situation. Normalize, support, and validate each person's experience.

Grieving in a Pandemic: Connection in a Difficult Time

As a culture we've been taught that grief is a problem to be solved, an unfortunate experience that's best put behind you as soon as possible. We try to cheer people up as best we can. This can backfire in the best of times, but it feels exceptionally wrong in the face of the COVID-19 pandemic. Grief and loss are everywhere, and we're not quite sure what to do with it. Our culture simply hasn't taught us how to come to grief with the skills needed to be truly helpful. Even professionals, as you may know, often feel awkward in the face of grief.

Grief is a lonely experience in the best of times. Feelings of isolation and "other-ness" are typical. While we can't "fix" grief, connection and validation go a long way. It's important to tell your families—and yourself—that there's no one "perfect" thing to say that will make someone feel better. Companionship alongside grief is the best thing we can offer.

Here's a quick primer to help you or those you work with to feel more prepared.

- Grief is a normal, natural process: that it feels bad doesn't make it bad. Grief doesn't need to be fixed, solved, or rushed through.
- Grief includes a range of emotions. It's perfectly normal to feel several things at once. There's no one "right" way to grieve.
- Grief lasts as long as love lasts. While you may interact with a person in the early days after their loss, grief will continue to unfold for years to come. This is normal.
- It's okay to feel awkward and helpless when faced with someone's grief. Remember that there is no one perfect thing to say. It can help to remember that it's not your job to remove someone's pain; rather, it's your job to help them feel heard and understood *inside* their pain.
- While we can't fix grief, we can reduce the grieving person's suffering by focusing on concrete, tangible things like improved sleep, emotional regulation, and finding new ways to connect with others.

Talking about grief as a normal and healthy part of life is important. In a culture that considers grief an illness, clients and families can feel overwhelmed with emotion, yet not feel they have the right to talk about it. Your acceptance and understanding will go a long way.

How we survive this pandemic depends on how well we take care of each other during this time. We'll have to bear witness to a lot of incredibly difficult things. As authors of this paper, we acknowledge the difficult work ahead and the toll it takes on you as leaders and providers. Acknowledgement is often the best medicine we have.

More resources, tips, and ideas on meeting grief and loss inside the pandemic can be found in the resources section of this document. And if you're curious about current and historical approaches to grief, please see Chapter 6 as well as the Addendum.

Suggestions for the Grief Process

The suggestions gathered below may help people connect from a distance as they celebrate and mourn the lives of loved ones. Offer these to the families with whom you work.

- Send a note without ever leaving your home. Apps such as *Ink*, *Felt*, and *Hallmark Shoebox* will allow people to send a highly personalized card, in an envelope (not a postcard), via the US

Postal Service, without ever having to leave their home. Most card-sending apps also allow people to personalize the note with a photo. In a time of isolation, receiving a card with a meaningful picture on it will be especially comforting.

- Just hearing someone else's voice can help. Calls don't need to be heavy or emotional, at least not every time.
- Brief check-ins, by text or email, such as "thinking of you" will let someone know you are "with" them without obligating them to respond. Another great way to be helpful from a distance is to lead with curiosity; for example, consider sending a text asking "What's today like for you? Happy to virtually have a cup of tea and talk about everything or nothing." Another option could be: "Do you need to vent, or do you need help problem-solving this thing?" Doing so may give them a better chance of delivering the support that the other person needs. Additionally, encourage people to try simple actions, using their existing technology and apps, to show their love and support.
- Have them set reminders in their calendar for important dates that might be rough for their friends or loved ones. These can include birthdays and big holidays, as well as Mother's Day and Father's Day, their kids' birthdays, and even a specific day of the week. People often feel forgotten, so point out how their calendar apps help them remember.
- Share the idea of ordering food or arranging some other errand for a newly grieving person. This is immensely helpful, as those details of daily life can feel overwhelming. This is especially true if the grieving person is the only adult in the house. Sharing the load of responsibility is a great gift.
- Parallel play can still be done virtually as lots of folks want company, not conversation. This could be as simple as sitting with a friend—each in their respective home—having a cup of tea and reading books. It could also be a shared art activity, such as each person painting or making a collage while connected via Zoom or Facetime. Companionship doesn't have to be fancy.
- End-of-life planning and conversations can relieve anticipatory grief and give an opportunity to honor and remember loved ones. The Conversation Project, Death Cafe, Engage with Grace and Death Over Dinner offer great framework for these conversations. Additionally, there are a variety of games that can take some of the pressure off of this conversation including The Death Deck, Go Wish, Karuna Cards, and After.
- Often after the death of a loved one, family caregivers can feel a loss of purpose. One way to remain connected to that sense of purpose is to pay-it-forward by honoring and thanking other caregivers. ARCHANGELS.me has a simple badge and poster that can be downloaded here: archangels.me/the-thank-you-digital-badge, then posted on social media or printed and shared so that other caregivers feel seen, loved and lifted up.
- If a person is able to move, encourage them to move their body while they are grieving to help their body stay healthy. While exercise might feel really ambitious some days, moving around is helpful. For some, grief can mean that they move around more, since it's great way to release

tension, stress, anger, and pent-up energy. Yet, grief can also have people moving around less; some days they might only have the energy to sit and just stare at a wall or lay in bed.

Remind them that whatever is going on, that they are not broken or permanently messed up. They might move around a lot for a while, then spend a whole year in bed catching up with their grief. Or they might suddenly get up off the couch and decide that it's the year they take on a new pose, like headstands in yoga. Regardless, remind them to be good to themselves, to find their limits and enjoy pushing themselves. Another interesting practice that they can investigate is grief-walking, which will allow them to get some sunshine and move their body through low-impact exercise.

Some movement resources include [Ryan Heffington's Instagram Dance Parties](#), [The Assembly](#), [Everybody Los Angeles](#), and [Pony Sweat](#) (the latter two being queer friendly and body positive).

If the person with whom you're consulting is not trying to move at all, encourage them to try to see their loved ones, or at least talk with them on the phone. When we're lacking physical intimacy, we can still show care and compassion for someone through our voice and facial expressions.

- Meditation practices can be helpful in managing both stress and grief. Chris Germer and Kristin Neff of the [Center of Mindful Self-Compassion](#) have outlined a brief practice for COVID-19 [here](#).
- Creative practices can be very useful in managing the intense emotions of grief. Painting, collage, mandala-making, and creating playlists are some of the many things people might find helpful.
- Encourage them to care for themselves in this stressful time and be kind to themselves. The connection between grief and food is stronger than what we eat. Grief can change when we eat, why we eat, how we eat, and with whom we eat. Sharing meals can be healing. Cooking for ourselves or others can be a great distraction. And finding friends to share a cup of tea with (even virtually) can mean a new ritual that helps someone through their grief.
- Sleeping while grieving can be hard for many reasons. People might be getting too much sleep because their body is in overload mode. Alternatively, they might not be getting enough of it because they can't stop thinking about their loved one or their schedule is thrown out of whack. Regardless of what's going on, remind them that their experience is common and normal, regardless of whether they can't get out of bed or they're counting sheep in an endless loop. Some resources to help people manage their sleep include the articles "[Grief and Getting a Good Night's Sleep](#)" featured on What's Your Grief? Website and "[How to Actually Fall Asleep](#)" featured in *The Cut* as well as HeadSpace's meditation for sleep. In our experience what we've learned is that a lot of it comes down to habit; apps and tools can be helpful; and what counts is what you do when you're not sleeping.

Further education on how to help grieving friends, family, and co-workers:

- For how to support a grieving friend, this [How to Help a Grieving Friend animation](#) is helpful, as is this article on "[11 Things to Do When You're Not Sure What to Do.](#)" A lot of the ideas there are adaptable to social distancing.
- Relieve anxiety or a sense of helplessness by letting support folks know they don't have to know what to say—awkward and heartfelt support is always better than nothing. There are resources for [supporters at this website](#).
- The DEI Collective has developed an excellent resource for employers and team members which you can find [here](#).

Educational resources for managing the physical and emotional symptoms of grief:

- Survival rules for early grief, which you can find both as an [article/list](#) and as a [pdf](#).
- An article for dealing with the [memory loss, confusion, and other cognitive issues](#) that may arise in grief.
- Anxiety is a huge issue in grief, even outside of the COVID-19 pandemic. With permission from the publisher, we've excerpted the anxiety chapter from the book *It's OK that You're Not OK*, which you can access [here](#). It includes trauma-informed care, exercises to help people ground themselves in the physical, present moment without relying on breath-focused meditations that can be contraindicated for some people.
- For additional support here are a few apps that could be helpful: [Liberate](#) (for POC), [Insight Timer](#), and [Better Help](#)
- To help people open conversations about grief— especially if they aren't sure how—encourage them to view the trailer of the new [PBS documentary *Speaking Grief*](#). (The full documentary will be out in May 2020 and can be requested from your local PBS station.)

Finally, here are some specific suggestions for managing your grief while working from home:

- Since many people might be working from home, whether on a long term basis or permanently, encourage them to explore resources that address their specific needs related to what it's like [to deal with grief while working from home](#), and often alone; while they're juggling a new way of working and other stresses in their life; [when bereavement leave isn't useful or possible](#); and when this heightened state of crisis means employers are focused on other things, and compassion, procedure, and [supportive resources and individuals might not be as available as usual](#).

Suggestions Specific for Children, Parents, Caregivers and Their Communities

Since children and their families have been home during this time, they are well aware of what is happening with COVID-19. Death is a natural part of life, and in normal times, one in fourteen children will experience the death of a sibling or a parent by the time they become an adult. We believe that parents can best give support to children by talking honestly to them about death and sickness in age-appropriate ways. Also, children should be included in funerals and memorialization of their loved ones, so that they know that they can count on adults and their community to be open and frank with them. Here are some suggestions as to guidance to offer those with whom you consult:

- We believe it is important to talk with children about what is happening. We recommend talking about death from a young age, so that children understand it is a natural process, and happens to everyone. Who better to learn about death from than the people who care for them the most?
- Have them try to include children in some way in the memorialization process. Have the children play a role by either reading a scripture, prayer, or favorite passage, or being invited to cook with the adults when they prepare a meal to honor the deceased.
<https://modernloss.com/7-ways-to-accommodate-little-kids-at-a-funeral/>
- Encourage children to express their feelings creatively through art or writing, and if they are younger, through play. Children can often work out complicated feelings through acting them out and processing them in creative ways, when they haven't yet developed the skills to name and express their emotions.
- There are some good games available that children can play as a way to help them process a death or to grieve someone who has died. Games such as [Apart of Me](#), a grief quest game that bereaved children helped to create, allows children a safe and familiar space in which to grieve. Games they already may play in their everyday life, such as Minecraft, provide an optimal way in which to mourn, by shifting the rules a bit to allow them to memorialize online.

A Special Note about Teachers and Community Leaders

We expect complex and ambiguous loss across the wider school community once schools return to session, both on students and adults. Finding new ways to enhance grief support for children will require us to also find ways to help adults navigate their own grief. We can expect a change in the way child-centered communities operate; teachers, administrators and paraeducators (sports coaches, scout leaders, dance instructors, classified staff) will be navigating their own loss while enduring the added stress of developing new ways to manage instruction, technology and classroom dynamics. Offering grief support to these individuals will naturally improve the support for the children in their care; this is an opportunity to improve grief literacy, both for the sake of students and adults. There may be an opportunity to reinforce existing support networks (teacher wellness centers, counseling support) or to introduce new tools and resources, many of which are listed in the appendix.

In order to support children, we'll need to offer grief support to the adults who make up the larger network of their community.

Coping with Death on the Front Lines, a Medical Perspective

Being a provider in the time of COVID-19 has inherently changed what it means to practice medicine. The level of uncertainty, quantity of suffering to be witnessed and often, an inability to “cure” has challenged providers. Perhaps the largest challenge, however, is the need to bear witness to death on a scale that compares in recent memory only to the HIV epidemic. For providers who entered healthcare to fulfill a calling to heal, this can be disconcerting. Death is in many ways, still equated with “failure,” and can be a source of moral injury and distress. This is compounded by a feeling of scrutiny, both self-scrutiny and the kind of medical dissection that occurs in venues such as “Mortality and Morbidity” conference. Providers expect and are expected to be strong enough to bear witness to death and suffering while being able to help others. This trauma is unique in that we are all processing it together, while still expected to tend to the emotions of others. It is a hopeful sign that many healthcare training programs now include death and dying in their curriculums, yet very few programs offer meaningful tools for coping with suffering and death in a healthy way. Providers are expected to withstand the pain, rather than be changed by it. And this leaves a gap to be filled on an individual, case-by-case basis.

The COVID-19 crisis has stressed an already fragile healthcare system and in many ways the challenges have added to the burden on providers. The contagious nature of the disease has left providers fearing for their own safety, insufficient resources have compromised their ability to serve the massive number of patients in an idealized manner. In locations experiencing a surge of patients, the high number of deaths in a short period of time, along with the isolation that comes with visitor restrictions has meant large numbers of patients dying with only the provider at the bedside. Witnessing grief as a clinician is different than bearing witness as a surrogate for family and has impacted the wellbeing of providers, with an acute stress evolving into a post-traumatic effect that has not yet evaluated. So much of the medical care is necessarily collaborative, dependent on family and visitor to uplift patients, orient to the familiar, prevent delirium, and provide historical context, that caring for patients without their loved ones at the bedside is necessarily fraught in a way that affects doctors and nurses used to relying on them to improve their experience of care. Add to this cognitive load, the fear of bringing disease home to loved ones, fear of becoming critically ill and the stress of having to take care of their own colleagues and it's easy to see how the fulcrum tips towards despair.

From a public health perspective, inequitable access to care and systemic racism compounds the emotional toll, as providers witness segments of population dying at much higher rates than the rest of the population. Being informed about and even being part of solutions for these issues can help providers reconnect to purpose. Debriefing through involvement in existing programs that are available to discuss these timely issues is also essential for healing (including Virtual Schwartz Rounds, Balint groups, and Narrative Medicine groups). Ensuring that decisions about allocation of resources are made in an ethical, non-biased and scientifically sound manner is critical, and Clinical Ethicists, Palliative Care Providers, and members of the community are needed to draft guidelines ensuring that these decisions are not improvised at the bedside by individual clinicians. This kind of advance-care planning at scale is essential to avoid the moral distress that is caused by having to allocate scarce resources. Having training in end-of-life conversations and access to technology to facilitate connection with families at the end-of-life for patients is also protective of the practitioner.

Teams will find few resources available for scaling this level of adversity. The same providers in need of support may find themselves being the source of support for others. It may be helpful to develop a meaningful ritual to honor each death. Drawing on resources available, one might enlist chaplains to offer a means of honoring deceased patients. These gestures can be quite simple, sharing a memory of a

patient, a meaningful interaction, or writing names of patients down and releasing them in a way that brings closure. Teams may write the names on paper with a colorful ink; then place each piece of paper in a jar of water, witnessing as the color of the water is changed by each person's name, mirroring how we are each changed by the patients who die

While creating supportive programs and initiatives is important, the role of leadership cannot be overstated. System-wide, coordinated leadership and effective management on the ground, that ensures adequate resources and staffing creates a feeling of psychological safety. Cultures that have psychological safety are more likely to speak up if these are lacking, and more likely to be supported. Given the current absence of national leadership, absence of a coherent policy and a defunded public health infrastructure, local highly-functional, visible leadership has become a necessity. On the management level, also critical are adequate breaks, staffing, free food, rotating hours and time off so there are always people who are "fresh." This support is offered to fend off acute stress disorders and anxiety that ultimately can escalate during a crisis.

Transparent communication is also essential for trust building within teams. Even difficult news is important to deliver with sincerity and an understanding that providers can often co-create solutions with leadership. Granular communication during crisis is key: this can include the number of cases in the entire hospital as well as in the ICU, the number of deaths, the number and percentage of employees testing positive compared with state average and the number of discharges. Having hospital leadership get daily messages and photos about small acts of kindness and compassion offered by staff and by members of the community can also be key. Support for employees that are living apart from their families is another way to mitigate the stress on frontline staff. This can be financial support, donated housing or coordination of hotel rooms for teams can be supportive.

Feeling supported by the community is key to provider wellness as well. Campaigns such as "We stay at work to help you - You stay at home to help us," provides a link to the community and allows teams to know their work is valued. Some systems project messages from the community onto hospital screens or print artwork from children and place them on patient doors. Feeling witnessed is as important for providers as it is for patients.

Grief Theories and the Thinking Behind Them

Candi K. Cann, Ph.D.

Grief theory is largely the product of the Protestant (and white¹) experience, and often emphasizes the Remembering of the Dead, rather than the Care of the dead, stressing the importance of grief “work” and grief “tasks” while working to a goal of reintegration without the deceased. Coenen’s excerpt (in the addendum) reveals the lingering problems of some grief theory, such as Elisabeth Kübler-Ross’s² stages of grief³ still remaining heavily visible in the public realm. Influenced by Kübler-Ross, but somewhat more commonly accepted and utilized, Lindemann’s⁴ model of grief work or Worden’s tasks of mourning⁵ also capitalize on the protestant emphasis of Calvinist work ethics. Erich Lindemann argued that there were three primary tasks of grief: 1) the emancipation of bondage from the deceased, 2) the readjustment to a new environment without the deceased, and 3) the formation of new relationships. While Lindemann’s model is more helpful than a stage-based model, it still takes its cues from the Protestant notion that the dead no longer occupy space in the living world, in contrast to many other religious worldviews that view the dead as occupying the world of the living in an altered state, or occasionally interacting with the living on specific religious holidays.

William Worden’s tasks of mourning are 1) to accept the reality of the loss, 2) to work through the pain of grief, 3) to adjust to an environment in which the deceased is missing, and 4) to find an enduring connection with the deceased while embarking on a new life.”⁶ In this sense, Worden’s theory of grief allows for an “enduring connection with the deceased,” but he still discusses mourning as though it should be something one “gets through,” or “completes,” rather than grief that one learns to live with. Similar to Worden, clinical psychologist Therese Rando’s tasks of mourning view grief as a shift from loss recognition to a readjustment to a new world without the deceased.⁷ The key similarity of all of these grief theories is that they assume a linear and progressive timeline for grief, which views grief as work or tasks to be undertaken by the bereaved. **Members of our collective have found that any discussion of grief through a stage-based lens, or work is not helpful, and in fact, may impede the grieving process.**

¹ It is imperative to note that all of these psychologists and theorists were white, and live(d) in the United States, the United Kingdom, and/ or Europe. As a result, much of grief theory has been written as though it is universal, when in actuality it reflects the white experience. This gap in the literature has recently received some attention, but grief theory has far to go in order to reflect a diversity of experience.

² Elisabeth Kübler-Ross. *Living with Death and Dying* New York: Macmillan, 1981.

³ Kübler-Ross’ stages—initially formulated as stages of the dying process—include the five stages of denial, anger, bargaining, depression and acceptance are supposed stages one passes through in grief. The problem here is that not only have these stages been mis-applied from dying to grief, but they are often interpreted as five steps that one must undertake to be considered a successful griever.

⁴ See Erich Lindemann’s *Beyond Grief: Studies in Crisis Intervention* New York: Aronson, 1979.

⁵ Worden, J. William. "Tasks and mediators of mourning: A guideline for the mental health practitioner." *In Session: Psychotherapy in Practice: Psychotherapy in Practice 2*, no. 4 (1996): 73-80.

⁶ J. William (James William) Worden. *Grief Counseling and Grief Therapy: a Handbook for the Mental Health Practitioner* 4th ed. New York, NY: Springer Pub. Co., 2009.

⁷ Therese Rando describes what she calls the 6 R’s of healthy grief: Recognize the loss, React to the loss, Recollect and Re-Experience the lost relationship, Relinquish, and put the loss behind you, Readjust, and Reinvest. Rando, Therese A. *Grief, dying, and death: Clinical interventions for caregivers*. Champaign, IL: Research Press Company, 1984.

So, what does healthy grief look like, then? Grief impacts people psychologically/emotionally, behaviorally, cognitively, physically, and socially, impacting individuals, families, and society. Members of our collective utilize a variety of methods and approaches, from the Dual Process Model to Continuing Bonds Theory to Narrative Grief Therapy, but all these grief therapies encourage someone to learn how to live with the grief, to incorporate the grief into their daily life, and share that grief with others, knowing that the way this grief feels and looks will shift on a regular basis.

Stroebe and Schut's dual-process model of grief suggests that the bereaved person oscillates between a loss orientation and a restoration oriented model of coping,⁸ in which a person may feel the loss of their loved one keenly, followed by periods in which they feel okay again, but the process continually shifts, and sometimes one feels both ways at once. The dual process model recognizes the ongoing unpredictability of grief and acknowledges that the living may continue to have a relationship with the deceased.

Expanding on this idea, Klass, Silverman, and Nickman's⁹ theory of "continuing bonds" describes what many around the world consider to be caring for the dead,¹⁰ and is a dominant grief paradigm in the non-western world. No longer viewed as part of a maladaptive grieving process, and re-evaluating the process of mourning in light of John Bowlby's Attachment Theory,¹¹ Klass, Nickman, and Silverman view the ongoing attachment to the deceased as healthy and even expected. Continuing Bonds Theory argues that grief may in fact be a life-long process—one that may not ever be completed, or finished—and validates continuing a new version of the relationship with the deceased. Relationships with the dead are not static ones, but changing and valuable ones that will continue to develop as we move through life. In short, this "model of grieving ...focuses on the complexity of human relationships and the ways in which people remain connected to each other in life and in death."¹² While Continuing Bonds Theory has seen wide acceptance in the United Kingdom and in Europe, it has not yet been broadly promoted in the United States, even though in some ways, it is one of the more pluralistic and ecumenical grief theories in the toolbox.

Finally, Robert Neimeyer's Narrative Grief Therapy¹³ utilizes a variety of narrative and artistic tools to encourage grievers to reconstruct meaning in a world without their loved ones. Being able to name one's feelings, find words to express our loss, and engage in artistic expression to convey our emptiness is no small thing in a world that has suddenly shifted, and in which the absence of another is a huge vacuum that others may not necessarily share. For Neimeyer, grieving "requires us to reconstruct a world that again 'makes sense,' that restores a semblance of meaning, direction, and interpretability to

⁸ See Margaret Schut and Henk Stroebe's original article. "The dual process model of coping with bereavement: Rationale and description." *Death studies* 23, no. 3 (1999): 197-224, and a ten year review was published in 2010 and is here: Stroebe, Margaret, and Henk Schut. "The dual process model of coping with bereavement: A decade on." *OMEGA-Journal of Death and Dying* 61, no. 4 (2010): 273-289.

⁹ Dennis Klass, Phyllis R., Silverman, and Steven L. Nickman, *Continuing Bonds : New Understandings of Grief*. New York: Routledge, Taylor & Francis Group, 1996.

¹⁰ I am indebted to Tony Walter for this distinction between Remembering and Caring for the dead.

¹¹ Bowlby, John. *Attachment and loss: Vol. 3: Loss*. Hogarth Press and the Institute of Psycho-Analysis, 1980.

¹² *ibid.* p. 22.

¹³ Neimeyer, Robert A. "Narrative strategies in grief therapy." *Journal of Constructivist Psychology* 12, no. 1 (1999): 65-85, and Neimeyer, Robert A. "Reauthoring life narratives: Grief therapy as meaning reconstruction." *The Israel journal of psychiatry and related sciences* 38, no. 3/4 (2001): 171

a life that is forever transformed.”¹⁴ Neimeyer’s meaning-making can take many forms in grief—whether ritual, narrative, art or community. The important part is that the world is built anew—with a recognition of loss and all the space that loss gives to create.

These grieving theories all share the same characteristics: they encourage us to grieve, to express ourselves, whether through words, art or music, and they validate the constant shifting we may feel as mourners. And they recognize that to live is to die, and to love is to grieve when that love is lost. While our collective consists of a variety of grief theory perspectives, we want you to know that grief is normal, and in fact, it is healthy, even if it is painful or seems unbearable. Finally, grief is a lifelong process that one learns to incorporate into one’s life. We hope you will find these many tools and resources valuable.

¹⁴ Neimeyer, Robert A. (2006). *Lessons of loss: A guide to coping*. Memphis, TN: Center for the Study of Loss and Transition, p. 92.

Helpful Resources

End of Life Resources: Dying, Hospice, and Funeral Planning

A Sacred Passing – www.asacredpassing.org

A Sacred Passing offers death and dying education to individuals, community associations, and medical organizations, offering supportive educational companions to guide and assist people towards a more conscious dying experience, while honoring individual autonomy.

Creative Rituals for Death in the Times of COVID-19 - www.youtube.com/watch?v=yHET_Q5fok4

A video from Australian designer Pia Interlandi

Dancing with the Bones: Distanced Grieving - <https://bit.ly/2WpOUYr>

Tools for showing up grounded and calm from Dina Stander

DoulaGivers International – www.doulagivers.com

Online and Live End-of-Life Doula Training. 24/7 Access to Doulagivers Invaluable End-of-Life Doula Trainings Programs for Both Professionals and Family Caregivers

Distance Funerals, Complicated Grief - <https://bit.ly/2VZjQ2M>

A webinar hosted by the *Chaplaincy Innovation Lab*

End of Life Collective - www.collective.round.glass/End-of-Life

The End of Life Collective is a free platform with content, tools, service providers, end of life leaders and a vast array of communities to facilitate conversations and planning for end of life care.

End Well - www.endwellproject.org

End Well is a platform that brings together thought leaders in design, technology, health, policy, media, education, the arts and patient advocacy to change the way we think about the end of life experience – so that we don't see it as a medical issue that needs to be solved, but as an essential part of the human experience that deserves our attention and care. Check out our video content [here](#).

Engage with Grace - www.engagewithgrace.org

Engage with Grace is a movement with one goal: to get people thinking and speaking intentionally to their loved ones about what they want their end of life experience to be. With one slide of five questions designed to facilitate the conversation, family members can empower one another with the knowledge of what to do in the event of death or critical illness. The one slide can be downloaded at engagewithgrace.org.

Going with Grace - www.goingwithgrace.com

To relieve the burden created without proper end of life documentation, Going with Grace exists to support people as they answer the question "what must I do to be at peace with myself so that I may die gracefully?" and to support family members in completing the affairs of their loved one's life after a death. We create comprehensive end of life plans that are suited to an individual's unique humanhood—a true expression of their life and the experiences they cherish. We also create peace of mind while supporting families as they complete the administrative affairs of recently departed loved one.

Keeper – www.mykeeper.com

Free online memorials and tributes.

Lantern - <http://www.lantern.co/>

Lantern provides free, step by step guidance for end of life planning, funeral planning and the logistics following a funeral. Only one resource needed to navigate the entire process. Lantern's COVID hub has specific articles and resources: <https://www.lantern.co/covid>

Loving, Living & Dying During COVID-1 - <https://bit.ly/3aZWqOI>

A 1-page guide from Minnesota Death Collaborative & others

Memoriam Services - <https://memoriam.services>

Short, focused rituals designed for small groups.

National Funeral Directors Association COVID guide - <https://nfda.org/covid-19>

National Hospice and Palliative Care Organization, Advance Directives – <https://bit.ly/2WqDBiv>

A free resource to download the advance care directive forms by state.

Nurture - www.nurture.co

Nurture is a site created by Sierra Campbell, a death doula for more than twenty years. The site offers free resources in advanced care planning, writing a legacy letter, and facilitating virtual funerals. The most utilized resource on the site is Five Critical Conversations. This free planning course covers Advanced Care Directives, how-to guides for conversations, and much more for those wishing to plan for care at the end. Understanding what to say and NOT to say in the conversation.

Pandemic Resources for Families Facing End of Life - <https://bit.ly/3dhL9v3>

A compilation from the National Home Funeral Alliance

People's Memorial Association - www.peoplesmemorial.org

While this is a Washington State nonprofit focused on funeral education and advocacy, the website has many resources including funeral and disposition authorization legal forms, information about alternative options, and resources to enable folks to have the conversation with their family and loved ones about their preferences and values at end of life.

Postponed Funerals - <https://bit.ly/2xtVe8K>

Video guidance from Josh Slocum, Funeral Consumers Alliance.

Quality of Life Care - www.qualityoflifecare.com/resources

Quality of Life Care empowers and supports the people who tend to our dying loved ones, from families to healthcare professionals. Free resources to accompany through covid-19

The Celebrant Foundation & Institute - www.celebrantinstitute.org

The Celebrant Foundation and Institute (CF&I) is a global online institute that has trained and certified nearly 1,500 Life-Cycle Celebrants® worldwide in the art of personalized ritual and ceremony that reflects the needs, beliefs, and values of the people they are honoring. The funeral celebrants within this network are skilled grief and memorial specialists who are here to assist their cohort in the deathcare collective during the pandemic and afterwards, whether that's preparing and presiding over graveside

services, designing and leading streamed services online, or custom-crafting ceremonies postponed to a later date when loved ones can safely gather and embrace. Visit the CF&I website to find a funeral celebrant in your area.

The Center for Living and Dying – www.thecenterfordyingandliving.org

BJ Miller’s organization, the mission is to reclaim illness, disability, and death as natural parts of the human experience. It is a great resource to read and post patient experiences.

The Conversation Project - www.theconversationproject.org

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. The goal: to make it easier to initiate conversations about how you want to live through the end of life and to encourage people to talk now, and as often as necessary, so that their wishes are known when the time comes. Too many of our loved ones are left feeling bereaved, guilty, and uncertain when these conversations don’t happen early. We believe that the place for this to begin is at the kitchen table—not in the intensive care unit—with the people we care about, before it’s too late. The Conversation Project offers tools, guidance, and resources to begin talking with loved ones about your and their wishes. Special guidance and support during the time of COVID-19 can be found [here](#).

Social Embers Digital Legacy Consultancy - <http://www.socialembers.com/>

A personal bereavement during 2012 led to the foundation of Social Embers in 2014. Sandy Weatherburn, our founder, became interested in the digital aspects of bereavement. We have evolved over the years and now Social Embers Digital Legacy Consultants offer a comprehensive range of end of life related services for individuals, small businesses, solicitors and hospices.

Zen Caregiving – www.zencaregiving.org

We train family, professional, and clinical caregivers to develop and apply mindfulness for engaged care.

Memorializing a Loved One & Celebrations of Life

GatheringUs - <http://www.gatheringus.com/>

Gathering Us brings communities together after the death of a loved one to support each other and celebrate their life. We enable family and friends to gather virtually, share stories and photos, fundraise to help the family with expenses, and donate to a nonprofit charity. GatheringUs [Virtual Events](#) create the feel of an in-person event with real-time interaction for all attendees, so that mourners can receive comfort from their community. Guests attend the event on their phone, tablet, or computer to see and hear the ceremony, participate in a story sharing, and pay their respects to the family. In addition to memorial ceremonies, we facilitate virtual "receptions" for more intimate conversations. In these gatherings, participants meet in smaller groups, similar to reception tables in real life — one for high school friends, another for co-workers, or various family branches. The bereaved visits with family and friends to receive comfort and support. Our team functions as the "go-to person" for the family, creating custom ceremonies and gatherings with a seamless tech experience. We coordinate event planning, logistics, program design, initiate the speakers and/or performers during the event, and provide tech support for all attendees.

LifeWeb 360 - www.lifeweb360.com

Memorial scrapbooks built by your friends and family. Memories shared are organized into a multimedia scrapbook which can be transformed into a physical book. Friends & family get reminders on key dates to check in with the family and support tools to organize tributes.

LifeWeb 360 and New Narrative Memorials have published two valuable free resources for planning funerals—one for families, and another for funeral directors. The one for families has all sorts of ideas for families wanting to be involved in planning the service for their loved ones, and can be found here: [Planning A Virtual Memorial Event A Free Step-by-Step Guide For Families To Create an Online Ceremony](#)

The one for Funeral Directors helps them develop and facilitate a robust Virtual Funeral service. It can be found here: [Creating and Facilitating Virtual End of Life Events: A Step-by-Step Guide To Support Funeral Directors Working With Families During Social Distancing](#)

New Narrative Memorials - <http://www.newnarrative.ca/>

Event planning company helping families coordinate the many details involved in creating a personalized and meaningful Celebrations of Life event. We're not your Grandma's funeral (...unless it's your Grandma's funeral). New Narrative provides guidance and planning expertise to families who are faced with coordinating a Celebration of Life or Memorial event. Now turning to Virtual Events, we are here to take care of the details so you can take care of yourselves. New Narrative has just launched three packages specialized for families who need someone to help them bring these amazing suggestions to fruition: we can help with anything from a [Virtual Funeral facilitation](#) or a one-hour "[Ask Me Anything](#)" block where anyone can book an hour to ask us questions, suggestions, or help to bring any amazing suggestions to fruition. We have also co-authored two specialized and **free** e-books with [LifeWeb 360](#) for families and funeral directors alike as they navigate digital memorials in the age of COVID-19.

Family E-Book: [Resource Guide For Families - How to Create a Meaningful Virtual Memorials](#)
Funeral Directors' Guide: [Supporting Funeral Directors with Virtual Ceremony](#)

Seeking Ceremony www.seekingceremony.com

Seeking Ceremony is driven by a desire to make ceremony and ritual more accessible, especially around grief and death. They examine ceremony through a secular, nature-based lens and encourage people to find creative, personal ways to honor times of change and transition. They share ideas, resources, and

stories to help people to see the possibilities that ceremony can bring, both individually and as a community. They're launching a tech platform in June 2020 that will offer a create-your-own-ceremony experience, including tools, techniques, and templates to draw from, with a focus on end-of-life ceremonies and rituals.

The Inspired Funeral – <http://www.theinspiredfuneral.com/>

Started by a licensed funeral director, and a funeral celebrant from two coasts, The Inspired Funeral offers a variety of services and ideas for supporting end of life issues and remembering loved ones who have died. Amy Cunningham is a New York state licensed funeral director and the owner of Fitting Tribute Funeral Services in Brooklyn which specializes in green burials, home funerals, cremation services and memorial events of all sorts. Kateyanne Unullisi is a Seattle, Washington, funeral celebrant and home funeral guide. She collaborated with Amy on TheInspiredFuneral.com's ceremonies and readings.

Your End of Life Guide - <http://www.yourendoflifeguide.com/>

The former Secretary and Conference Coordinator for the *National Home Funeral Alliance (NHFA)*, and former Membership Coordinator for the Board of Directors, *National End-of-Life Doula Alliance (NEDA)*, Kim Adams is a sought after speaker and workshop facilitator who has started her own virtual funeral company to offer guided resources to help both families and funeral directors aiming to stream funeral services.

General Grief Resources

Alica Forneret - <http://www.alicaforneret.com/>

Alica Forneret is a writer and facilitator creating spaces for people to explore their grief. She is fiercely committed to making sure that we have more conversations about grief, death, and dying - whether that's at home, at work, or with strangers on the bus. Alica is a member of the BC Women's Health Foundation's Young Women's Council, an Associate board member of Our House Grief Center, and hosts Dead Moms Club events in Canada and the US. Alica's written work has been featured on the pages of popular magazines and books, including (but not limited to) *Modern Loss*, *Grief Dialogues*, *Vancouver Magazine*, *Loam*, and *Kinfolk*. And her story and voice have been featured on CTV News, *Grief Out Loud*, *InStyle*, and more. You can find her writing her newsletter *The Mourning Herald* from coffee shops in Vancouver, running workshops with *Reimagine* in NYC, and hosting *Death Over Dinner* events across the United States and Canada. Blog: www.alicaforneret.com/blog
Newsletter - *The Mourning Herald*: www.alicaforneret.com/newsletter

Allison Gilbert - <http://www.allisongilbert.com/>

Allison Gilbert is one of the most thought-provoking and influential writers on grief and resilience. The author of numerous books including, *Passed and Present: Keeping Memories of Loved Ones Alive*, she serves on the Board of Directors for the National Alliance for Grieving Children and the Advisory Board for Tragedy Assistance Program for Survivors, the preeminent national organization providing grief support to families of America's fallen heroes.

ARCHANGELS - www.archangels.me

ARCHANGELS is a platform recognizing and honoring caregivers for the critically important work they do caring for a family member or loved one. Because caregivers are often in "survival mode" and unaware of help that is available, ARCHANGELS provides a frequently updated list of state-by-state resources here: archangels.me/resources, as well as a "Library of Care" here: archangels.me/helpful-information which includes links to resources about managing stress and mental health when caring for someone who is very ill.

Claire Bidwell Smith - www.clairebidwellsmith.com

Claire is a therapist specializing in grief and the author of three books about grief and loss. Her most recent book is *Anxiety: The Missing Stage of grief*. Claire offers online grief support, courses, meditations and virtual discussions about grief.

Grief Coach – www.grief.coach

Our personalized text messages help you stay connected and supported, as you grieve. Even from a distance. We'll text you resources and tips, all year long, to help you feel less alone. If your friends want to help, but aren't sure how, we'll text them suggestions too.

Grief Dialogues - www.griefdialogues.com

Grief Dialogues erases the stigma surrounding dying, death, and grief. Using theatre, visual art, film, music, podcasts, poetry, and narrative, Grief Dialogues opens new conversations between grievers, those with terminal or chronic illness, and their health care providers. We believe out of art comes understanding, compassion, and empathy for all involved in grief.

Grief Dialogues created Grief Dialogues Health Care Education (GDHCE), established to create and deliver short plays, for health care providers, followed by a moderated discussion with this audience

usually includes CE. GDHCE uses theatre as the artistic expression most likely to reach an audience on a personal level. Theatre is the ultimate empathy generator allowing individuals and society to face the untold, unheard, and often misunderstood tales of life and death.

Good Grief - www.good-grief.org

Good Grief provides free support to children, teens, young adults, and families after the death of a mother, father, sister, or brother through peer support programs, education, and advocacy.

Heal Grief - <http://www.healgrief.org/>

HealGrief®, a social support network that is there when everyone else goes away, and the real grieving begins. Everything we do is inspired by our core belief that no one should ever grieve alone. HealGrief® provides the tools and resources to guide one's journey with grief into a healthy personal growth.

Hope Edelman - www.motherlessdaughters.com

Hope Edelman is the internationally bestselling author of *Motherless Daughters*, *Motherless Mothers*, and *The Aftergrief*. She is a world-renowned expert on early mother loss. Her books have been published in 15 countries and 12 languages and she is a sought-after speaker in the bereavement field. Through the Motherless Daughters brand she leads retreats, workshops, online courses, virtual support groups, and one-on-one coaching for women who have lost their mothers as well as for any adult bereaved as a child. In 2020 Hope received a Community Educator award from the Association of Death Education and Counseling (ADEC) for her 25+ years of work with motherless women.

Megan Carmichael - www.dailylifeanddeath.com

Megan Carmichael works with individuals and businesses to develop tools and share ideas that help people navigate the intersection of death & our daily lives. In addition to writing about the experiencing of parenting through grief & loss, speaking about economic trends within the US deathcare industry and working with various independent business owners operating in the end of life space, she offers advanced planning and at-need funeral arrangements for families along California's central coast. Megan and her husband own a private cremation garden in the Mojave desert through their company, California Scattering Services.

Megan Devine - www.refugeingrief.com

Psychotherapist Megan Devine believes that making the world a better place starts with acknowledging grief, rather than seeking to overcome it. She advocates for a revolution in how we discuss loss – personally, professionally, and as a wider community. She runs the Writing Your Grief online community, connecting grieving people all around the world, and provides training resources for professionals and organizations. Megan is the author of the best-selling book, It's OK that You're Not OK: Meeting Grief & Loss in a Culture that Doesn't Understand. Her best-known work, the animated "how to help a grieving friend" video, distills a complex issue into simple, actionable steps in just over seven (adorable) minutes. Gaining over 35 million views in its first few months, the animation is now used in training programs all around the world. Her latest collaborative project, Speaking Grief, is out in 2020 from PBS.

Modern Loss – www.modernloss.com

A website offering candid content, resources and community on loss and grief.

National Hospice and Palliative Care Organization - www.nhpco.org

Founded in 1978, the National Hospice and Palliative Care Organization is the nation's largest membership organization for providers and professionals who care for people affected by serious and life-limiting illness. Its broad community of members includes local hospice and palliative care providers, networks serving large regions of the United States, and individual professionals.

New York Zen Center for Contemplative Care - www.zen-care.org

The New York Zen Center is an educational non-profit organization dedicated to transforming the culture of care through contemplative practice, meeting aging, sickness and death with wisdom and compassion through education, care and Zen practice. The Zen Center's offerings are through our three pillars. **Care:** Grief and Bereavement support for individuals and groups, Clinician & Family Support Groups, Contemplative Based Resilience Training for Clinicians & Caregivers, and Community Groups for LGBTQIS, 12 Step meetings, Elder Support, and Community Rituals and Celebrations. **Education:** Medical Education, Foundations in Contemplative Care, Symposium on Palliative and End of Life Care, Certificate in Contemplative Care, ACPE Accredited Chaplaincy Training, and Master in Pastoral Care and Counseling. **Zen Practice:** Practice Periods, Daily Meditation Training, Retreats, and Formal Zen Study

Open to Hope – www.opentohope.com

Open to Hope's Mission is centered on helping people find hope after loss. OpentoHope's vision is to provide an online forum to support people who have experienced loss: to help them cope with their pain, heal their grief and invest in their future. OpentoHope.com is an online website where people can share inspirational stories of loss and love. We encourage our visitors to read, listen and share their stories of hope and compassion.

Option B – www.optionb.org

OptionB.Org is dedicated to helping you build resilience in the face of adversity—and giving you the tools to help your family, friends, and community build resilience too. They released a free excerpt from *Option B* with a new forward about resilience during a crisis - find it at <https://optionb.org/bookexcerpt>. On their social channels, they are sharing expert advice, including a series of Facebook Lives with thought leaders like Joe Primo (CEO of Good Grief), who discussed grieving and supporting others who are grieving during the pandemic. And their "Option B: Coping with grief" group on Facebook provides a place for you to connect with others who have lost loved ones.

SAMHSA's National Helpline - <http://www.samhsa.gov/find-help/national-helpline>

SAMHSA's National Helpline is a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders.

The Compassionate Friends: Supporting Family After a Child Dies - www.compassionatefriends.org

The mission of The Compassionate Friends: When a child dies, at any age, the family suffers intense pain and may feel hopeless and isolated. The Compassionate Friends provides highly personal comfort, hope, and support to every family experiencing the death of a son or a daughter, a brother or a sister, or a grandchild, and helps others better assist the grieving family.

The Dinner Party – www.thedinnerparty.org

The Dinner Party is a platform for grieving 20- and 30-somethings to find peer community and build lasting relationships. We screen, train and support a growing network of peer hosts, and connect them to 12-15 people nearby, who share a similar age and loss experience.

THE HUMAN JOURNEY® - www.The-Human-Journey.com

THE HUMAN JOURNEY® is a facilitated ritual that addresses anticipatory grief. The experience can be conducted either online or in person, and by either a professional or a volunteer with group facilitation skills. The purpose of The Human Journey®, which comes in the guise of a board game, is to help families in a way both playful and meaningful to cultivate belonging and to expand members' ability to make meaning in the face of loss. Family members also build skills in asking each other questions that matter and in listening well to the answers. In the course of the THJ® experience, participants gather what keeps them together as a family, surface and share in a safe way the spiritual resources they've each found helpful in adulthood, and collectively envision a shared future that carves out the ability to see beyond the death of their loved one—so that the death is not the “end of the story.” Practically, THJ® can be conducted in a single two-hour session or in four parts when participants may not have the concentration to do a lot at once; each of the four parts has a “payoff” so that, even if participants never pick up the next session, they have a positive experience. Conductors can be trained online in two two-hour live webinars. <https://www.the-human.journey.com> .

The Karuna Project - www.thekarunaproject.com

Claudia Coenen is a thanatologist and certified grief counselor with experience in anticipatory grief, bereavement and vicarious trauma. She develops creative tools to use in grief processing including The Karuna Cards and is the author of *Shattered by Grief: Picking up the pieces to become WHOLE again* and *The Creative Toolkit for Working with Grief and Bereavement: A Practitioner's Guide with 30 activity sheets* (release date July 23, 2020). Claudia is in private practice in Hudson, NY and is seeing clients via video from the corner of her sitting room.

The Order of the Good Death - www.orderofthegooddeath.com

The Order was founded in 2011 by mortician and best-selling author, Caitlin Doughty. This nonprofit organization provides resources, support and information about death and dying through their website, YouTube Series, a podcast, articles and events. The Order works to protect and inform the public about their rights and choices surrounding death and the law, and seeks to address and support other nonprofits that work to counter the disparities in deaths experienced within marginalized communities. Order director, Sarah Chavez created this Covid-19 Toolkit, which is continuously updated with facts, resources, and support surrounding dying, death, funerals, and grief under Covid-19.

Too Damn Young – www.toodamnyoung.com

A community + resource for teens and young adults who are navigating grief.

What's Your Grief - <http://www.whatsyourgrief.com/>

To put it simply, this website is about grief. That probably sounds *oversimplified*, but grief is a complex, heavy, frustrating, scary, enormous...ahem, big topic. It starts with a death and envelopes everyone from family to friends, to friends of family and friends. Not only is grief an emotional, logistical, and existential nightmare, but it is taxing. It requires us to navigate the world without someone important, deal with complex feelings and emotions, and figure out ways to move forward when everything seems kind of bleak.

We are Baltimore-based mental health professionals with 20+ years of experience in grief and bereavement. More importantly, though, we have both experienced the death of a parent and have dealt with life after that loss. Neither of us knew what resources were available to us at the time, and we fumbled through the darkness alone. Later we wondered why should anyone have to feel alone

when so many of us have been through grief ourselves? For this reason, we are committed to delve into anything and everything grief-related and to provide a place where people can come to support and be supported.

Grief Resources for Children, Caregivers & Communities

Apart of Me – <http://www.apartofme.app/>

A game app available on the app store or google play called *Apart of Me* is a quest into grief and loss, and is designed for children and young adults set on a magical island, providing a safe space online to explore feelings and learn effective coping strategies. *Apart of Me* provides young people with a safe space to grieve, where they can hear from others who know how it feels and find strength and wisdom. A unique experience that talks their language, whenever they need, in a format they understand, designed specifically for them.

Children's Grief - www.childrensgrief.net/books

Linda Goldman, an expert on children's grief and has written many books and articles. She has made some of these resources available for free download on her website, Children's Grief. Linda has worked as a consultant for the National Head Start Program, National Geographic, and was a panelist in the National Teleconference: *When A Parent Dies: How to Help The Child*.

Compassion Books – www.compassionbooks.com

We offer exceptional materials to people of all ages to help them grow through the losses they experience in life. We honor people of various beliefs and strive to be sensitive to the differences and similarities in their meaning-making process. Our mailorder collection offers hope but it will never deny that the journey through grief may be painful and hard to bear. We offer information on our materials to all that ask. As a company and as individuals we strive to practice kindness, compassion and peaceful action.

Dougy Center - www.dougy.org

The mission of The Dougy Center is to provide support in a safe place where children, teens, young adults and their families grieving a death can share their experiences. Through our *Pathways* Program we provide a safe place for families facing an advanced serious illness.

Funerals Service Foundation – <https://bit.ly/3c12tnA>

Understanding the important role funerals and memorialization play in the lives of youth

K-12 Death and Dying Curriculum - <https://bit.ly/2YvGAsz>

A rich 15 page resource document with helpful resources, books, projects, and ideas to talk about death and dying with children from age five to eighteen.

National Alliance for Grieving Children's "Responding to Loss & Change" Toolkit -

<https://adobe.ly/2SwSr5V>

A wonderful inter-active grief toolkit, this 14 page document provides support for both grieving children and their caregivers with practical action-oriented ideas and tools.

Alternate & Creative Disposal Options

Artful Ashes – www.artfulashes.com

Handmade glass art memorials

Better Place Forests - www.betterplaceforests.com

Your final resting place can be a private tree in a beautiful, protected memorial forest.

BiosUrns – www.urnabios.com

Bios Urn is a biodegradable urn designed to convert you into a tree after life.

Crazy Coffins - www.crazycoffins.co.uk

Crazy Coffins brings together a small team of joiners, designers and artists, who for twenty years have been hand-producing coffins which no-one else has been willing to make. The team has built coffins as boats, guitars, ballet shoes and even as pieces of luggage. Coffins to be buried, cremated or simply kept in the house. Each coffin is hand-built and bespoke. Each one has been individually commissioned and ordered; not one is supplied off the shelf.

Eternal Reefs – www.eternalreefs.com

An Eternal Reef combines a cremation urn, ash scattering, and burial at sea into one meaningful, permanent environmental tribute to life. An Eternal Reef is a designed reef made of environmentally-safe cast concrete.

Eterneva – <http://www.eterneva.com/>

Eterneva turns the cremains or hair of both humans and animals into beautiful lab-grown diamonds, in a color and size you select. In addition, they offer a memorialization wall, and virtually walk with families through their memorialization process as the lab creates a diamond over the eight-month process

Everence - www.everence.life

Everence makes custom jewelry and safe tattoo additives from cherished material (including DNA, hair, and ash) from loved ones. Everence works with scientists from Brown, Duke, and Cornell Universities to develop a process for micro-encapsulating material from loved one's DNA, hair, or ash. They can also use sand, soil, rock, grass, or flower (e.g., from a memorial site) for custom made jewelry or a tattoo additive (that mixes with congenital tattoo ink). For jewelry, they enclose your source into a durable aerospace resin which is then added, by hand, to your bracelet, necklace, ring, or charm. They are offering a 30% discount for those who have lost loved ones to COVID-19 with discount code: TOGETHER2020

Leaves With You – www.leaveswithyou.com

Leaves With You provides rituals to create healing and ceremony at one's end of life. Our main offering is a biodegradable coffin made using macramé, the ancient process of tying rope. Leaves With You invites family members and mourners to participate in and weave their thoughts and prayers into the coffin's creation. The act of weaving the coffin provides space for mourners to be present with their own grief and healing process. The deceased is then wrapped in an object of love that their family and friends created.

Parting Stone – <http://www.partingstone.com/>

Many people just see cremation as a convenient form of disposition. Parting Stone sees it as a platform for healing, growth, and engagement. We are witnessing the beginning of a death movement away from the limitations of traditional funeral solutions. Parting Stone is mobilizing in this unique moment to create a new foundation for an inspired future for death and dying. Parting Stone transforms ashes of both humans and animals into beautiful stones that can be treasured at home and remind you of your loved one.

Recompose – <http://www.recompose.life/>

Recompose offers an alternative choice to cremation and conventional burial methods. Our service gently converts human remains into soil, so that we can nourish new life after we die.

Spirit Pieces - www.spiritpieces.com

Spirit Pieces carries a wide selection of handmade cremation ash keepsakes online and we're thrilled to be working with dozens of talented artists to have this happen. If you would like to meet our artists (now 40+), [click this link](#).

Virtual Memorials & Art Exhibitions

Love After Death - www.loveafterdeath.co.uk

*(Documentation of Legacy Agreements can be found at www.digitaldeath.eu)

Love After Death (2016 - current) is a touring installation that questions how future technologies and aesthetics augment our relationship to end-of-life planning? It uses critical design to engage the public in a range of performances and pop-ups in festivals, libraries and hospices and in this way introduces people to planning end of life wishes using artistic research methods and playful prototypes. These prototypes have included Legacy Agreements* (for your dead body and creative bereavement) and Tickets for the Afterlife that aid in challenging top down approaches to legacy planning by positioning potential futures as options to be chosen.

Reimagine – www.letsreimagine.org

Reimagine is a nonprofit sparking grassroots experiences and festivals that transform our approach to life and death. Reimagine End of Life is a community-wide exploration of death and celebration of life through creativity and conversation. Drawing on the arts, spirituality, healthcare, and design, we spark experiences and festivals that break down taboos and bring diverse communities together in wonder, preparation, and remembrance. Reimagine envisions a world in which we are all able to reflect on why we're here, prepare for a time when we won't be, and live fully through the end. In facing death, we begin to live fully.

The Art of COVID – www.theartofcovid.org

The Art of COVID was inspired by the kindness and creativity that has led people to make masks for themselves, loves ones and strangers. The project centers on the symbolism of the mask as emblem of the COVID-19 pandemic, collecting images of masks and the stories of how they came to be. Follow them on Instagram (@theartofcovid) or on Facebook to upload your own masks and stories: <https://www.facebook.com/theartofcovid/>

Tribute – www.tribute.co

Tribute allows anyone to use their phone to video record message and upload the video to a "Tribute Wall". It's very simple, someone sets up the wall (as an example this was done for a friend's recent birthday, a link was shared out- each person recorded a video message, clicked the link and uploaded the video). This platform could be used to create a tribute wall to recall memories for departed loved ones to share with their families.

Unspoken Project: www.its-your-dash.com/index.php/unspoken-project

When someone we love dies there are often words that will remain forever unspoken. Sometimes those words are the most important ones that should have been said. We encourage you to write out those words here at this [Facebook site](#) and we will pin them for you anonymously to our wall. [Here](#) is the link to fill out your unspoken.

Continuing the Conversation on Death

Bevival – www.bevival.com

Is a death literacy media platform gently curating the cultural conversation around death and dying. Bevival advocates for preparing to prepare, *long before the end*. Founded by former creative director and producer, Caren Martineau, Bevival positions itself as a gateway, an entry point for talking about death, *differently*. The organization creates content, learning experiences, and produces edutainment events such as: *Dying 2 Know Day*, home of America's grassroots #dodeathdifferently movement; *Celebrating Aging in Film Series*; the *Long Before The End* podcast and local book group chapters; *EOL Navigators: The Beauty Within*, photographic exhibition.

Death Café – www.deathcafe.com

At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death. Our objective is 'to increase awareness of death with a view to helping people make the most of their (finite) lives'. A Death Cafe is a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session.

Our Death Cafes are always offered: On a not for profit basis, In an accessible, respectful and confidential space, With no intention of leading people to any conclusion, product or course of action, Alongside refreshing drinks and nourishing food – and cake!

If you're interested in holding a Death Cafe please see our how-to [guide](#).

Death Over Dinner – www.deathoverdinner.org

How we want to die – represents the most important and costly conversation America isn't having. We have gathered dozens of medical and wellness leaders to cast an unflinching eye at end of life, and we have created an uplifting interactive adventure that transforms this seemingly difficult conversation into one of deep engagement, insight and empowerment. We invite you to gather friends and family and fill a table. Click Get Started to plan a test dinner. We call it a test dinner because trying out this process in no way commits you to follow through with an actual dinner. [Learn More](#).

Elana Zaiman - www.elanazaiman.com

Chaplain, Rabbi, author, and speaker Elana Zaiman helps families facing end of life issues to achieve authentic closure and peace. In her book, *The Forever Letter*, Elana encourages readers of all ages to deepen, heal, and uplift their relationships with the people who matter most through a powerful letter writing experience. She's a chaplain at Seattle retirement community The Summit at First Hill, a certified Wise Aging instructor (IJS), an Adjunct Faculty at Seattle's Harborview Hospital CPE Program, and the Ethics and Spirituality columnist for *LivFun*, a publication for Leisure Care retirement facilities in 10 states.

End Well - www.endwellproject.org

End Well is a platform that brings together thought leaders in design, technology, health, policy, media, education, the arts and patient advocacy to change the way we think about the end of life experience – so that we don't see it as a medical issue that needs to be solved, but as an essential part of the human experience that deserves our attention and care. Check out our video content [here](#).

End of Life University Podcast - www.eoluniversity.com/podcast

Real talk about Life and Death hosted by Karen Wyatt, MD.

Journey with Deanna - www.qualityoflifecare.com/blog

Dissecting the issues of the day as we accompany our loved ones, friends and communities to die well in this modern age. Deanna has over 20 years of experience as a hospice RN, palliative educator and end-of-life doula mentor.

Phyllis Shacter - www.phyllisshacter.com

Author, speaker, and life coach Phyllis Shacter is committed to a 'good death!' Her website and her book, "*Choosing to Die*" about her husband's choice to voluntarily stop eating and drinking (VSED) after being diagnosed with early-mid onset Alzheimer's are the most complete collection of personal, medical, and legal information about VSED.

The Nurse with the Purple Hair - www.thenursewiththepurplehair.com

The Nurse with the Purple Hair is a warm and inspiring documentary about end-of-life care. The film features hospice nurse Michelle Lasota and is directed by filmmaker Sean Cunningham.

Candi K. Cann – www.candikann.com

Featured on C-SPAN's BOOK TV, NPR's *Science Friday*, BBC, *National Geographic* and countless others, Dr. Candi K. Cann received her Ph.D. and A.M. from Harvard University following an M.A. from the University of Hawaii. An Associate Professor, Faculty of Residence, and Baylor Fellow at Baylor University, her research focuses on death and dying, and the impact of remembering (and forgetting) in shaping how lives are recalled, remembered, and celebrated. She is the author of three books, *Virtual Afterlives* and *Dying to Eat* with the University Press of Kentucky, and *The Routledge Handbook of Death and Afterlife* with Routledge, as well as many articles, book chapters and textbooks. When she is not giving talks about death and grief, she focuses on living well, and is an avid reader, semi-foodie, and coffee drinker.

Resources for Medical Professionals

American Medical Association – <https://bit.ly/2SqGu1N>

Caring for our caregivers during COVID-19

Cleveland Clinic Patient Experience Courses - www.clevelandclinic.org

Build your knowledge and improve your skills with guidance from experts who have a passion for compassionate care giving. Cleveland Clinic Experience Partners offers a variety of learning opportunities that tackle some of the foremost topics related to patient experience. The courses are based on the R.E.D.E. to Communicate Model® of relationship-centered communication and how it applies to any clinical practice. This peer-led course is grounded in evidence-based practices, adult learning theory and experiential learning.

Death over Diner Healthcare Edition - <http://www.deathoverdinner.org/healthcare>

During the event, healthcare providers share their feelings about taking care of patients at the end of life reflecting on the meaning and natural aspects of death and dying. This experience provides an opportunity for teams of medical professionals, trainees and students to process grief and stress resulting from caring for patients at the end of life while honoring those who died by experiencing “The Pause”

End of life Book Clubs

Book clubs help caregivers support each other and stay resilient through the emotional ups and downs allowing caregivers to share own experiences in a safe, nonjudgmental environment. These interactions might help caregivers imagine ways to cope and incorporate lessons learned from the books into their work and life.

The Schwartz Center for Compassionate Healthcare – <http://www.theschwartzcenter.org/>

The Schwartz Center for Compassionate Healthcare is a national nonprofit dedicated to putting compassion at the heart of healthcare. Since 1995, the Schwartz Center has provided education, training and support to hundreds of thousands of healthcare professionals at organizations across the U.S. and in Canada, the U.K., Ireland, Australia and New Zealand. Healthcare organizations, leaders and frontline caregivers rely on the Schwartz Center’s programs, education and resources to support clinician well-being, enhance the quality of care, enable better outcomes, and create a more positive and rewarding experience for all members of the care team, patients and their families. The Schwartz Center is working to support caregivers, healthcare leaders and others to create a world where all who seek and provide healthcare experience compassion.

The Pause App – www.thepause.me

Amid the work of saving lives, teams of clinicians witness the end of life with heartbreaking regularity—and then move on to the next patient in need—without a pause. Having experienced this scenario countless times, Emergency Department nurse Jonathan Bartels chose to speak up about this tamping down of emotions and encourage his peers to stop for a moment; transforming this passage into a ritual of respect and renewal. “The Pause” is a 15- to 30-second period of silence at the time of a patient’s death shared by the team at the bedside to honor the human life and the efforts of the team. It is initiated by the physician, the nurse or any other team member and participation is voluntary. “The Pause” has since been embraced by teams and hospitals across the country, as well as codified and translated into more than six languages.

VitalTalk – www.vitaltalk.org

VitalTalk makes communication skills for serious illness learnable. Our evidence-based trainings empower clinicians and institutions.

Resources for Navigating Grief & Death with Mindfulness

Free

Insight Timer App (iOS & Android) – www.insighttimer.com

The largest free library of guided meditations on earth, including some dedicated to life during the pandemic. 2. 10 Self-Compassion Practices for COVID-19

Center for Mindful Self-Compassion <https://centerformsc.org/> Authored by By Chris Germer & Kristin Neff Co-Developers of the Mindful Self-Compassion Program

Self-Compassion in the Midst of a Pandemic (2-hour zoom workshop)- [VIDEO](#)

Recording of a live online session with Mindful Self-Compassion co-founders Kristin Neff, PhD and Chris Germer, PhD

Free During COVID-19 Era

Calm Together - <https://www.calm.com/blog/take-a-deep-breath>

Includes some of the Calm staff's handpicked favorite meditations, sleep stories, movement exercises, journals, and music. All of the resources on this page are free to use, and to share.

Coronavirus Sanity Guide - <https://www.tenpercent.com/coronavirussanityguide>

Teaching and practices from some of the most respected English-speaking teachers & includes daily live meditations at 3pm EST... posted for free in app later. Also, here's a cool [handwashing 20 second lovingkindness poster](#) they've created)

Headspace during COVID-19 - <https://www.headspace.com/covid-19>

Offering select meditations for free to the public during this time.

For Kids and their Caretakers

Mindful Games - <https://www.susankaisergreenland.com/mindfulness-for-kids>

Co-Founded by child mindfulness expert, [Susan Kaiser Greenland](#), Mindful Games are activity-based mindful games for the whole family. Guided mindfulness exercises and activities, meditation for children and parents, videos, podcasts, songs, and more.

Inner Kids Online Mindfulness Classes - <https://innerkids.org/>

In response to the worldwide outbreak of COVID-19, Inner Kids is offering mindfulness classes for children, teenagers, parents, caregivers, and educators to help everyone cope with new levels of stress. We are interested in who you are, why you're here, and what would best meet your needs during the pandemic.

Stop, Breathe & Think - <https://www.stopbreathethink.com/kids/>

A Kid's app for the web, iOS, Android, and Google Play, STB Kids offers emoticon-based emotional check-ins and tailored animated/gamified meditations for children. This app, designed by Jamie Price (Co-Founder of Stop, Breathe & Think) and Susan Kaiser Greenland (Inner Kids) helps kids check in with how

they are feeling and choose from a number of “missions” to help create their very own forcefield of calm. For children ages 5–10. Free lifetime subscription for educators.

Guided Meditation for Children - <https://annakaharris.com/mindfulness-for-children/>

A resource from [Annaka Harris](#), this resource contains an incredibly helpful and diverse set of guided meditations specifically designed for children to do with their caretakers.

Mindfulness Lessons for Children - <https://annakaharris.com/mindfulness-lessons/>

Includes illustrated spoken word videos that teach children fundamental aspects of mindfulness, such as “What is the present moment?” and “Why do we practice mindfulness?”

Being With What Is: A Short Talk & Guided Meditation - <https://annakaharris.com/being-with-what-is/>

Caretakers have their work cut out for them, especially during the age of COVID-19. This short talk and guided meditation addresses the needs specific to adults during this time.

Mindfulness for Children by the NY Times - <https://www.nytimes.com/guides/well/mindfulness-for-children>

Incredibly helpful guide for teaching mindfulness to kids, from infancy through teenage years.

For more Mindfulness tools, visit Michael R. Whinton’s continually updated list at the following link [**Resources for Navigating Grief & Death with Mindfulness During the COVID-19 Era**](#)

The Virtual Funeral Collective Members and White Paper Contributors

Consisting of a group of over seventy doctors, nurses, scholars, grief therapists, psychologists, funeral home directors, hospice workers, thanatologists, chaplains, hospital administrators and end-of life-practitioners from around the globe, the Virtual Funeral Collective is a group of specialists who work with dying, death, and grief on a daily basis, and are uniquely situated to offer solutions, resources, and training to those dealing with dying, death, and disposal issues from COVID-19. The views and opinions expressed in this white paper have been gathered collectively and do not necessarily reflect the official policy or position of any of the individual members or the agencies and organizations they represent. This document is a work in progress, please alert us to any errors or suggested improvements. In light of the immediacy of the need to distribute this document we have issued this version with full knowledge that it is a work in progress.

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Addendum A.

Excerpt from *The Creative Toolkit for Working with Grief and Bereavement: A Practitioner's Guide with Activities and Worksheets*

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Pages 34 - 39

KÜBLER-ROSS'S FIVE STAGES

Elisabeth Kübler-Ross was a Swiss medical student who emigrated to the USA where she continued to train to be a psychiatrist. During her residency, she worked with terminally ill patients and was shocked at their treatment by the medical profession. She wondered if these patients knew how ill they were, and was puzzled by the doctors who refused to address the facts about their condition with the patients and with their families.

It was common practice in the early 1960s for doctors and family members to withhold information about disease prognosis from patients. Kübler-Ross believed that this caused undue distress in these patients, especially when they were aware of their own deteriorating condition, and in most cases, could intuit that they were indeed dying. She felt that dying people deserved to have a voice, so she began speaking with them to find out how they felt and what they knew. She discovered that in many cases, they were grateful for the opportunity to speak about it and were grateful to finally have someone who was willing to listen to how they felt. She began using these conversations as a teaching tool in seminars for psychiatry and medical students.

Kübler-Ross observed some common themes in what these patients expressed. Her first book, *On Death and Dying*, was published in 1969 and identified five commonalities that terminally ill patients coped with, with their impending death. One important factor in her work is that she never expected these common themes, which she referred to as stages, to become a model for every person who is dying. Kübler-Ross did not identify these stages as a linear path that must be followed. She states clearly that some people only felt one of these stages, while some felt two or three. These stages were not meant to be in any particular order; rather, Kübler-Ross noted that the 200 or so patients she spoke with coped in some of these ways. She even has a disclaimer in this book, saying that these are not meant to be taken as a straight-line model.

Her subsequent book, *On Grief and Grieving*, was written with her associate David Kessler as Kübler-Ross herself was dying (see the Resources section at the end of the book). She did not live to see its completion. In this book, Kübler-Ross and Kessler applied these five "stages" to bereavement. They also referred to the stages as defense mechanisms. Again, they clearly state that it is not necessary to "complete" all five or even any of these stages, as they were never meant to be a definitive method for coping with grief.

The stages have evolved since their introduction, and have been very misunderstood over the past three decades. They were never meant to help such messy emotions into neat packages. They are responses

to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives. (Kübler-Ross and Kessler 2005, p.7)

While many people do experience variations of anger, denial, bargaining, depression, and acceptance, a grieving person might experience two or even more of these “stages” at once, or go back and forth between different them or even skip some of them. The thanatology community generally objects to the word “stages” because they seem too passive; they might be better understood as “states” rather than “stages.” In fact, Kessler now refers to them as “areas” of grief rather than stages.

In my opinion there are three problems with the five stages of grief:

- One, every grieving person is unique, and so the way they grieve will be subtly different from another person. When helping a grieving client, it is important to understand their family history, how they are used to expressing emotion, their culture, the type of relationship, as well as the type of event that caused them to grieve.
- Two, using this model as it has been popularly misunderstood leads to the concept that there is a right way to grieve, which means there must be a wrong way. Many doctors, nurses, and healthcare professionals as well as uninformed lay people have the erroneous idea that if the grieving person can move through five steps in a certain amount of time, their grief will be over and done with. This view then leads to judgment on the part of professionals that there is not only a right way to grieve but also a finite amount of time in which to conclude this grief. The idea that grief must be completed in stages and within a certain amount of time dismisses the internal experience of the bereaved person and can lead to incorrect labels of psychological disorders when, in fact, grief takes longer than most people can accept.
- Three, this model is 50 years old. There has been a large body of research done on bereavement and how we grieve since then, and many of these models are more flexible, more useful, and contain a more cogent view of grief in modern times.

While many people will experience one or more of these identified states, we don’t have to apply this model (or any one way of working through grief, for that matter) as if it is *the best and only way*. The question is, how will our clients cope with their reactions to any of these states if they do arise?

Denial Kübler-Ross identified denial as the first stage. In *On Death and Dying* (Kübler-Ross 1969, p.51) she calls this stage “Denial and Isolation,” and says that terminally ill patients have difficulty believing that the diagnosis is true. Patients, often wisely, seek second or third opinions or alternative treatments. This is similar to a condition of shock that often exists in early grief. A common refrain I hear from my bereaved clients in the first few months after a death is this: “I can’t believe she is gone.” While this sounds like denial, it is actually part of the long process of adjustment that leads to acceptance. Statements like these are not a denial of the event; rather, the person is expressing that at the moment, it is too much to bear or to integrate.

I am not particularly fond of the word “denial” because it seems dismissive. People on the outside have been heard to say, “He’s in denial,” which implies that the griever should just get a grip on reality. Instead, I witness again and again that to accept the radical change that death can create in a person’s life takes time. The shock and sorrow fluctuate with awareness of these changes. The back and forth between disbelief and figuring out how to cope with death continues for a quite a while, usually much longer than the griever is comfortable with. It certainly continues longer than corporations or some

medical professionals expect. In my opinion, we need to be very careful to recognize that each person's grief will take a unique amount of time and not hurry them with words suggesting that they are too slow to process their reactions to grief. There is enough pressure from the outside world with misguided suggestions to just buck up and get on with life. The grieving client does not need to encounter this from the person they have come to for help.

Questions such as "Are they really dead?" or "How did this happen?" or "Why me?" are common in early grief. These help the reality trickle in, which is a process that requires exploration. It is our job as practitioners to allow for this time, and to encourage our clients to take it.

It is important to allow our clients to feel and then explore their sense of shock and disbelief. It is important for them to be given time to learn how to live again. For some people this can take between six months and a year, but for most, the extreme fluctuations of grief can take one to three years before the person begins to feel regulated and comfortable in their new life.

Anger Many people feel angry when someone dies. This may be related to the circumstances of the death or to the age of the person. Anger may arise when the death is sudden or the changes in the bereaved person's life seem to be radical now that this person is gone. Some people feel angry at the doctors who diagnosed the disease—perhaps if they had "caught" the disease sooner the person would have been able to survive. I have witnessed this angry response even when a person was terminally ill for many years.

Anger is one of the strongest and often loudest emotions. In some people, it bursts out like a flame thrower, strafing everyone in its path. In others, it is a slow, simmering burn. If it is not released in some way, it can sear a person from the inside. Therefore, a good way to process anger is from the inside out.

Anger has a purpose. Allow your client to express their anger, explore it, and see what is behind it. Often, anger is a protective mechanism because the pain inside is too hard to hold:

If we ask people to move through their anger too fast, we only alienate them. Whenever we ask people to be different than they are, or to feel something different, we are not accepting them as they are and where they are. Nobody likes to be asked to change and not be accepted as they are. We like it even less in the midst of grief. (Kübler- Ross and Kessler 2005, p.14)

Bargaining This stage is definitely more prevalent in terminal illness and does not show up as much after the death. There is really nothing to bargain with once the person is gone, so I don't feel that bargaining is particularly present in bereavement.

There is, however, often a period in which the person questions whether there was anything that could have been done that would possibly have changed the outcome. Perhaps a third opinion would have offered a new treatment that would have cured the cancer? A grieving person might state, "If only I had convinced him not to drive in that thunderstorm," taking on the responsibility for an accident. Guilty

feelings and “If only...” questions do arise. Kessler and Kübler-Ross include these in their bereavement bargaining stage.

Depression The emotions of grief are hard to manage. If a widow or widower has been married a long time, learning to live without a partner they spent the majority of their lives with is very hard. When an adult loses a parent they considered a best friend, they have lost an ally, a regular conversation partner, and a supporter. And in the case of child loss, parents reel from the shock of such a terrible injustice for a long time. These situations are terribly dark and the bereaved person has trouble seeing any hope of a real life after this death.

This looks and feels like depression. Grievers have trouble getting out of bed or completing normal tasks. Concentration is affected by grief and some people feel as if they are floating slowly through the world or walking through mud. This also sounds like depression.

Grief leaves many people feeling empty and without a sense of purpose. They may have trouble imagining how they will live without this important person. Yet, this depressive reaction is generally different than classic clinical depression that often has no discernable causality. It is important to be aware of this when working with a grieving person, to validate their depressive feelings as normal as well as to be aware of any previous underlying depressive tendencies that may have existed before the death. Knowing the client’s psychological history will help you parse this out, and it is wise to periodically check in with the client to notice the difference. In cases where your client has had a history of clinical depression, be mindful that grief can stimulate this prior history.

Grief-related depression is not something to be fixed, but we can help our clients manage these feelings as well as encourage them to allow them to arise. Remember, life has changed radically for the client and they need to engage with all the emotions in order to move through them. Kübler-Ross suggests viewing depression as a slightly unwelcome guest:

Invite your depression to pull up a chair with you in front of the fire, and sit with it, without looking for a way to escape. Allow the sadness and emptiness to cleanse you and help you explore your loss in its entirety. When you allow yourself to experience depression, it will leave as soon as it has served its purpose in your loss. As you grow stronger, it may return from time to time, but that is how grief works. (Kübler-Ross and Kessler 2005, p.22)

Acceptance Accepting a death is a long and tricky process with many parts. One part is accepting that life has changed now that this person is no longer alive. The type of relationship, the type of death, and how a person’s life is therefore affected by this fact will influence how the griever comes to terms with the death and its impact. In spousal loss, there are so many issues surrounding the death of a partner. A widow now has to assume the daily tasks that her partner took care of. She might have suddenly become a single parent and has to juggle twice as much since she no longer has the partner’s help. Perhaps an elderly widower never had to cook for himself or write a check, and now he has to figure out where the bank is and how to feed himself healthy food.

Another problem for widowed people is the loss of physical closeness and intimacy. Some widowed people develop what is called “skin hunger,” a physical longing for touch. There is often a dilemma

about which side of the bed to sleep on, whether or not to change the decor in the bedroom or elsewhere in the home. Reminders are everywhere, and it is both hard to see them and difficult to remove them. How long should the clothes of the deceased remain in the closet? How does the griever feel about photographs, setting the table for one less person, or doing all the driving when the other partner was the one who usually drove?

As practitioners whose focus should be on allowing the bereaved person to figure out what is right for them, we should be very careful not to apply any particular timeline to any of these issues. There is a wide spectrum of time in which people feel able to deal with the belongings of their dead spouse. There are people who immediately divest of clothes and personal items, but most people wait. Some wait a year or more. Please be sensitive to what feels right for your client and recognize that it is different for each person. And sometimes a person may state that they are ready and then discover that they are actually not.

It is very likely that a parent will never accept the death of a child and a widowed person might always have some trouble fully integrating the changes in their life after a spouse dies. People who are widowed early feel cheated by not being able to grow old with their partner as they expected. People whose marriage lasted 30, 60, or 70 years have difficulty coping with being alone as they may not have lived alone, ever. Complete acceptance of an event implies that one's emotional reaction to it is over and done with. In many cases, a bereaved person is never finished with grief because it will rear up again, triggered by new events where that person is missing. New losses can also trigger grief reactions relating to prior ones. But if acceptance means learning to be comfortable in your own life after a significant person is no longer in it, then acceptance can be achieved.

I hope you have received the message that these five stages, while felt by many bereaved people, do not represent a simple, five-step method to "get over" grief. Grief is a lifelong process, and it takes time to integrate loss into your life and learn how to live with it.

Addendum B. Acceptance

Hope Edelman, the author of *Motherless Daughters: The Legacy of Loss*, explains Elisabeth Kübler-Ross' state of Acceptance in more detail:

Stage theories of grief invited mourners to perceive the experience as a sequential, time-limited event. What is often summarily referred to as “acceptance”, “resolution”, or “closure” is now believed to be a much more nuanced and multi-dimensional phase that may extend for the rest of one’s life. After the acute responses to a death start to subside, grief transforms into something else, something softer and quieter and persistent. It becomes what professionals refer to as long-term bereavement, and what mourners come to know simply as “loss”.

This ongoing phase is where stories of loss are revisited and often revised. We may see this happening quickly among mourners who’ve lost loved ones to COVID, especially as new information emerges and vaccines or cures are developed. The long arc of grief is also where perspective shifts and a strong sense of meaning can develop. We may hear the bereaved begin to speak about some of the less acknowledged outcomes of a loss, such as appreciation, gratitude, humility, or awe. Listening to and encouraging this process can be an important way to “companion” others in their long-term process and provide ongoing support.

Research in the field of post-traumatic growth reveals that within just a few years, a majority of trauma survivors can identify at least one positive outcome of their struggles. These include an increased sense of empathy; a deeper appreciation for life; a radical restructuring of priorities; and a feeling of inner fortitude. Mourners who are able to make meaning of their experiences also exhibit lower levels of complicated grief and better mental and physical health later on. In fact, meaning-making after trauma is the most powerful predictor of good long-term outcome among adults.