

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

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#### THE VALUE OF ADVANCE DIRECTIVES CONTINUES TO BE DELIBERATED BY EXPERTS

**A blog on *SevenPonds* explores the continuing conversation about the possibility that we are getting end-of-life planning wrong.** The blog, while not having new information, does a review of the various expert understandings about advance care planning. The blog notes, among others, a 2021 op-ed in *JAMA*, and Judith Graham's work in *Kaiser Health News*.

**A 2021 op-ed article in *JAMA*, by physician Sean Morrison turned our traditional thinking about advance care planning "on its head."** Decades of research, says Morrison, show that "advance directives almost universally fail to help patients have the kind of end of life [sic] experience they want." Physician Diane Meier, who co-authored the *JAMA* op-ed, says that after all the "time, effort, money, blood, sweat and tears" that have gone into promoting advance care planning, the evidence shows that "It doesn't achieve the results we hoped it would."

**One of the biggest problems is that it is "virtually impossible" for us to look forward to hypothetical healthcare decisions and predict the care we would want.** And many people expect their directives to protect them if they should become incapacitated, says James Tulsky of the Dana-Farber Cancer Institute in Boston. "They won't," says Tulsky.

**We change our goals as we experience changes in our health, says the blog.** And vague and inaccessible documents complicate decision-making. And some wishes, like wanting round-of-clock care in our own homes, may not be possible.

**Other leaders in palliative care do believe that our efforts at advance care planning have gone well says the blog.** Physician Rebecca Sudore founded PREPARE for your care, "an online tool that helps the public develop advance directives and discuss end-of-life goals." Sudore says that advance directives have moved away from imagining hypothetical situations and toward addressing our goals and values when we become seriously ill.

**Physician Randall Curtis, director of Cambia Palliative Care Center of Excellence, has ALS.** Curtis says discussion of possible future situations results in "immeasurable benefits" and helps him prepare for what's to come." Though he has not made "specific decisions" on care, the conversations bring him "comfort and prepare me for making decisions later."

**For too many, says Meier, completing advance directives is a "check-the-boxes" event rather than "a reflection of meaningful discussions about personally held values and beliefs."** Meier supports making "decisions in the moment." And a key one of these decisions is naming a power of attorney for healthcare. Sharing "values, preferences and beliefs as well as what you may want if a health crisis occurs," says Meier, is important. This surrogate should be someone in whom you have deep trust to face the difficult decisions when the time comes. She also encourages people to name a secondary surrogate in case the primary proxy cannot serve for any reason.

The first link below is to the blog of *SevenPonds*. The others links are to items reported on in earlier issues of *HNN* and cited by this blog. These include the earlier *JAMA* op-ed titled "What's Wrong with Advance Care Planning?", and the report by Judith Graham for *Kaiser Health Network* titled "A New Paradigm Is Needed: Top Experts Question the Value of Advance Care Planning." Included also is a link to PREPARE for your care, also cited in the blog. (*sevenponds*, 4/21, <https://blog.sevenponds.com/something-special/end-of-life-planning-are-we-getting-it-wrong#more-87277>; *JAMA*, 10/8/21, <https://jamanetwork.com/journals/jama/article-abstract/2785148>; *Kaiser Health Network*, 1/6/22, <https://khn.org/news/article/advance-care-planning-palliative-care-experts-paradigm-shift/>;

## CONSUMER FEEDBACK ON ADVANCE DIRECTIVES

**In addition to the experts' feedback, consumer feedback about advance directives and advance care planning reflect more light on the process.** Recent research sought to understand consumers' experiences. "How Traditional Advance Directives Undermine Advance Care Planning; If You Have It in Writing, You Do Not Have to Worry About It" appears in *JAMA Internal Medicine*. The article offers insights from research into consumer's feelings about the advance planning process.

**Researchers utilized "interviews with community-dwelling adults" after they came home from the hospital.** Participants were over age 65 and had chronic illnesses. Themes emerged from the interviews. People felt the advance directive (AD) forms were generic forms with few details. And they were often done with an attorney rather than with a clinician or family member. Participants did not remember the details of the ADs they completed. And, once completed, most did not revise it. Most people felt that once they completed the document, they did not have a conversation with healthcare providers or family that led to serious advance care planning. (ACP)

**The article, offered at the link below, offers a number of specific feedback examples from the participants.** Overall, the findings "suggest that AD completion should not be viewed as the equivalent to engaging in ACP." The documents do not usually reflect values and beliefs. Instead, completing the AD "often lessened the patient's willingness to engage in more nuanced conversations about their current clinical status." It became clear that there is a real distinction between AD completion and serious conversation for ACP.

The researchers conclude "that research sponsors and policy makers should continue to support efforts to improve the quality and frequency of goals-of-care conversations." And, **promoting and completing of ADs, without conversations and prioritizing of goals, should be stopped.** (*JAMA Internal Medicine*, online 4/25, doi:10.1001/jamainternmed.2022.1180)

## HOSPICE NOTES

**\* Maryland's Calvert Hospice has signed a letter of intent "to explore the acquisition of Calvert Hospice by Hospice of the Chesapeake."** There will be a discovery period of 45 to 60 days. The two "like minded not-for profit organizations" want to strengthen their ability to offer access to hospice care for the citizens of Calvert county. (*Southern Maryland Chronicle*, 4/27, <https://southernmarylandchronicle.com/2022/04/27/calvert-hospice-signs-letter-of-intent-to-join-hospice-of-chesapeake/>)

**\* Hospices, facing disruptions in care and pervasive consolidation and mergers, can plan strategically to "expand their geography, diversify the scope of their services to get further upstream, and otherwise be more attractive to payors, including managed care plans."** In a podcast titled "Strategic Restructuring for the future: Exploring Upstream Revenue Opportunities for Hospices," In this podcast, Husch Blackwell LLP attorneys address these issues. The podcast is online at the link below. (*JDSupra*, 4/28, <https://www.jdsupra.com/legalnews/strategic-restructuring-for-the-future-38669/>)

## PALLIATIVE CARE NOTE

**\* Summit Health Oregon and Partners in Care are partnering to better serve patients who need palliative care.** They hope to work together to reach more patients and offer palliative care "further upstream." (*The Nugget News*, 4/26, <https://nuggetnews.com/Content/Health/HEALTH/Article/Summit-Partners-in-Care-expand-partnership/117/221/32050>)

## END-OF-LIFE NOTES

\* **Arizona now has a law that requires that “spiritual care visitors” be able to visit residents in nursing homes and hospices.** The law, HB2449, passed with bipartisan support. Clergy will continue to be required to follow facility safety measures. The bill also protects facilities from liability for “civil damages resulting from death or injury from a communicable disease resulting from the visitation” as long as the facility abides by “health and safety precautions.” (*Arizona’s Center Square*, 4/26, [https://www.thecentersquare.com/arizona/arizona-ensures-in-person-clergy-visitation-to-long-term-care-facilities/article\\_f6ba9ffa-c59b-11ec-b9d3-eb442847cc68.html](https://www.thecentersquare.com/arizona/arizona-ensures-in-person-clergy-visitation-to-long-term-care-facilities/article_f6ba9ffa-c59b-11ec-b9d3-eb442847cc68.html))

\* **Death is made more difficult by “stress, disorientation, isolation, pain, and understanding one’s circumstances and other factors”** says Anne Neumann in her book **“The Good Death.”** *Policy Genius* ranked the states as best and worse places to die. They used seven factors for their ratings. These include costs of funeral services; green burial options; palliative care availability; ratio of Medicare providers to 100,000 residents over age 75; higher percentage of people who die at home; and easier estate settlement laws. Vermont, Utah, and Idaho top the list. The full results are online at the link below. (*Policy Genius*, 4,13, <https://www.policygenius.com/life-insurance/best-places-to-die/>)

\* **Medpage Today offers input from two physicians who feel differently about the outcome of the acquittal of William Husel, who was accused of murdering 14 patients by prescribing high doses of fentanyl.** Dr. Joel Zivot, who was the only defense witness, talks with physician Wes Ely, who was one of 53 witnesses called by the prosecution. One of the outcomes of the trial, says Ely, is that the Society of Critical Care Medicine will “review this for the upcoming guidelines of pain, anxiety, and delirium...” The challenge to physicians, both seem to agree, is to actively relieve suffering and pain without intentionally shortening human life. The transcript of their conversation is online at the link below. (*Medpage Today*, 4/27, <https://www.medpagetoday.com/special-reports/exclusives/98345>)

\* **Vermont first legalized assisted suicide in 2013. Now the state has enacted a law that allows a patient to receive help in dying by meeting with a physician via telemedicine.** Gov. Phil Scott signed S.74 on 4/27. A patient who has been diagnosed with a terminal illness and informed about hospice care as an option is eligible for this intervention. Ten states and D.C. have laws offering assistance in dying, and Vermont has been the only state to not allow the telemedicine option. The video meeting must be on “a platform that complies” with HIPPA. The earlier law called for multiple evaluations before physicians could prescribe life-ending medications. Critics have voiced concerns about this change in the law. (*HealthLeaders*, 4/28, <https://www.healthleadersmedia.com/telehealth/vermont-amends-assisted-suicide-law-include-telemedicine>)

\* **Geripal highlights the work of Nathan Gray, a palliative care physician and assistant professor of Medicine at Johns Hopkins.** Gray creates comics and artwork to “share his experiences in palliative care and educate others about topics like empathy and communication skills. Gray’s website, *Ink Vessel*, includes numerous examples of Gray’s works. The article includes samples of Gray’s work that convey how he uses his work to create better awareness of the need for real connection between practitioners and patients. A podcast with Nathan Gray, as well as the samples of his work, appear at the link below. (*Geripal*, 4/28, <https://geripal.org/comics-and-humor-in-palliative-care-a-podcast-with-nathan-gray/> NOTE: The note below is also about Gray and his work.)

## GRIEF AND ADVANCE CARE PLANNING NOTES

\* **The LA Times offers “Op-Comic: My patient wrestle with end-of-life care, even if there’s a living will.”** The comic, written by Nathan Gray, from John Hopkins University School of Medicine. Gray is an artist who draws comics about medical topics. Within his comics, he portrays feelings of people who are very ill; addresses issues with advance directives; offers reflections by physicians who deal with patients nearing life’s end; examines the development of advance directives and their original intent; and explores the choice of hospice. (*LA Times*, 4/25, <https://www.latimes.com/opinion/story/2022-04-25/living-will-end-of-life-care-die-hospital-home>)

\* **“Grief and Love: How to Cope When You Know a Loved One Is Going to Die” appears in the independent Epoch Times.** The article explores anticipatory grief. In her book “Loss, Grief, and Bereavement,” Barbara Rubel defines anticipatory grief as a reaction “related to impending loss; including mourning, coping, interaction, planning, and psychosocial reorganization before a death.” Author Penelope Burr recalls the experience of several people who are dealing with anticipatory grief. She particular notes the three challenges of anticipatory grief,

mourning, coping, and planning. Burr addresses each of these challenges. (*Epoch Times*, 4/26, [https://www.theepochtimes.com/grief-and-love-how-to-cope-when-you-know-a-loved-one-is-going-to-die\\_4423436.html?welcomeuser=1](https://www.theepochtimes.com/grief-and-love-how-to-cope-when-you-know-a-loved-one-is-going-to-die_4423436.html?welcomeuser=1))

## OTHER NOTES

\* **C-TAC has released its strategic plan for 2022-2025.** The first goal is to “fix” Medicare and Medicaid by having them offer support to patients and unpaid caregivers of the seriously ill. The second goal is to mobilize their own coalition to best “influence lawmakers to act on our policy agenda.” Goal 3 is to acquire funding “through a diverse group of funders and members.” (C-TAC, <https://www.thectac.org/strategic-plan-2022-2025/>)

\* **The Home Centered Care Institute offers a free on-demand .5 CME educational event titled “Diversity, Equity, and Inclusion for Home-Based Care.”** Details are online at the link below. (Home Centered Care Institute, <https://education.hccinstitute.org/Public/Catalog/Details.aspx?id=bE73ON8tCeY%2BOsbKDMzOww%3D%3D>)

\* **Yale research psychologist Becca Levy has completed research that “has demonstrated that age discrimination can take years off one’s life.”** She conducted a longevity study in 2002 that found elders with “the most positive beliefs about aging” live 7.5 years longer than the most negative elders. The article includes information that can be used to be more aware of language we use with elders and the power of the words we use. (*New York Times*, 4/23, <https://www.nytimes.com/2022/04/23/health/ageism-levy-elderly.html>)

\* **UCSF is offering a webinar on bringing family members into patient care conversations.** UCSF says they have done this successfully without creating extra stress for the care teams. In the webinar participants will hear about the systems UCSF is using, the improvements for families, and increased control for clinicians. There is no cost for the webinar but registration is required from the link below. The event is on 5/10 from noon to 1 CT and will be available on-demand several days later. (*Becker’s Hospital Review*, <https://go.beckershospitalreview.com/expand-your-reach-how-ucsf-health-is-bringing-families-into-care-conversations>)

Thanks to Don Pendley for contributions.

Correction: Please note the correction of a note in the 4/26 issue of HNN: **In 2020 ~~1920~~, NPR offered a “Life Kit” with tips and support in “starting an advance directive to prepare for a good death.”** The kit works to help people understand that they do not need a lawyer or special training to plan for end-of-life care. Even among the patients who are most ill, fewer than 50% have talked with someone about the care they prefer to receive. A recent encore NPR program talks about the Life Kit.

*Hospice Analytics is the national sponsor of Hospice News Network for 2022. 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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