
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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WHAT DO WE DO WHEN A DOCTOR'S CONSCIENCE CONFLICTS WITH A PATIENT'S WISHES?

Some physicians in Vermont are suing to challenge their state health department's interpretation of the Patient Choice and Control at End of Life law (Act 39). Officials say that Act 39 requires physicians who are morally or ethically opposed to physician-assisted suicide (PAS) to inform patients about this option, or refer them to a physician who will. Opponents of the law – and of this interpretation – cite the American Medical Association's 1994 Code of Ethics stating that PAS “is fundamentally incompatible with the physician's role as healer.”

Author Ann Jackson, who served as CEO of the Oregon Hospice Association from 1998 to 2008, wrote an article printed in *VT Digger* that supports Vermonters who are in favor of the law. She notes that pro-PAS advocacy groups such as Patient Choices Vermont, Compassion & Choices and Death with Dignity National Center support Vermonters' choices as well. She says, “Physicians shouldn't impose their personal values on their patients by blocking them from receiving information about all their end-of-life care options.” Jackson, who initially opposed Oregon's movement to PAS, says, “The truth is fears raised by opponents of the Oregon Death with Dignity Act turned out to be 100 percent unfounded.”

Jackson points out that the Vermont lawsuit plaintiffs fail to mention that the AMA is currently reconsidering its stance on PAS. With physician-prescribed, lethal medication now legal in a number of states, the tide seems to be turning against opponents within and beyond the medical community who view PAS as a dangerous trend, unworthy of the medical profession and its commitment to the sanctity of life, says Jackson. **Despite resistance, she writes “A growing number of national organizations representing health care professionals have endorsed or taken a neutral position on medical aid in dying as an end-of-life care option for mentally capable, terminally ill adults.** They include the American Medical Student Association, American Public Health Association, American Medical Women's Association, American Academy of Legal Medicine, and American Academy of Hospice & Palliative Medicine.”

Jackson argues that Oregon is a long-time leader in the quest for greater access to physician-assisted suicide, and says that that the state's success with its Death With Dignity Act is a model for the rest of the country. She quotes the *Journal of Palliative Medicine* as saying, “It is possible the Oregon Death with Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care

training of physicians, and more efforts to reduce barriers to access to hospice care...”

Jackson insists that the legalization of physician-assisted suicide has made end-of-life conversations easier for everyone. “Oregon’s hospice workers, both those for and against the concept or practice of medical aid in dying, agreed that it was much easier to have open and honest conversations with terminally ill patients about end-of-life care options after the law took effect.” **According to Jackson, more than 90% of PAS users are enrolled in hospice care, which helps assure that their unique needs are being met.**

Jackson concludes by writing that Vermonters should have access to all the options at the end of life, including information about physician-assisted suicide. **If some physicians are not willing to have this conversation, they should refer to others who will.** “Without information about all options, terminally ill Vermonters cannot make fully-informed decisions about their end-of-life care that are consistent with their own values and faith and most important for them and for their families. Doctors’ values should not trump their patients’ needs during their last and most vulnerable stage of life.” (*VT Digger*, 9/26, vtdigger.org/2016/09/26/ann-jackson-doctors-personal-values-trump-patients-needs/)

WHAT IS THE VALUE OF ICU CARE AT THE END OF LIFE?

The role of the intensive-care unit has traditionally been one of prolonging life at all costs. For many patients, says an article in *NEJM Catalyst*, this is exactly what is needed. With the help of emergency interventions and curative treatments, many individuals are able to go on to live healthy, happy lifestyles for many more years. “Unfortunately,” says Thomas W. Feeley, MD, “that positive outcome does not happen as often as we would all like.” With the enormous cost, both economic and human, of the ICU, Dr. Feeley considers the value that hospital-based intensive care units offer to patients at the end of life. What, if any, is the value of ICU for patients in their last days, weeks, months of life?

“For far too many patients, their critical care experience is of very low value.” Two thirds of Americans say that they would prefer to die at home if it would not be too great a burden on their families. Yet more than one-fifth of deaths in the United States happen either in the ICU, or immediately following a trip to the ICU. Only about 20% of Americans ultimately die at home. **“We in health care are not doing a great job matching what people want with the outcomes they get.”**

Dying at home is the most traditional end-of-life experience. “For thousands of years, people died at home surrounded and supported by their family and friends. While not always pleasant, it was the way it was.” With the emergence of the hospital systems in the 19th century, and the ICU in the 20th century, the locus of the end-of-life experience rapidly shifted away from the home and to medicalized environments. Despite all the benefits that modern medicine has provided, **“The advent of the ICU transformed dying from a natural process to one where care stopped only when death was imminent.”**

The economic costs are at least as great as the social ones. Fully one quarter of US health care spending goes to the 6% of individuals who die each year, and 20% of costs stem from time spent in the ICU. “Dying in the ICU is both more expensive than dying at home and less

desirable in the eyes of most people.” **Despite all this, the system continues, largely unchallenged. Why?**

One reason is, we don’t always know (or refuse to accept) that we’re going to die. When in doubt (or denial), most Americans still choose to assume that they have a shot at getting better. With that assumption, they often want all the curative care they can get. “Another problem is that most ICU patients lose their ability to make informed choices once they arrive, because of illness and treatment. Decisions are then delegated to families and significant others, who often neither understand the patient’s wishes nor have sufficient confidence to make a decision to end life support.” **Advance directives are meant to help here, but the reality is that they are often cast aside in moments of crisis.**

Given all this, how do we design a health care system that respects the wishes of all patients, and avoids the painful and costly patterns of end-of-life care in the ICU?

Uncertainty clouds easy decisions, says Dr. Feeley. “Since physicians can rarely predict when someone will die... the default position is to help. ... Often it does not become clear that death is inevitable until patients are well into life support ICU care.” **When in doubt, many doctors, patients, and families default to aggressive curative treatment.**

Feeley argues that only patient engagement can effectively change the present end-of-life dynamic in America. “We need patient engagement. Not just when they are ill, but when they are well. The best time to have a conversation about the end of life is not when the patient is in impending respiratory failure, but when everyone is well and clear-headed.” Patients need to understand how the ICU really works, and what end-of-life care typically looks like in a hospital environment. Given enough information, many patients might make different choices – and communicate those choices to their families.

Ultimately, planning is a huge element in transforming end-of-life care. “We should plan for dying the way we plan for births,” says Feeley. “We should feel comfortable talking about death with our loved ones.” Much responsibility falls to physicians as well. In spite of the fast pace of American medicine, he says, “Physicians need the time and support to have frank conversations with their patients about their wishes.” **What would it mean for clinicians to slow down and develop meaningful relationships with their patients – and with the palliative care teams that will serve them?**

Feeley concludes with an appeal for limits in health care, learning what is beneficial and what is harmful – both for the individual and for our society. **“While physicians should not be rationing care, there need to be limits to what we do at the end of life. Just because we can do something in an ICU does not mean we should.”** Addressing these issues is an important role of the health care team. “Value for the patient means providing the outcome they want based on their unique situations. Unless we ask, we will not know.” (*NEJM Catalyst*, 9/28, catalyst.nejm.org/value-icu-care-end-of-life/)

HOSPICE AND END-OF-LIFE NOTES

*** Jerika Bolen was a 14-year old who entered hospice care after a lifelong struggle with spinal muscular atrophy type 2.** Jerika, whose decision to end life-extending treatment drew

both sympathy and criticism from disability rights activists, has died in hospice care. (See HNN, Volume 20, Number 30) (*Sheboygan Press*, 9/22, www.sheboyganpress.com/story/news/2016/09/22/jerika-bolen-dies-after-ceasing-treatment/90848584/, 9/28, www.sheboyganpress.com/story/news/2016/09/27/disability-groups-call-jerikas-death-injustice/91130250/)

* **The Conversation of a Lifetime Campaign is gaining ground in New Jersey.** “We know that when it comes to end-of-life care, New Jersey is one of the states that’s most challenged,” said Linda Schwimmer, the New Jersey Health Care Quality Institute's chief executive officer. “There’s a real disparity between what we say we want in terms of end-of-life care, and what we actually end up getting. ... The Conversation of a Lifetime campaign ‘has been a tremendous success,’ Schwimmer added, and three counties are now starting work to spread the campaign further. The institute hopes to expand the project statewide.” (*Courier Post*, 9/27, www.courierpostonline.com/story/life/2016/09/27/conversation-lifetime-campaign-spreads-nj/89928720/)

* **Silencing end-of-life conversations only does harm to the most vulnerable, says Dr. Jerry Ballentine.** “Doctors, nurses and other caregivers are often reluctant to discuss end-of-life plans with terminal patients. Death is considered a taboo topic, until after a patient has died. This lack of patient-provider communication frequently leads to degraded care and needless suffering.” (*KevinMD*, 9/22, www.kevinmd.com/blog/2016/09/silencing-end-life-discussions-fails-terminal-patients.html)

* **A Kansas hospice is hosting a three-day intergenerational retreat for those experiencing the loss of loved ones.** The Comfort Zone Family Retreat in Scott City, Kansas, “is an opportunity for individuals, families, children, teens or adults who have experienced the loss of a loved one to gain tools to help them as they walk their grief journey.” (*The Hutchinson News*, 9/23, www.hutchnews.com/news/local_state_news/hospice-offers-family-retreat/article_b26d15e3-b5f2-5780-b294-8bf600503b1c.html)

* **The cost of caregiving can be high, including for the careers of those who care for loved ones at the end of life.** According to Caring.com’s Caregiver Journey survey for 2016, “the dollar cost is substantial to a caregiver: 42 percent of family caregivers say they spend \$5,000 or more each year on caregiving-related expenses.” (*BenefitsPro*, 9/19, www.benefitspro.com/2016/09/19/caregiving-is-costly-for-careers-employment?&slreturn=1475251711)

* **Bringing end-of-life forms into the digital age could prove to be complicated.** “Advocates and lawmakers in New York are now pushing to shift the paper system to a mandatory electronic database for better access. But the requirement would call for a technology fix that’s not coming easily.” (*WXXI News*, 9/28, wxxinews.org/post/push-take-end-life-forms-digital-reveals-complicated-path-ahead)

* **Confusion on end-of-life forms may lead to unwanted care for seniors.** A study published in the *Journal of Post-Acute and Long-Term Care Medicine* concludes, “Patients and proxies may believe that making choices and documenting some, but not all, of their wishes on the MOLST form is sufficient for directing their end-of-life care. The result of making some, but not all, choices may result in patients receiving undesired, extraordinary, or invasive care.” (*JAMDA*,

9/27, [www.jamda.com/article/S1525-8610\(16\)30310-3/pdf](http://www.jamda.com/article/S1525-8610(16)30310-3/pdf); *University of Buffalo NOW*, 9/29, www.buffalo.edu/ubnow/stories/2016/09/end-of-life-forms.html)

* **Two physicians write about the barriers they faced in working to provide care for loved ones nearing life’s end.** Dr. Robert Cain is Minnesota Chair in Long-Term Care and Aging, Health Policy and Management at the University of Minnesota, and author of “The Good Caregiver.” Dr. Jennifer Browkaw is a board-certified emergency physician and a founder of C2it, which provides support to those caring for seriously ill persons. Their article in *Time*, “End-of-Life Care Needs and Overhaul,” shares their concerns, and calls for change. They say, **“If not even people like us—with all our resources and personal connections—could not get the acute medical and long-term care that honors the wishes of patients and families to have a gentle and dignified end, the system is broken.”** (*Time*, 9/29, <http://time.com/4513741/end-of-life-care-concerns/>)

* **What’s the right way to say goodbye?** In preparing a photo exhibition of several seniors who are experiencing their own end-of-life journeys, photographer Andrew George seeks to share their stories about their own goodbyes. (*California Healthline*, 9/29, californiahealthline.org/news/saying-goodbye-the-right-way/)

* **Norma Bauerschmidt became somewhat of a media star when, at age 90, she decided to forego medical treatments for her uterine cancer and, instead, to travel in an RV with her son and daughter-in law.** During their travels, they shared regularly via their Facebook page, Driving Miss Norma. “ ‘I think we’ve given people permission to talk — to think outside of the box — on these things,’ ” said Ramie, Norma’s daughter in law. Ramie plans to keep the Facebook page going. Norma died on September 30 in the RV that had become her home. (*Toledo Blade*, 10/2, <http://www.toledoblade.com/Deaths/2016/10/02/Bucket-list-RV-road-trip-was-a-social-media-hit.html>)

OTHER NOTES

* **Will people of color in California choose to avail themselves of the state’s new physician-assisted dying law?** In Oregon and Washington, those using “physician aid in dying” have been overwhelmingly white. Yet California has markedly different demographics. Will the demographics of PAS also prove unique? (*Capital Public Radio*, 9/27, www.caprado.org/articles/2016/09/27/will-people-of-color-in-california-use-the-aid-in-dying-law/)

* **The CDC’s new guidelines for how and when to prescribe opioids for chronic pain has been a source of controversy in the medical community.** Bob Twillman, PhD, is Executive Director for the American Academy of Pain Management. In his address at the academy’s annual meeting, Twillman “emphasized the fact that these CDC guidelines are expert-based and not evidence-based. In addition, most of these experts are strongly biased, as indicated by their affiliations to, for example, anti-opioid advocacy groups.” (*Clinical Pain Advisor*, 9/22, www.clinicalpainadvisor.com/aapmanagement-2016/the-issues-with-the-cdc-guidelines-on-opioids-for-chronic-pain/article/524976/)

* **The Indiana State Medical Association has come out as formally opposing physician-assisted suicide.** “The association says this was one of the most debated resolutions discussed. Delegate Andrew Mullally, MD, says this made the meeting go over the scheduled time due to the many physicians that wanted to speak out against the practice.” (*21Alive*, 9/27, www.21alive.com/news/local/Indiana-medical-professionals-formally-oppose-physician-assisted-suicide-394811621.html)

* **The National Academies of Science – Engineering and Medicine published a report titled “Families Caring for an Aging America.”** The report identifies “serious concerns about the current state of family caregiving of older adults in the United States.” The report suggests action steps to address the issue. (*The National Academies of Science – Engineering and Medicine*, September 2016, http://nationalacademies.org/hmd/~media/Files/Report%20Files/2016/Caregiving-RiB.pdf?utm_source=Member+Alert&utm_campaign=ce2a68ad13-Member_Alert&utm_medium=email&utm_term=0_e1d9f6f769-ce2a68ad13-150801781)

* **JAMA posted “Workforce for 21st-Century Health and Health Care” online on 9/26.** The article comes from the Vital Directions initiative of the National Academy of Medicine. **One of the five recommendations deals with “Caregivers at the end of life.”** The authors say, “For much too long, the end-of-life care needs of these patients have been served as an extension of the workforce that cares for those with advanced illness. Investing in and training more palliative care and hospice care professionals would help to lessen the dependence on health care professionals whose skills and talents are best suited to caring for individuals with acute or advanced illness or chronic disease. **With added capacity in palliative and hospice care, the United States could provide people with the end-of-life experience they desire—a choice that everyone deserves.**” (*JAMA*, 9/26, <http://jama.jamanetwork.com/article.aspx?articleid=2556009>)

* An article in *Huffington Post* shares about an update on Medi-Cal coverage. **“California is the first state to recognize that spiritual care is a standalone discipline in health care and a trained and certified palliative care chaplain must be available for any patient who wants one.”** (*Huffington Post*, 9/30, http://www.huffingtonpost.com/eric-j-hall/californi-is-the-first-st_b_12249344.html)

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