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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

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## PATIENTS AND DOCTORS WRESTLE WITH CALIFORNIA'S ASSISTED SUICIDE LAW

**On June 9, California became the fourth state in the nation to legally permit assisted suicide for terminally ill individuals.** The state's lawmakers approved the law last year after the terminally ill California resident Brittany Maynard received widespread attention from her decision to move to Oregon. She made the move in order to take advantage of that state's assisted-suicide laws, which have allowed the practice since 1997. **Yet even as California's legislation comes into effect, state residents are wrestling with the implications of the new law and what it means for life – and death – in the Golden State.**

**“The California legislation is strict,” writes Jennifer Medina for *The New York Times*.** Patients requesting physician-assisted suicide are required to make multiple requests for life-ending medication, and they must have a prognosis of less than six months to live. “Many hospitals have not yet released policies for dealing with the law. And no doctor, health system or pharmacy will be required to comply with a patient's request. **Doctors who object to the practice are not even required to refer patients who request the medication to another physician.**”

Roman Catholic and other religious health care providers have already indicated that they will not participate. “We are crossing a line — from being a society that cares for those who are aging and sick to a society that kills those whose suffering we can no longer tolerate,” says José H. Gomez, Catholic archbishop of Los Angeles.

**The *Times* article provides four profiles – two of patients and two of physicians – to give a glimpse into how Californians are grappling with this new angle on end-of-life issues in their state.** Medina features a 63-year old woman who is terminally ill and looks to the new law to provide a way to avoid becoming a burden to her family. Another man, 88 years old and living with multiple myeloma, “does not know what will push him to the edge to ask for the medication. ... [But he] relishes the idea of having the right to choose precisely when and where to die.”

**Among the physicians profiled in *The New York Times* article is Dr. Sunita Puri, a palliative medicine specialist at Keck Medicine of the University of Southern California. She describes how reaction to the new law is unfolding among clinicians**

**there – and why most doctors aren’t comfortable taking part in legal suicide.** Some of Puri’s colleagues are uncertain about the details of the medications and how they will affect their patients. Others are uncomfortable with the changing role of physicians in society – from those who prevent death at any cost, to those who in some cases usher it in. Many doctors are concerned about the mental health implications in requests for life-ending drugs. How does one know if a patient really wants to die, or if the patient is suffering from pain that counseling, palliative care, and hospice could alleviate?

**Not all doctors are sympathetic to these concerns.** Dr. Lonny Shavelon, a private practitioner in Berkeley, is frustrated when doctors speak to him of their discomfort participating in legalized suicide. “What I’ve said to them is, ‘Were you comfortable the first time you did chest surgery? Were you comfortable the first time you drew blood?’ I don’t understand when being uncomfortable became a reason not to do something in medicine.” **Dr. Shavelon has opened a practice that will provide care for “those seeking to end their lives.”** Shavelone says, **“The most important issue is to listen to the patient and hear the choices that they truly want to make for themselves.** “We always listen to the patient. We never tell a patient: ‘This is what you have to do. You have no choice.’” (*The New York Times*, 6/9, [www.nytimes.com/2016/06/10/us/assisted-suicide-california-patients-and-doctors.html](http://www.nytimes.com/2016/06/10/us/assisted-suicide-california-patients-and-doctors.html))

## **STUDY UNCOVERS FOUR PATHS TO THE END OF LIFE, AND ONE THAT IS MORE EXPENSIVE THAN THE OTHER**

**“Last-ditch, high-tech heroic treatments. Days in the hospital intensive care unit. You might think this is what makes dying in America so expensive - and that it’s where we should focus efforts to spend the nation’s healthcare dollars more wisely. But a new study finds that for nearly half of older Americans, the pattern of high spending on healthcare was already in motion a full year before they died.”**

Researchers with the University of Michigan and the Dartmouth Institute for Health Policy and Clinical Practice have discovered that **there are four patterns that characterize end-of-life health care spending: High Persistent; Moderate Persistent; Progressive; and Late Rise.** Each of these patterns of health spending indicates a markedly different way of engaging with the medical system, and one of them results in starkly higher costs.

**This came as a surprise.** Lead author of the study, Matthew A. Davis, PhD, MPH, an assistant professor at the University of Michigan School of Nursing, explains, “We were expecting to find the most common pattern to be explosive healthcare spending in the final months of life. In fact, only 12 percent of older adults in our study showed this ‘late rise’ pattern of healthcare spending.” **The Late Rise pattern is actually the least expensive of the patterns, which could be viewed as problematic from a purely cost perspective, since 88% of patients follow another pattern.**

Here’s a look at the four patterns and what they mean for cost and treatment in the aging

US population:

**High Persistent:** This pattern is characterized by a high cost of medical care throughout the last year of life, slowly rising to a peak near the time of death. This is far and away the most expensive pattern, accounting for a median of \$59,394 in costs during the last year of life. It is also the largest group, including more than half of the Medicare participants studied. This group had more than twice as many outpatient visits to medical specialists, and were more likely to spend time in medical facilities and receive life-prolonging treatments – such as a respirator, dialysis, or feeding tube.

**Moderate Persistent:** This group made up about 29% of patients included in the study. Patient costs started moderately high towards the beginning of the last year of life, dipped down slightly towards the middle, and then spiked at the end. These patients had a median health care cost of \$18,408 in their last year of life.

**Progressive:** This group is the smallest, accounting for only 10% of patients, but the costs associated with this group are second-highest, weighing in at \$39,036 median cost in the last year of life. Individuals in this group had very low spending early on, but saw their expenses rise markedly throughout the course of the year. “This group was also the most likely to use hospice care, perhaps because they and their families and physicians had a good sense that they did not have long to live.”

**Late Rise:** This is another small group, with only 12% of the total. The Late Rise group also has the lowest costs – a median of \$11,116 in the last year of life. People in this group had very low health spending until the last months before death. They had far fewer physician visits or hospital stays, and often experienced no chronic conditions. This group was more likely to die during a hospital stay that included time in the ICU. They had the second-highest use of life-prolonging treatments.

**Why do different individuals end up in one of these four groups?** Researchers found that the primary factor in end-of-life cost patterns is not the type of disease, but rather the number of different health conditions that an individual is experiencing.

The study – which included data from nearly 1.3 million Americans aged 66 to 99 who died during the period studied - accounted only for Medicare spending, and did not include out-of-pocket or prescription drug spending. (*University of Michigan Health*, 6/15, <http://www.uofmhealth.org/news/archive/201606/four-paths-end-life-one-far-more-expensive-others-emerge-new>)

## HOSPICE AND END-OF-LIFE NOTES

\* **The FBI is investigating a North Texas-based hospice. The aim of the investigation is not yet clear.** “The FBI is investigating a Plano-based hospice company with offices around the state, according to news reports.” (*The Dallas Morning News*, 6/14, [thescoopblog.dallasnews.com/2016/06/the-fbi-is-investigating-a-plano-based-hospice-](http://thescoopblog.dallasnews.com/2016/06/the-fbi-is-investigating-a-plano-based-hospice-)

company.html/)

**\* When admitting patients to hospice, asking them where they want to die can lead to fewer hospitalizations.** So says a new study led by researchers at the Icahn School of Medicine at Mount Sinai and published online in the July issue of the journal *Medical Care*. **The study also determined that for-profit hospices have persistently high rates of hospitalization “regardless of preferred practice implementation.”** (*Medical Xpress*, 6/15, [medicalxpress.com/news/2016-06-patients-die-hospice-linked-hospitalizations.html](http://medicalxpress.com/news/2016-06-patients-die-hospice-linked-hospitalizations.html))

**\* “Culinary grief therapy”? Yeah, it’s a thing! The College of Dupage Culinary Arts program and Alexian Brothers Hospice are combining cooking instruction with support for people moving past the death of their spouses.** Each semester, David Kramer, Associate Professor of Culinary Arts, and Laura Lerdal, Culinary Market Supervisor and Lab Coordinator, present “Culinary Grief Therapy,” a free workshop that focuses on cooking techniques for one. Participants also have a chance to help each other as they learn to live on their own. (*Daily Herald*, 6/13, [www.dailyherald.com/article/20160613/submitted/160619646/](http://www.dailyherald.com/article/20160613/submitted/160619646/))

**\* End-of-life care in hospitals has a lot of room for improvement, says Atul Gawande.** About end-of-life care conversations, he says, “Hospital leaders have an opportunity to reduce suffering and improve patient well-being by making these conversations a routine part of care.” Though some forms of end-of-life care are improving, there’s still a lot of room for growth. Poorly executed or overly aggressive treatments are still far too common. (*Health Leaders Media*, 6/16, [www.healthleadersmedia.com/quality/end-life-care-hospitals-has-long-way-go](http://www.healthleadersmedia.com/quality/end-life-care-hospitals-has-long-way-go))

**\* “It’s time to train all doctors on how to talk to patients about end-of-life care,” says Laura J. Morrison, a palliative care and geriatric medicine doctor and clinician-educator.** “A recent national poll found that although 99% of the physicians feel end-of-life and advance care planning discussions are important, nearly half reported they do not know what to say, and fewer than a third reported any prior training for these conversations.” (*The Huffington Post*, 6/15, [www.huffingtonpost.com/laura-j-morrison-md/its-time-to-train-all-doc\\_b\\_10471852.html](http://www.huffingtonpost.com/laura-j-morrison-md/its-time-to-train-all-doc_b_10471852.html)Document7)

**\* Should medical residents be trusted with end-of-life conversations? Ravi Parikh, a “resident physician in-training,” shares that medical residents are not currently permitted to have end-of-life conversations with patients – and shares why he believes that they should.** Parikh shares the story of his interaction with a patient who asked him about this. “I said what I was supposed to say, ‘I don’t know. Let’s ask your oncologist in the morning.’ I left her room, hoping that death wouldn’t reach her before her longtime oncologist could explain that there would be no more treatment. She died the next morning, before she could have that conversation.” (*Stat News*, 6/13, <https://www.statnews.com/2016/06/13/medical-residents-end-of-life/>)

**\* “Confronting a ‘Conspiracy of Silence’ With End-of-Life Care in Ethnic**

**Communities”** is an article in *Voice of OC (Orange County, CA)*. Patients and physicians alike, says the article, may dread end-of-life conversations – perhaps especially when crossing ethnic or cultural boundaries. The article provides data about various ethnic groups and their engagement in end-of-life discussion and planning. Vincent Nguyen, palliative care director at Hoag Hospital, raises several questions. **How do we break through ‘the conspiracy of silence’ that impedes these important conversations?** “How do we cross this cultural bridge where death is not talked about? People say, gosh, do you want it [death] to come? You cursed this person to die sooner,” said Nguyen. “That taboo needs to be gently approached...so people talk about what’s important, before a life-or-death situation comes.” (*Voice of OC*, 6/15, [voiceofoc.org/2016/06/confronting-a-conspiracy-of-silence-with-end-of-life-care-in-ethnic-communities/](http://voiceofoc.org/2016/06/confronting-a-conspiracy-of-silence-with-end-of-life-care-in-ethnic-communities/))

\* **Patient wishes aren’t always easy to see in electronic health records, and end-of-life preferences frequently aren’t being carried out, writes Christopher Snowbeck for the *Star Tribune*.** “Less than one-third of ER doctors feel very confident they could locate information in the electronic record, according to a survey published by medical researchers in May. It also found that most physicians surveyed said advance care planning documents are important for patient care.” (*Star Tribune*, 6/11, [www.startribune.com/patient-wishes-tough-to-see-in-health-records/382583641/Document7](http://www.startribune.com/patient-wishes-tough-to-see-in-health-records/382583641/Document7))

\* **“Awake at the Bedside: Contemplative Teachings on Palliative and End-of-Life Care”** is a book “about the intimacy and fierce compassion that is available in the moments everyone will face – when we become sick and move into our dying process.” Read the full interview with author Koshin Paley-Ellison at eHospice.com (*eHospice*, 6/9, [www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/19635/language/en-GB/View.aspxDocument7](http://www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/19635/language/en-GB/View.aspxDocument7))

\* ***Washington Post* reporter Travis Andrews shares the poignant story of parents who allow their 5-year-old daughter to talk with them about the decision to forgo painful treatment.** Julianna Snow was forced to consider and reckon with her own mortality at that young age. The article shares about conversations that Julianna had with her parents, about her suffering with medical treatments, and about the parents’ decision to allow her to be engaged in making the decisions. **“Heaven is good, but I don’t like dying,” Julianna said.** (*Washington Post*, 6/15, <https://www.washingtonpost.com/news/morning-mix/wp/2016/06/15/i-dont-like-dying-5-year-old-who-chose-to-forgo-treatment-sparking-debate-has-died/TraviWa>)

\* **The American Medical Association is receiving praise for its choice to consider a resolution that would “lead to a study of aid in dying as an option for terminally ill adults.”** The assisted-suicide advocacy group Compassion & Choices thanked the AMA, “for responding to physician and public sentiment to reexamine its position on medical aid in dying.” (*Yahoo! News*, 6/14, [www.yahoo.com/news/ama-praised-action-leading-study-aid-dying-191500905.html](http://www.yahoo.com/news/ama-praised-action-leading-study-aid-dying-191500905.html))

## PALLIATIVE CARE NOTES

\* **Delegates to the American Medical Association’s annual meeting urged the AMA to drop pain as a “fifth vital sign”, suggesting that such measurements negatively impact reimbursement.** “Just as we now know earth not flat, we know that pain is not a vital sign. Let’s remove that from the lexicon,” said James Milam, MD, of Vernon Hills, Ill. “Whether the Joint Commission says they didn’t ever say pain is a vital sign, or whatever it’s going to take to no longer include pain as a vital sign ... Let’s just get rid of the whole concept and try to move on.” (*Medpage Today*, 6/13, [www.medpagetoday.com/MeetingCoverage/AMA/58486Document7](http://www.medpagetoday.com/MeetingCoverage/AMA/58486Document7))

\* **A study published in *The Journal of Palliative Medicine* provides recommendations for death pronouncements, based on a survey of bereaved family members.** “More than 90% of family members recommended that physicians act calmly, have a suitable appearance for the situation, introduce themselves to family members, explain the cause of death explicitly, and conduct a check using a light and stethoscope for death pronouncement.” (*JPM*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0333](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0333))

\* **A \$22 million palliative care facility is planned in New Hampshire.** The Jack Byrne Center for Palliative and Hospice Care at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire “will provide integrated care for patients with life-limiting illness and complex medical needs and to strengthen palliative and hospice care region-wide.” (*NHBR*, 6/15, [www.nhbr.com/June-24-2016/22-million-palliative-care-facility-to-be-built-at-Dartmouth-Hitchcock/](http://www.nhbr.com/June-24-2016/22-million-palliative-care-facility-to-be-built-at-Dartmouth-Hitchcock/))

\* **A conversation game effectively engaged groups in discussions about death and dying, according to a study published in *The Journal of Palliative Medicine*.** “This study established that healthy volunteers enjoyed engaging in a two-hour discussion about [end-of-life] issues when framed as a game. The game experience was a positive, satisfying, and enjoyable activity for participants. Further studies are needed to determine if health games can promote effective [advance care planning].” (*JPM*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0390](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0390))

## OTHER NOTES

\* **Jay Evensen, senior editorial columnist at *Deseret News*, thinks that states should resist physician-assisted suicide. Why? Because, he says, life is sacred.** “If we step away from an ethic that holds life sacred and prohibits humans from ending it for things other than capital crimes, we begin the dangerous task of assigning values to different manifestations of life.” (*Deseret News*, 6/16, [www.deseretnews.com/article/865656256/Why-states-should-resist-assisted-suicide.html](http://www.deseretnews.com/article/865656256/Why-states-should-resist-assisted-suicide.html))

\* **The American Medical Association is calling gun violence “a public health crisis.”**

**The physicians' organization is making lobbying for gun control a top priority.**

“With approximately 30,000 men, women and children dying each year at the barrel of a gun in elementary schools, movie theaters, workplaces, houses of worship and on live television, the United States faces a public health crisis of gun violence, AMA president Dr. Steven Stack said in a statement.” (*US News*, 6/14, [www.usnews.com/news/articles/2016-06-14/ama-calls-gun-violence-a-public-health-crisis](http://www.usnews.com/news/articles/2016-06-14/ama-calls-gun-violence-a-public-health-crisis))

**\* Making art can lead to stress reduction, no matter what your skill level may be.**

Researchers at Drexel's College of Nursing and Health Professions have published research in *Art Therapy*, saying, “**75 percent of the participants' cortisol levels lowered during their 45 minutes of making art.** And while there was some variation in how much cortisol levels lowered, there was no correlation between past art experiences and lower levels.” (*Science Daily*, 6/15, [www.sciencedaily.com/releases/2016/06/160615134946.htm](http://www.sciencedaily.com/releases/2016/06/160615134946.htm))

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