



What the Media Said about End-of-Life Care This Week January 11, 2021 A Service of Your State Association

HOME FUNERAL MOVEMENT BRINGING RESOURCES TO DEAL WITH DEATH IN FAMILY-CENTERED WAYS

An article in *New York Times* magazine explores “The Movement to Bring Death Closer.” The practice of home funerals allows families and loved ones to spend more time with the bodies of the deceased and share rituals that, for some, are empowering and meaningful.

The article takes an extensive look at our funeral rituals, the history of the funeral home industry in our country, and the emerging and re-emerging traditions and practices in dealing with bodies after death. The story also gives a step-by-step description of how Heidi Boucher works to help families prepare the body of a newly-deceased love one for burial. Boucher has “helped ‘more than 100 families take care of loved ones’ bodies in the hours and days after death.” Boucher describes herself as a “home death-care guide.” She also produced “In the parlor: The Final Goodbye,” a documentary of home funerals.

The family of Susan L’Heureux is one of a number of families that Boucher has made plans to help with bodies of loved ones after death. The article details the actions of Boucher and L’Heureux’s family in the time after Susan’s death. L’Heureux’s daughter, who was her primary caregiver, her brother, and her father all agreed to accept Boucher’s help. The article describes how they washed L’Heureux’s body, added a favorite scent, used dry ice to help slow decay of her body, chose clothing, and dressed her. For most families that Boucher works with, the patient then remains at home for up to three days.

In the US, says the article, death is an emergency. Calls are quickly placed to police, emergency workers, physicians and the funeral homes are all typical. Corpses are often hustled away. “There may be no other rite of passage around which we have become more passive,” asserts the article. Until the early 20th century, death was closer. Bodies were washed and dressed, friends and family visited, and we were more present with death. According to the article, this began to change during the time of the Civil War. With so many dying, and with bodies needing to be transported home, the emergence of embalming began and the funeral home industry was born. Then, in the 1930s, death occurred more often in hospitals and the funeral industry grew. By mid-century, a majority of bodies were embalmed. Now, however, about 50% of bodies are embalmed.

The funeral industry has a history worthy of examination. Lobbyist for the industry helped to create laws about who can embalm and bury bodies. And, in 1963, “The American Way of Death,” criticized embalming and decried funeral directors as “swindlers, peddling products and services that people didn’t mean and couldn’t afford.” A decade later, there was a public outcry about hidden pricing and other problems. In 1984, “over the objections of the funeral industry,” the FTC required funeral directors to provide pricing information and disclose if embalming is required by the state.

Tanya Marsh, a law professor at Wake Forest University School of Law, says “We were complicit in handing over control of this sphere of life to a profit-making industry. If we don’t like it, we can take it back.”

Some religions and cultures practice rituals that are similar to what Boucher does with families. In fact, a 2017 study of 57 cultures found that “most of them included death rituals in which people viewed corpses.” The article describes the power of being with a person as they die, and being with the body after death. Essayist and poet Thomas Lynch says, “Seeing a dead body ‘is the hardest and most helpful part’ of accepting that a death is real.”

The article quotes several funeral industry leaders who support more attentive, less rushed and family-centered funeral and cremation processes. Home-funeral guides, though still few in number, are growing, as are alternative funeral organizations and the article includes some information about these practices. Cremation has grown since 1980, when less than 10% chose cremation, until, by 2020, that number grew to 53%. And it is projected that by 2035 that number will grow to 80 percent.

Death rituals are further complicated by variances in state laws. In Nebraska and New York, a funeral staff member must be present at a burial. And if a body crosses state lines between Alabama to Mississippi, it must first be embalmed. More inconsistencies and confusing laws are examined as well.

Hospitals also “often have policies and practices that make it difficult for families to spend several hours or more with a dead body, or prohibit them from taking their dead loved one’s home.” The *National Home Funeral Alliance* is helping organizations push for new policies, and individuals learn how to be advocates for having more space and time to exercise the rituals that feel important to them.

The article tells some of the stories of the families, including her own, that Boucher has accompanied through these deaths. The article is online at the link below. An audio reading of the article is also online at this same link. The link to the audio reads “America’s home-funeral guides want us to be less afraid and more in touch with death.” (*New York Times*, 12/21) [Read more...](#)

HOSPICE NOTES

* *Palliative Medicine Reports* shares the findings of a survey designed to understand the “knowledge, attitudes, and beliefs” of hospice and palliative care healthcare professions related to COVID-19.” The survey found that nearly 40% of respondents identified themselves as high risk for infection of COVID-19. Nearly 75% felt neutral to uncomfortable dealing with infected patients. The findings are shared in an article available at the link below. The authors conclude that more staff knowledge and information “would enhance staff safety, improve patient care, and relieve anxiety.” (*Palliative Care Medicine* 12/23) [Read more...](#)

* “I’ve said goodbye — twice — to loved ones in hospice this year. Tips from experts, and from me” is written by Christina Schoellkopf, an assistant editor for the *Los Angeles Times*. When her grandfather died in April, his widow entered hospice. Due to COVID, grief has been difficult. Schoellkopf shares what hospice providers have taught her, and tells what she has learned herself, about “saying goodbye to a loved one while social distancing.” In addition to sharing ideas about how she supported her loved ones, she also shares ways that she empowered them to give to her. Before he died, she asked her grandfather to write her a note to read later. She also took his thumbprint and made a necklace of it. (*Los Angeles Times*, 12/20/20) [Read more...](#)

* Advanced Illness Partners (AIP) is a partnership “geared for participation in the direct contracting payment models from the Center for Medicare & Medicaid Innovation.” The partnership includes seven nonprofit organizations. The group says it is an innovative effort “to bring advanced illness care upstream and serve patients with complex, chronic disease in the home setting for the long-term.” An article about the work and ambitions of the group is detailed in an article cited below. AIP, notes the article, is one of 51 “direct contracting entities” that have been approved by CMMI.” (*Hospice News Network*, 1/6) [Read more...](#)

* “Healing with Harmony,” on *CBS This Morning*, features two nurses who use music and poetry to support frontline medical workers. Hospice nurse Erin Pomeranz, one of the two nurses profiled in the article, supports patients as they are dying. Pomeranz writes poetry and takes photographs, and shares both with families to ease all suffering. (*CBS*, 1/5) [Learn more...](#)

* Hospice of Santa Barbara is continuing its “Illuminate Spirit Series,” held virtually. On January 21, the featured speaker is Katy Butler, journalist and author of “The Art of Dying Well.” Butler will speak on “Ritual and Resilience: Building Meaning and Connection in a World Turned Upside Down.” (*Hospice of Santa Barbara*, 1/6) [Details and free registration available here.](#)

* *Grave to Great* is a podcast series hosted by Tracey Wood, President and CEO of Alleo Health System based in Chattanooga, TN. The weekly podcasts “tackle tough conversations around death and dying.” The latest installment features an interview with Dr. Martina Harris about her end-of-life curriculum development at Chattanooga State Technical Community College. The link to the press release is below. The second link is to the *Grave to Great* site. (*Grave to Great*, [Press release.](#); www.gravetogreat.com)

* According to a report by *Statista*, U.S. hospices had, by December 26, 2020, cared for 8,772 patients who died from COVID-19. At that time, 301,679 U.S. deaths were reported. (*Statista*, 1/4) [Learn more...](#)

PALLIATIVE CARE NOTES

* “Inspiring ‘Creativity’ in Palliative Care and End of Life” describes a pilot project at the Henry Mayo Newhall Hospital in Santa Clarita, California. The project is a partnership between the hospital, *CalArts*, and *Reimagine Well*. The project provides a “dynamic digital guide – offering patients and families ‘creating healing solutions that reduce anxiety, enable mindfulness experiences, create memories, and ease the fear of the unknown.’” Through the program, patients are given ideas about ways to provide legacy-type remembrances to their loved ones. The ideas include ideas as varied as leaving favorite recipes, to creating video and virtual events. One option, the “Life Quilt” provides an interactive pdf available within the article below. (*PR Newswire*, 12/1) [Read more...](#)

* “With COVID-19, It’s Time to Talk End-of-Life Care” appears in *U.S. News and World Report*. The commentary notes the importance of advance care planning, and encourages people to engage in the practice, especially in the time of COVID-19. A link to AARP’s site, that provides advance directive forms for each state is provided. (*U.S. News and World Report*, 1/5) [Read more...](#)

* “5 things to know about palliative medicine,” appears in North Carolina’s *StarNews*. Physician Kelly Erola, chief medical officer of Lower Cape Fear LifeCare, describes key understandings of palliative care. She shares that palliative care provides symptom relief, provides comprehensive care to patients, is independent of prognosis, is available for all ages and for any serious illness, and is available while receiving curative care. (*StarNews Online*, 1/5) [Read more...](#)

* Missouri has given *Proper Cannabis* the first state license to grow marijuana and manufacture medical marijuana. The company is setting up now into its facility and hopes to have products to Missouri dispensaries by April. According to the news story cited below, there are about 80,000 Missourians who have registered for medical marijuana. (*KMOV4*, 1/8) [Read more...](#)

END-OF-LIFE NOTES

* “What to Do When a Loved One Dies,” appears in *Consumer Reports*. The article addresses practical and needful actions that take place after a death. Very practical steps for immediate action, action within a few days, and additional actions needed are all noted. There are also notations about special considerations during the pandemic. CDC funeral guidance is also noted. (*Consumer Reports*, 1/5) [Learn more...](#)

* Hospice and palliative care physician and author BJ Miller writes a piece for *New York Times* titled “What Is Death?” As much as he has pondered this, says Miller, he still does not understand, and is unable to describe, what death is. The opinion piece explores how the pandemic is “changing our understanding of mortality.” (*New York Times*, 12/18) [Read more...](#)

* An article in *Source* is titled “Oregon Voters Said Yes To Using Psilocybin As A Mental Health Therapy. What’s Next?” The article examines the path toward implementation of Oregon’s vote to allow licensed centers to provide psilocybin for patients with mental health issues, PTSD, and “end-of-life psychological distress.” Governor Kate Brown has approved \$5.6 million for the 2021-2023 budget to implement the measure. An advisory board of 14 to 16 people will oversee the process. (*Source*, 1/5) [Read more...](#)

* Georgia’s *Rockdale Newton Citizen* shares a book review of “Dear Life” that says the book “explores the beauty of end-of-life experiences.” The book is authored by palliative care physician Rachel Clarke. Clarke helps her patients talk about impending death. Small acts of kindness are encouraged and encouraging. The article examines the care Clarke’s hospice offers. She offers stories, saying of her patients, “Their days prior to death are quiet and serene, with no fear, no pain, and minimum of loose ends left.” Hospice is a place people die, “but first, happiness sneaks in sometimes.” (*Rockdale Newton Citizen*, 1/2) [Read more...](#)

* A very ill Montana man was in the hospital for a cardioversion to relieve painful symptoms. He had completed a DNR and made it clear that if his heart failed he wanted to avoid intervention to be revived. In fact, when he was found slumping against a hospital bathroom wall, he was coded and given CPR. Angry, in pain, and frustrated, he hired a law firm to sue the hospital and a physician. An article in *Boston Globe* explores this case and the movement for more patients to claim “end-of-life liberty.” A year after his death, the hospital was found guilty and a payment was made to his widow. (*Boston Globe*, 12/26) [Read more...](#)

* New Mexico legislator, Rep. Debbie Armstrong, Democrat, is sponsoring HB 47 that “would let doctors prescribe life-ending drugs to terminally ill but mentally competent patients who want to end their suffering and take their own lives.” The measure has been before the states’ legislators twice before and, says Armstrong, “just a few votes shy to pass the bill. (*Santa Fe New Mexican*, 1/8) [Read more...](#)

* Florida’s *Bradenton Herald* explores the work of death doula. Specifically, an article in the newspaper examines the work of Anna Adams in San Antonio, Texas. In general, the article explores the basic work of death doula. Doula’s work involves three stages – end-of-life planning, vigil at the end of life, and addressing survivor guilt. The article also notes the relationship between the doula and local hospice providers. (*Bradenton Herald*, 1/10) [Read more...](#)

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