



What the Media Said about End-of-Life Care This Week April 19, 2022 A Service of Your State Association

USA TODAY ARTICLE ASKS: ARE AMERICAN'S VIEW OF DYING FINALLY CHANGING?

USA Today published an article that explores if American's views of dying are changing. Though we have long been reticent to talk about death, says the article, there seems to be a change now in how we deal with death. The article explores why the shift in end-of-life discussion is changing.

The article mentions the company Empathy, "that helps families navigate the death of loved ones." Ignoring pain and loss, says Ron Gura, co-founder and CEO of Empathy, "serves to deepen the pain." Americans need to be more comfortable talking about death and dying. The shift in cultural attitudes is happening in a "historically deadly time" of the pandemic. Physician Dr. Shoshana Ungerleider, founder of EndWell, says that living in the time of an "infectious disease that's killing people of all ages" creates a changed approach and perspective of living and dying.

The use of technology is cited as one factor guiding the change. The article mentions a virtual reality game, "Before Your Eyes," which shows the perspective of a soul's journey on its way to the afterlife." Another game, "That Dragon, Cancer," has the players of the game be the parents of a child who died with cancer. Many of the players, says the article, report that the game helps them realize they are not alone.

Movies about death and dying are increasing, and the article mentions "Extremis" and "End Game." The entertainment community is more accurately exploring hospices and conversations with patients. Another visible change is the growth in death doulas. Additionally, end-of-life rituals are being noted as a change in facing death.

Talking about death is important, Ungerleider says, even when we are not always comfortable. Baylor death scholar, Dr. Candi Cann, says talking with others is important. "Mourning alone," says Cann, "can result in your sadness turning inward, leading to issues like depression or unresolved grief." Gura says, "We all lose by not talking about it." (*USA Today*, 4/11, <https://www.usatoday.com/story/life/health-wellness/2022/04/11/death-dying-becoming-less-scary-ash-diamonds-doulas/7229902001/>)

HOSPICE NOTES

*** New York's Hospice of Westchester is the subject of a recent article in *Westfair*.** The article explores the hospice's bereavement program. The hospice has two bereavement coordinators who offer "individual and group counseling with families," and also serve the community. The complementary care services offered by the hospice, that serves 82 patients, include "art therapy, massage, and reflexology." The article explores difficulties faced during the pandemic. The hospice expresses gratitude for the advocacy of the Hospice and Palliative Care Association of New York State for helping the staff get "vaccinated during the initial wave of inoculations." (*Westfair*, 4/11, https://westfaironline.com/146684/hospice-of-westchester-emerges-from-pandemic-with-renewed-focus/?utm_source=rss&utm_medium=rss&utm_campaign=hospice-of-westchester-emerges-from-pandemic-with-renewed-focus)

*** Ohio's Hospice of the Western Reserve and Ohio's Stein Hospice have united under a new "organizational structure," and now have become one organization.** The two programs have collaborated for decades. With the increased competitive environment, says Bill Finn, president and CEO of Hospice of the Western Reserve, this change "ensures future generations will continue to have access to the best and most comprehensive end-of-life services available anywhere." (*Ohio's Morning Journal*, 4/11,

<https://www.morningjournal.com/2022/04/11/hospice-of-the-western-reserve-stein-hospice-unite-under-new-organizational-structure/>

* **A *Forbes* article that explores value-based care (VBC) says the transition to VBC, “including Medicare Advantage, accountable care organizations, and bundled payment models,” faces challenges.** The principle of VBC is working to “lower cost of care for a population of patients, while aiming to improve outcomes.” But in the “real world,” this sometimes look different. The article shares the story of a woman, served by a Medicare Advantage Plan. She was dismissed too soon from a hospital and had to face a return there. Another time, she was “denied access to a tertiary cancer center.” Yet another time, she was denied access to an appropriate specialist. “Aggressive bed day management,” says the article, “often translates into lower hospitalization rates and shortened hospitalizations, but it can sometimes leave patients and families feeling rushed and uncared for in their most vulnerable moments.” Many VBC groups “prioritize palliative care and proactively transition patients to hospice.” This is done, in part, because “it’s often the right thing to do.” But it is also done because these patients are often hospitalized and receive expensive and futile care. To avoid this, these patients sometimes feel rushed toward palliative care and hospice.” (*Forbes*, 4/12, <https://www.forbes.com/sites/sachinjain/2022/04/12/what-is-value-based-healthcare-really/?sh=63e2e2b1d8af>)

* **Clearwater-water based Empath hospice and Sarasota-based Tidewell Hospice have merged. The merger creates one of the country’s largest hospice and palliative care organization.** A byline in the article, in *Business Observer Florida*, says, “A gusher of challenges lies at the foot of the hospice industry. One bold organization attacks the obstacles with a bigger-is-better mindset.” The new organization believes that, by facing together the challenges of payment rates, growing competition, and staff and labor concerns, the new organization will be better positioned to serve patients. The article, says that with its fast growth of an aging population, Florida has a “big need for hospice care.” The article, online at the link below, lists the largest hospices in the country. The article also offers an exploration of the issues hospices are facing, and gives a deeper examination of both Empath and Tidewell. (*Business Observer Florida*, 4/14, <https://www.businessobserverfl.com/article/dollar351m-hospice-aims-to-use-size-increase-access-points>)

* **Husch Blackwell posted a podcast of their Hospice Audit Series. The podcast is titled “Audit Overlap: Connections and Contradictions Among Audits, Auditors and What to Do About Them.”** The podcast discusses “the increasing prevalence of simultaneous audits, what it might mean and what to do about it.” The podcast is online at the link below. (Husch Blackwell, 4/13, <https://www.huschblackwell.com/newsandinsights/hospice-audit-series-audit-overlap-connections-and-contradictions-among-audits-auditors-and-what-to-do-about-them>)

PALLIATIVE CARE NOTE

* **The National Academies of Sciences, Engineering, and Medicine issued a consensus study titled “The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff.”** The paper, sponsored primarily by The John A. Hartford Foundation, with support from other funders, explores why, despite “three decades of efforts to improve the quality of care in nursing homes, significant challenges still remain.” The committee report, along with highlights, is available online at the link below. The committee members concluded that the “current state of nursing home care... does not align with the committee’s vision of high-quality nursing home care.” **Among its numerous recommendations, the committee says: “HHS should fund the development and adoption of new measures to Care Compare, including in the areas of palliative care and end-of-life care,** implementation of the care plan, receipt of care that aligns with the resident’s goals, staff well-being, psychosocial and behavior health, emergency preparedness, and health information technology adoption and interoperability.” (National Academies of Sciences, Engineering, and Medicine, April 2022, https://nap.nationalacademies.org/resource/26526/Nursing_Homes_Highlights.pdf care)

END-OF-LIFE NOTES

* **“Art of the Wish” is an art celebration that explores “the wishes of elders” and works to protect “the**

interests of those whose voices have not been heard or heeded.” The Center of Practical Bioethics, Kansas City, is hosting a special event to view this one-of-a-kind art exhibit and talk with the artists/creators, Andy Newcom and Marn Jensen. Both of the artists have been part of the Hallmark creative community for many years. In preparing for “Art of the Wish,” Newcom and Jensen visited with over 200 older adults across America, asking them about their wishes for the world. From the powerful sharing of these elders, the two created “50 pieces of art expressing the lived experiences of older adults conveyed in the form of their wishes for the world...” Details about the event are online at the links below. The event will occur on May 12, and the exhibit itself is available through May 2022. (Center for Practical Bioethics, <https://www.practicalbioethics.org/in-the-news/exhibit-celebrating-the-wishes-of-elders-evokes-strong-emotions/>; <https://www.practicalbioethics.org/events/art-of-the-wish/>)

*** *Honolulu Civil Beat* features an article that asks why it is so difficult for suffering patients to access medical aid in dying (MAID) in Hawaii.** House Bill 1823, if passed, will “will lower barriers to medically assisted suicide by making it easier for doctors to prescribe medications and lowering wait times. The article shares personal stories of how difficult it has been for some to find the help they want. Opponents to the bill, however, are concerned that the loosened requirements might enable patients to act too quickly, and empower healthcare professionals who “may not have the expertise to recognize signs of mental illness that would otherwise disqualify a patient from medically assisted death.” Hawaii is the only state with legalized MAID that requires patients to have a mental health assessment to be sure that they do “not suffer untreated depression or other illness that may compound the person’s ability to make informed decisions,” says the article, which leads to patients needing to talk to, and receive signoff, from three healthcare providers. The article gives an overview of the current law, how it has been utilized thus far, and difficulties that patients report. (*Honolulu Civil Beat*, 4/11, <https://www.civilbeat.org/2022/04/why-wont-anybody-help-us-patients-are-dying-before-they-can-get-help-to-kill-themselves/>)

*** “A New Take on Death and Dying,” in Columbia University’s *Columbia News*, examines the range of “death care rituals” and suggests possibilities for change.** Globally, says the article, about 165,000 people die each day. The authors of “The Future of the Corpse: Changing Ecologies of Death and Disposition,” authored the article. We are now at a turning point in terms of “reimagining end-of-life care, funerary services, human disposition methods, memorializing, and mourning,” says the article. Authors Karla Rothstein and Christina Staudt discuss the book with *Columbus News*, sharing about why they wrote the book. The “American expectation of a burial plot in perpetuity for each individual,” they say, “is at odds with the density and spatial limits of urbanity.” And cremation is considered wasteful “by those prioritizing ecological impact.” They suggest that current cemeteries can serve more people via “new, sustainable forms of corpse disposition that engage the body biologically and contribute to enduring civic-sacred spaces supporting grief and remembrance.” They, along with others, “are developing mortuary options that are gentle on the earth while also remaining proximate to where we live. The pandemic, says the article, has pushed us into new thinking. (*Columbia News*, 4/11, <https://news.columbia.edu/news/new-take-death-and-dying0>)

*** An article on CNBC says “67% of American have no estate plan.” And then the article offers advice on getting such a plan started.** The article emphasizes the benefit of planning, and encourages people to become informed and to find online resources to help. (*CNBC*, 4/11, <https://www.cnbc.com/2022/04/11/67percent-of-americans-have-no-estate-plan-heres-how-to-get-started-on-one.html>)

*** Connecticut citizens, after more than a decade of exploring aid-in-dying legislation, will have to wait at least another year as the bill failed –again—to get out of the Judiciary Committee.** Republicans called for a “rarely-used parliamentary move” at the Judiciary Committee’s vote. It called for the nine Senators on the 39-member panel to vote first. When they voted five to four in opposition, the bill was blocked from moving forward. (*CT Examiner*, 4/12, <https://ctexaminer.com/2022/04/12/aid-in-dying-bill-fails-again-at-state-capitol/>)

GRIEF AND ADVANCE CARE PLANNING NOTES

*** VITAS Healthcare commissioned a poll to examine “trends among different generations and ethnic/racial groups” regarding end-of-life planning.** “As fears and restrictions related to the COVID-19 pandemic ease, and as the death toll declines, Americans are also reporting they are now less likely to discuss or document their plan for end-of-life care, compared to a year ago,” the report reveals. The survey found that healthcare professionals are missing opportunities to open these conversations. In fact, “71% of Americans say a doctor has not raised the topic” of advance planning. Vitas shares the results of the survey in a news release at the link below. (*PR Newswire*, 4/12, <https://www.prnewswire.com/news-releases/on-national-healthcare-decisions-day-americans-momentum-for-end->

of-life-planning-slows-as-pandemic-wanes-301523544.html)

* **NHPCO issued a media release in anticipation of National Healthcare Decisions Day on 4/16.** The release spoke about the importance of advance care planning and referred readers to free resources on CaringInfo.org. Edo Banach, CEO of NHPCO. Said, “Hospice and palliative care providers always put patients at the center of the care plan.” (NHPCO, 4/13, <https://www.nhpc.org/national-healthcare-decisions-day-april-16/>)

OTHER NOTES

* **Billionaire entrepreneur Mark Cuban says the “fulfillment he feels from seeing people gain access to more affordable drugs and medications is unmatched.” He wants his personal legacy to be the work of creating a disruption of the pharmaceutical industry.** Mark Cuban Cost Plus Drug Co., which has just finished its first quarter, is organized as a public-benefit organization. It is for-profit “but claims its social mission of improving public health is just as important as the bottom line.” To date, the company has added more than 50 medications it can offer. The drugs “are sold with a 15 percent markup price, a \$3 pharmacy fee to pay the pharmacists it works with and a fee for shipping.” Cuban says he will take no venture capitalists in the company, saying “I don’t want this to be about having to make somebody else any money.” Cuban says he has a singular vision of offering the lowest cost on drugs. (*Becker’s Hospital Review*, 4/8, https://www.beckershospitalreview.com/strategy/mark-cuban-is-ready-to-say-no.html?origin=DigitalE&utm_source=DigitalE&utm_medium=email&utm_content=newsletter&oly_enc_id=4546C5822612C9X)

* **New York has waived the requirement that a nurse practitioner (NP) must have “a written practice agreement with a physician.”** Twenty-four states and D.C. also have this law. NPs can provide the “full scope of services they are educated and clinically trained to provide.” (*HealthLeaders*, 4/11, <https://www.healthleadersmedia.com/nursing/new-york-grants-full-practice-authority-states-nurse-practitioners>)

Note of Correction: One word was wrong in a note in last week’s HNN and is noted below. * Canada, beginning in March 2023, will be one of the few nations to allow “medical aid in dying, or MAID, for people whose ~~would~~ sole underlying condition is depression, bipolar disorder, personality disorders, schizophrenia, PTSD and any other mental affliction.” There is a deep division among leaders in the mental health field about this action. The link below leads to an article that explores the complexities of this decision. (*National Post*, 4/4, <https://nationalpost.com/health/canada-mental-illness-maid-medical-aid-in-dying>)

Thanks to Don Pendley for contributions.

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.

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