



## **What the Media Said about End-of-Life Care This Week**

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### **ABIDE BY END-OF-LIFE ORDERS OR FACE LAW SUITS**

Especially since the beginning of the pandemic, more Americans are taking seriously the need and desire to specify their end-of-life medical care wishes. But, an article in *New York Times* asks, “are medical providers listening?” The author is Paula Span, columnist for *New York Times*’ series, “The New Old Age.” Span threads the story of Gerald and Elaine Greenberg throughout the article. Both dentists, they were brought to face a difficult journey in 2010. With a diagnosis for Gerald Greenberg of early-onset Alzheimer’s disease, they knew what might be ahead and worked with an attorney to complete his advance directives. He was very clear. He wanted “No cardiac resuscitation or mechanical respiration. No tube feeding. No antibiotics.”

Gerald Greenberg became unresponsive, hospitalized, and very close to death in 2016. But his clear directives were not followed. And his wife’s instructions to a doctor were not followed. Gerald Greenberg received “antibiotics and other unwanted treatment and tests.” The interventions, according to the article, “made the end of his life horrible and painful and humiliating.” Courts are now calling such actions “a compensable injury.”

The completion of advance directives has increased during the pandemic. “The crisis has made such questions less abstract and the need to honor documents more urgent.” The article fairly notes that some of the issues encountered are due to advance directives that don’t get where they need to be in order to protect patient wishes. Sometimes they are not updated and the named decision-makers may not be available. Some are too vague, notes the article, and using language like “avoid heroic measures” are not useful.

In Greenberg’s case the attitude of the providers was, “Nobody was hurt.” But Gerald Grunsfeld, Dr. Greenberg’s attorney says, “But there was physical hurt, emotional hurt, a lot of hurt.” And in the past few years, courts are beginning to agree. The article gives examples of patients whose wishes were not followed, and settlements that were won by family members. A Georgia family received a \$1 million settlement. In Montana, in perhaps the first verdict in a “wrongful life case,” the court awarded the medical costs and \$200,000 for the suffering of the family. A Maryland court awarded a “satisfactory” sum to another family. The person in that case was resuscitated against her wishes that were in a MOLST form. The funds helped to pay for the round-the-clock care she received for the last seven years of her life.

A California story gives another chilling outcome. A facility was providing just palliative care to a patient and was reported to adult protective services. The county removed his wife as his proxy and the man received care he did not want. The man suffered longer, says the attorney who helped the family find the removal of care from his wife to have been fraudulent. In the end, she received reimbursement for attorney fees and \$1 million settlement from the county. Additionally, “Two lawyers representing the county now face disciplinary charges from the California state bar.”

Similar suits are pending in several states. And Dr. Greenberg’s attorney has filed suit against the medical facility where Dr. Greenberg’s wishes were not honored. It will take time, and perhaps a lot of time. His last month of survival, against his wishes, “He lay unconscious, diapered, in restraints and moaning in pain” his wife recalls. In defiance of choices he made, his wishes were not respected, she says. “I don’t want anyone else to go through what we went through.”

An article in *JDSUPRA* responds to Span’s article and says, “We have a lot of work to do, individually, collectively, and in ethical and legal terms, to improve the chances we see the compassionate medicine we want at life’s end — by engaging in tough thinking ourselves, talking deeply with loved ones, and consulting with our doctors and lawyers.

(*New York Times*, 1/22) [Read more...](#); (*JDSUPRA*, 2/1) [Read more...](#)

## HOSPICE NOTES

\* Florida hospice workers ready to receive the COVID-19 vaccination have not been deemed to be frontline workers, and have not been eligible to receive the vaccine. “Seasons Hospice and Palliative Care found a loophole by partnering with an assisted living facility to vaccinate their employees alongside the long-term care staff.” And they want the same opportunity for all hospice staff. The *Florida Hospice and Palliative Care Association* petitioned the state to include all hospice workers to be prioritized for the vaccine. Long-term care facilities are telling hospice that their staff need to be vaccinated, and some hospice patients and their families are fearful of staff who have not been vaccinated coming into their homes. (*WTFS Tampa Bay*, 1/22) [Read more...](#) (*Newsy*, 1/25) [Read more...](#)

\* “Medical students ranked 7 of the 11 care goals [of hospice patients] differently than hospice patients” did for themselves. Concerns such as not burdening families, having more time with those they love, dying at home, and others were included in a survey. The researchers conclude that, though the students are empathetic, they “were generally unsuccessful in perceiving end-of-life goals of hospice patients in the psychosocial and spiritual domains.” The disconnect might be “generationally based.” Researchers call for “increased age awareness” and recognition of “the greater dimensionality of the dying in order to provide the most complete patient-centered care.” (*American Journal of Hospice and Palliative Medicine*, February 2021) [Read more...](#)

\* *Vitas Healthcare* received \$100,000 of supplies like face coverings and hand sanitizer from *AT&T*. According to the press release. “*AT&T* is a healthcare technology collaborator with *VITAS*.” *AT&T’s FirstNet*, which *VITAS* was the first hospice to join, offers “priority communications” for the hospice. And *VITAS* uses the network to provide virtual reality experiences for their hospice patients. patients. (*PR Newswire*, 1/28)

[Read more...](#)

\* A study of family caregivers in Taiwan is published in *American Journal of Hospice and Palliative Care*. The study examined the caregivers’ experiences in the use of DNR’s while their love ones were served by hospice. From interviews, researchers identified four themes that they heard in the surveys. They wanted to respect the patients’ wishes but not feel like they were giving up. While not wanting to intensify the patients’ suffering, caregivers struggled to accept death. The worried about how other family members would do with accepting the DNR orders. And, they relied heavily on learning from and being guided by medical professionals. (*American Journal of Hospice and Palliative Medicine*, February 2020) [Read more...](#)

## END OF LIFE AND PALLIATIVE CARE NOTES

\* When palliative care is integrated with oncology care, patients with acute myeloid leukemia (AML) experience improved quality of life, better end-of-life care, and less psychological distress. *Cancer Network* reports on an article in *JAMA Oncology* The study also revealed that these patients who receive integrated “were more likely to report discussing end-of-life care preferences than patients who only receive usual care.” (*Cancer Network*, 1/25) [Read more...](#)

\* Kenneth Dickerman shares a photo review of real persons dealing with COVID-19. His article, “As covid patients are denied visits from their families, these hospital chaplains provide vital comfort,” appears in *Washington Post*. The photo journey is available line, along with more of Dickerman’s story. (*Washington Post*, 1/25) [Read more...](#)

\* “Too many Covid-19 patients face death alone. Vaccinated volunteers could change that” appears in *STAT*. Written by Ben Moor, an anesthesiologist, the article describes his own experiences of offering help and support to dying patients, and shares his anguish about the lives lost to the pandemic. After his long shifts, Moor, who has now had the vaccine, voluntarily visits dying patients and offers the support and care he can. He calls for “an army of vaccinated volunteers to support patients and be a conduit for their families, to help them through the worst days—and sometimes the last days—of their lives.” (*STAT*, 1/27) [Read more...](#)

\* In 2015, Matthew Teague wrote “The Friend” for *Esquire* magazine. The article shared the story of the two years he spent caring for “his wife, Nicole, who learned she had terminal cancer at age 34.” The story, which tells the brutal truth of Nicole’s “deterioration and death” won a National Magazine Award. And a floodgate of response from people who had their own stories of pain became an ongoing reality for him. There were opportunities to turn the essay into a movie. Now called “Our Friend” the movie is in theaters and on demand. Early reviews were tough for Teague, who says, “It’s not a gentle industry.” (*New York Times*, 1/20) [Learn more...](#)

\* “How to Hold a Virtual Memorial Service,” in *New York Times*, shares the author’s experiences and tells the positive aspects of a Zoom funeral. He encourages readers to hold funeral and memorial services, using Zoom, Google Meet, Skype, and GoTo Meeting, saying we don’t know how long it will be before the pandemic is over. Author Steven J. Birenbaum offers practical and technical tips to help in planning virtual funerals. (*New York Times*, 1/14) [Read more...](#)

\* Stanley Tucci and Colin Firth star in a new movie, “Supernova.” While the couple in the story “have been together for decades,” the movie focuses on the serious illness of one of the men, Tucker. They know their time together is limited, and that Sam will soon need to serve as a full-time caregiver, a role that frightens him, even though he is committed to filling the role. The writer of the review, on *New Country* 96.3, says, “the emotion of the situation comes through loud and clear.” (*New Country* 96.3) [Read more...](#)

\* New Mexico’s House Bill 37, which would allow “death with dignity,” passed the House Health and Human Services Committee on January 29. But, says an article in *Santa Fe New Mexican*, the bill “faces some fierce opposition as it makes it way through the Legislature. The bill now moves forward to the House Judiciary Committee. (*Santa Fe New Mexican*, 1/27) [Read more...](#)

## **ADVANCE CARE PLANNING AND GRIEF AND BEREAVEMENT NOTES**

\* Death of a parent is always difficult. “Beautiful Something Left Behind,” is a documentary of the powerful and profound loss that young children experience when a parent dies. The film explores the lives and experiences of these children during their time at a special facility made just for them. The facility, called *Good Grief*, is in New Jersey. In one scene, a child tries to color his feelings. Included in the film are group sessions, group sessions and raw exposure of the children’s feelings and thoughts. The talking in the movie is all done by the children themselves. *New York Times* features a review of the movie. (*New York Times*, 1/7) [Learn more...](#)

\* *New York Times* features a book review and a view into the life and writing of Emily Rapp Black. Black's latest book, "Sanctuary," says the reviewer, "is, over all, a brutal book to read." With more editing, she says, "this otherwise often beautiful jewel of a book would have gotten there." What Black focuses on the death of her young son, the breakup of her marriage, and her own suicidal thoughts. Her main question, is "how to live faithfully in the present without betraying the past?" And that past leads to her earlier experience, and her earlier writing, of "The Still Point of the Turning World." The earlier book was written as her toddler, Ronan, was dying with Tay-Sachs. (*New York Times*, 1/19) [Read more...](#)

\* *WebMD* features a video and transcript with Dr. John Whyte, from *WebMD*, Carole Fisher with the National Partnership for Health Care and Hospice Innovation, and Jennifer Baldwin with Capital Caring Health. The focus of the discussion is on bereavement care. (*WebMD*, 1/21) [Learn more...](#)

## OTHER NOTES

\* A research article in *American Journal of Hospice and Palliative Medicine* explores how caregiver and professional healthcare provider communications impact quality of care received and burden level of patients and caregivers. The study found that when caregivers engage with professional providers about their questions and seek information, caregiver stress decreases and caregivers report "a higher quality of life." The authors conclude that "hospice and palliative care providers should identify and provide support for caregiver communication difficulties in order to positively influence caregiver quality of life and anxiety. (*Journal of Hospice and Palliative Medicine*, February 2021) [Read more...](#)

\* A bill pending in NJ, A1058, would require "senior care providers that receive funding from the state to complete cultural competency training focused on sexual orientation." The bill would help to create more understanding of LGBTQ issues. Seasons Hospice and Palliative Care is noted as having received training from SAGE, a national organization that support and advises LGBTQ seniors. (*North Jersey*, 1/26) [Read more...](#)

\* An Arkansas bill proposes to assure that no child is ever denied DNR orders, life support, or organ donation without a parent's consent. A parent could make these decisions, if two witnesses are present. The bill is based on a similar bill in Missouri that was passed in May 2019 after a child was removed from life support without the parents' engagement in the decision. The Arkansas Hospital Association says they have no knowledge of such an event ever occurring, but they have no objection "to putting the mandate in the law." Their biggest question "is what to do if one parent gives consent and the other doesn't." Details of the story are included at the link below. (*Arkansas Democrat Gazette*, 1/30) [Read more...](#)

*Hospice Analytics is the national sponsor of Hospice News Network for 2021. Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of- life care. For additional information, please call Dr. Cordt Kassner, CEO, at 719-209-1237 or see [www.HospiceAnalytics.com](http://www.HospiceAnalytics.com).*

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