

What the Media Said about End-of-Life Care This Week December 7, 2021 A Service of Your State Association

ARTICLE ASKS: “IS ‘DEATH WITH DIGNITY’ REALLY POSSIBLE?”

During the past few decades, says an article in *Psychiatric Times*, “death with dignity has become a kind of battle cry.” The term has become almost synonymous with physician-assisted suicide (PAS). But in spite of his opposition to PAS, physician-author Ronald W. Pies says, his goal in this article is to “take a deep dive into the notion of death with dignity by asking 2 main questions.” “Is death with dignity even a viable concept?” “A fervent fixation on death with dignity,” says Pies, “can blind us to human values of greater depth and import.

He opens the article by sharing about his mother’s death. She refused any efforts at pain management, saying she wanted to keep a clear head. His mother died, says Pies, “in her own way, stoically enduring her pain, guided by her own idea of “death with dignity.”

In 1974, Paul Ramsey, a Christian ethicist, wrote a controversial essay and said, ““There is nobility and dignity in caring for the dying, but not in the dying itself.” While Ramsey’s essay was “complex and convoluted,” Pies says Ramsey was clear that our ““dying with dignity’ encompasses...the final indignity of death itself, whether accepted or raged against.” Sherwin B. Nuland, in “How We Die” wrote, “I have not often seen much dignity in the process by which we die. The quest to achieve true dignity fails when our body fails.”

Pies takes a deep dive exploring the questions. He takes a look at some of the perspectives of Jainism, the oldest of the Indian religions. He looks at the life of an Englishwoman, Hilary Lister, “who died at the age of 46 after a long voyage of pain, endurance, and courage.” In her life, says Pies, she exemplifies “*life with dignity*, even in the face of profound suffering and incapacity.” Pies notes he is not judging those who commit suicide. He says it is important, while we are healthy, to engage in advance care planning.

In conclusion, Pies circles around to his beginning question, asking if there even is death with dignity. “If there is,” he writes, “I believe it consists of facing death with courage and equanimity.” Dignity, Pies believes, grows out of how we live each day of our lives. Dignity “emerges from the moral choices we make; from our acts of courage, kindness, and forgiveness; and from the beneficial contributions we make to our family, our loved ones, and society. Dignity grows in us when we ‘live steadfastly and calmly.’” And dignity in death—if such a thing exists—is far less central to our humanity than dignity in life.”

Pies closes by quoting philosopher Baruch Spinoza, who said, ““The free person thinks least of all of death, and his wisdom is a mediation not on death, but on life.”” (*Psychiatric Times*, 11/30, <https://www.psychiatristtimes.com/view/is-death-with-dignity-really-possible->)

WHEN THE DYING DON’T DIE

Retired pastor Larry Patten writes in *Next Avenue* about life for caregivers “caught in the ambiguity of the dying process.” For eight years Patten ran a website about hospice and end-of-life issues. He describes himself as a “non-medical guy with a hospice background.” In this role, he wrote his blog posts. But no post ever garnered the attention and feedback as the post he wrote, in 2016, about “the dying who don’t die.” And, he says, “the responses never stopped.”

Patten says about 60% of all hospice patients live beyond one week, “but most die prior to the six-month mark.” But, what happens when the dying don’t die? Caregivers who have responded to Patten’s blog share with him the experiences and reactions of weary caregivers. One says that nurses tell her to take one day at a time;

but after months of 24/7 support, “the ‘one day’ troupe is another emotional knife wound.” Caregivers say that visitors become less frequent. One reports that a minister says, “‘This is part of God’s plan.’ For some caregivers, God joins the liars, cliché-givers and those who no longer visit or call.”

From the thousands of comments, Patten discovered two themes. “Exhausted caregivers *need* to tell their raw, vulnerable stories.” And, when they learn about other struggling caregivers, they feel less alone.

Patten noticed several concerns about peoples’ hospice experiences. He notes that there is a lot of information given to families as hospice begins. For patients who stay alive, caregivers need more reminders about what sources of support are available, and information on what the dying process entails. And, Patten says, caregivers “don’t want more brochures,” but do need hospice to share information. And all staff should be trained to refrain from clichés and prediction. Try to encourage additional support, Patten says, and he recognizes this can be difficult. “Everly single one needs to know they are not alone.” (*Next Avenue*, 12/1, <https://www.nextavenue.org/what-if-the-dying-dont-die>)

HOSPICE NOTES

*** Husch Blackwell offers a new podcast titled Strategic Restructuring for the Future, Think Before You Sign: Five Key Insights for VBID and Managed Care Contracts.** The presentation addresses the expected changes in the provision of hospice care over the next five years. “It is unquestionable that the carve-in to Medicare Advantage, the rise of value-based care and steady market consolidation is changing the playing field. How do hospices respond?” In a series of podcasts the issues facing the provision of hospice are explored. In this podcast, the presenters say, “We unpack five takeaways learned in working with hospices on their managed care contracts. Private payor contracts will define future revenue for hospices.” The podcast is online at the second link below. (Husch Blackwell, 12/2, https://www.healthcarelawinsights.com/2021/12/strategic-restructuring-for-the-future-think-before-you-sign-five-key-insights-for-vbid-and-managed-care-contracts/?utm_source=Husch+Blackwell+-+Healthcare+Law+Insights&utm_campaign=28375b3513-RSS_EMAIL_CAMPAIGN&utm_medium=email&utm_term=0_9c468d829c-28375b3513-86099043; Husch Blackwell, 12/1, <https://www.huschblackwell.com/newsandinsights/strategic-restructuring-for-the-future-think-before-you-sign-five-key-insights-for-vbid-and-managed-care-contracts>)

*** NHPCO issued a release that “Endorses Legislation to Help Address Workforce Challenges in Hospice and Palliative Care.”** The two pieces of legislation include the Healthcare Workforce Resilience Act, focused on improving the shortages of physicians and nurses, especially by offering more visas to these medical workers. The second legislative action is the Provider Training in Palliative Care Act, which will offer support to encourage training for palliative care medical providers by offering financial and other incentives. (NHPCO, 11/30, https://www.einnews.com/pr_news/557318252/nhpc0-endorses-legislation-to-help-address-workforce-challenges-in-hospice-and-palliative-care)

*** “Carrefour Associates LLC; Crossroads Hospice of Cincinnati LTC; Crossroads Hospice of Cleveland LLC; Crossroads Hospice of Dayton LLC; Crossroads Hospice of Northeast Ohio LLC; and Crossroads Hospice of Tennessee LLC (Crossroads Hospice), operating in Ohio and Tennessee, have agreed to pay \$5.5 million to resolve allegations that they violate the False Claims Act by submitting claims to Medicare for non-covered hospice services.”** The announcement by the Department of Justice says the Special Agent in Charge said, “The decision to provide hospice services should be prompted by a patient’s terminally ill medical diagnosis and desire for palliative care, not a hospice provider’s desire to boost its profits.” The settlement began with a whistleblower report, and the release by the Department of Justice describes the process to settlement. (Department of Justice, 11/23, <https://www.justice.gov/opa/pr/crossroads-hospice-agrees-pay-55-million-settle-false-claims-act-liability>)

*** The Department of Justice arrested two persons in Los Angeles who are accused of aiding “illegal kickbacks for the referral of Medicare beneficiary information that could be used to bill for purported hospice services.”** If convicted, the maximum penalty is 35 years in prison. (Department of Justice, 12/2, <https://www.justice.gov/opa/pr/two-arrested-los-angeles-their-roles-hospice-fraud-conspiracy>)

*** Arizona’s ABC5 reports that Mesa-based Valley Hospice of Arizona has declared Chapter 11 bankruptcy.**

“Documents on file with U.S. Bankruptcy Court for the District of Arizona show that the company owes money to 77 creditors, many of which are unsecured.” (ABC55, 11/24, abc15.com/news/business/mesa-based-valley-hospice-of-arizona-files-for-chapter-11-bankruptcy)

* **Medpage Today shares the story of an end-of-life doula and the changes of her work during COVID.** Doulas, notes the article, help in planning, preparing and processing end-of-life care for dying patients, and doulas are “story catchers.” COVID brought an environment where doulas were kept away from physical contact with patients. Francesca Lynn Arnoldy, the doula profiled in the article, turned her energies to working with others to establish StoryListening Study, “an IRB-approved research project focused on pandemic grief.” People who have experienced grief share their stories with a listening doula. (Medpage Today, 12/3, https://www.medpagetoday.com/opinion/second-opinions/95995?xid=nl_secondopinion_2021-12-05&eun=g963454d0r)

* **The Center for Medicare and Medicaid Innovation (CMMI) has ceased the Seriously Ill Population (SIP) option.** C-TAC reports that Dr. Pura Rawai, CMMI’s Chief Strategy Officer, said on a panel, “The Innovation Center is committed to testing interventions focused on improving care for seriously ill beneficiaries,” and are exploring other ways to serve these beneficiaries. (CAPC, 11/30, <https://www.capc.org/blog/the-seriously-ill-population-sip-medicare-payment-model-terminated/>; C-TAC, 12/1, <https://www.thectac.org/2021/12/cmmi-cancels-sip-model-reconfirms-commitment-to-those-with-serious-illness/>)

* **“Two Novus Doctors Sentenced to Combined 23 Years in Prison for Healthcare Fraud,” is the headline of a US Department of Justice News Today.** The two physicians were found guilty of conspiracy to commit healthcare fraud, as well as other charges. One physician was sentenced to pay nearly \$28 million in restitutions and to spend 13 years in federal prison. The second physician was ordered to pay \$16 million in restitution and spend 10 years in federal prison. Evidence presented at the trial show the two helped the Novus CEO “defraud Medicare by, among other things, illegally admitting patients who were not appropriate for hospice and submitting materially false claims for hospice services.” (US DOJ News Today, 12/2, <https://usdoj.today/2021/12/02/two-novus-doctors-sentenced-to-combined-23-years-in-prison-for-healthcare-fraud-usao-ndtx/>)

* **NHPCO released a statement saying “Congress’ Continuing Resolution Fails to Address Impending Cuts to Medicare.”** NHPCO says the statement speaks for the “collective concern of the hospice community about the negative impacts on patients of the Continuing Resolution (CR) under consideration in Congress to extend the government’s current budget through February 18.” Two cuts to Medicare hospice payments will mean a 6% decrease to Medicare hospices starting in January. The same level of care will need to be provided, and the ongoing staff shortages and “economic realities” make the cuts even more painful. NHPCO also recently sent a joint letter, along with the National Association for Home Care and Hospice and Leading Age to Congressional leaders calling for their help to address this concern. (NHPCO, 12/2, https://www.nhpc.org/nhpc-statement-congresses-continuing-resolution-fails-to-address-impending-cuts-to-medicare/?_zs=8kKKC1&_zl=HcNW6; NHPCO, 11/22, <https://www.nhpc.org/hospice-aging-and-home-care-organizations-urge-congress-to-delay-payment-cuts-due-to-pandemic/>)

PALLIATIVE CARE NOTES

* **Mississippi’s only children’s hospital, Children’s of Mississippi, offers palliative care for complex patients.** The program won a bronze reward in the national Tipping Point Challenge, designed to “spark innovation that will result in positive change in the care of serious illnesses.” Program leaders say focus on patient- and family-centered care are central to their work, and that they focus on “the importance of hope and joy, even in the midst of serious illness.” (Madison County Journal, 11/24, <https://onlinemadison.com/stories/childrens-palliative-care-program-earns-bronze-medal,36026>)

* **A partnership between Livio Health, a Minneapolis-based palliative care provider and Blue Cross Blue Shield of Minnesota, works to demonstrate “the value of home-based palliative care to payers, including Medicare.”** During COVID in 2020, the partnership found “a 21%% reduction in hospitalizations among a cohort of roughly 600 chronically ill patients and a projected cost savings of about \$2.5 million in unnecessary care.” Early data indicate that reduction has continued in 2021. While Medicare does not currently cover palliative care as it does hospice, efforts to change that are ongoing. The Livio Health and BCBS Minnesota partnership hopes to extend

services to Minnesota's Medicaid program. The hope is to demonstrate that the services improve the lives of patients and save costs for insurers. (McKnight's Home Care, 11/17, <https://www.mcknightshomecare.com/minnesota-partnership-proving-the-value-of-palliative-care/>)

* ***Journal of Hospice and Palliative Nursing* offers “2021: A Reflection of Service” written by the journal's editor-in-chief, Betty Ferrell, PhD, FAAN, FPCN.** Ferrell says palliative nurses have been on the forefront of COVID care and have endured the new normal that has unfolded. She acknowledges this time of “crisis, illness, trauma, despair and injury.” And yet, looking closely, “there has been healing amid the fragmentation and in how our field has transcended disciplinary boundaries and merged energies to alleviate suffering during the worst of times.” This year Ferrell read Rachel Naomi Remen's “Kitchen Table Wisdom.” For palliative care nurses, service has been on the level of Remen's concept of “Serving.” Now, as 2021 ends, Ferrell encourages all to pause and consider the service given as palliative care nurses—and to renew “commitment to this sacred work.” (*Journal of Hospice and Palliative Nursing*, December 2021, https://journals.lww.com/jhpn/Fulltext/2021/12000/2021__A_Reflection_on_Service.1.aspx)

END-OF-LIFE NOTES

* **End of Life University features a podcast with Pepper Cappuccio, an on-call hospice nurse.** He is often present as patients die, and he shares about his work. The podcast is online at the link below. (End of Life University, 11/29, <https://eolupodcast.com/2021/11/29/ep-327-warm-water-the-last-act-of-compassion-in-hospice-care-with-pepper-cappuccio-rn/>)

* **An article in *The Hill* shares that Switzerland has approved the use of a “suicide pod” and it has “cleared legal review in the country and could start operating some time next year.”** The pod is a single entity that someone can enter, answer a series of questions, and push a button when ready for death. The pod floods nitrogen into the space, and, according to the article, provides a quick death with “no panic, no choking feeling.” It is developed by an international nonprofit called Exit International. (*The Hill*, 6/6, <https://thehill.com/changing-america/well-being/584513-assisted-suicide-pod-approved-in-switzerland>)

* **Physician Randy Curtis is an expert in end-of-life care who has ALS.** Throughout his career, Curtis has worked to help seriously ill patients make treatment decisions. Curtis is co-director of the University of Washington Medicine Cambia Palliative Care Center of Excellence. Since his ALS symptoms began, Curtis is spending more time with family and is still working. Curtis speaks honestly, saying, “I've had times since the diagnosis when I'm really able to focus on joy and gratitude, but I've also had times when I'm overwhelmed by sadness and loss and I wish my experience in palliative care would make that sadness and loss easier, I don't think it does. It's just something I have to go through, there's no shortcut around that.” NBC's *K5* in Washington featured a story on Curtis, and a video and text are online at the link below. (*King5*, 11/23, <https://www.king5.com/article/news/health/it-was-shattering-uw-medicine-doctor-who-studies-end-of-life-care-talks-about-als-diagnosis/281-9482d49e-9ca0-49b9-ac55-e38016557f68>)

GRIEF AND OTHER NOTES

* **End of Life University shares a podcast titled “The Sweetest Therapy: How Baking Heals Grief,” featuring social worker Chase Cassine.** Through his own losses, and his experiences as a therapist, he shares about his work. The podcast is at the link below. (End of Life University, 11/22, https://eolupodcast.com/2021/11/22/ep-326-the-sweetest-therapy-how-baking-heals-grief-with-chase-cassine-lcsw/?mc_cid=f295df72b8&mc_eid=d0771da91c)

* **C-TAC shares “5 Reasons Why Community Health Workers Are the Future of Care for Serious Illness.”** The article takes an in-depth look at addressing disparities in care for seriously ill patients, and identifies the importance of community health workers. The article is online at the link below. (C-TAC, 11/24, <https://www.thectac.org/2021/11/5-reasons-why-community-health-workers-are-the-future-of-care-for-serious-illness/>)

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