
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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WANT END OF LIFE CONVERSATIONS? BILL FOR THEM

Two recent articles highlight the headway being made in the US Congress to empower physicians to have deliberate end-of-life conversations with their patients. While doctors are routinely compensated for performing procedures and consulting on other matters, there is often little incentive for clinicians to set aside time in their practice for discussing end-of-life choices. Yet, there may be a bipartisan consensus emerging that could change all that. **In an article for *Bloomberg.com* and in a post on *The New York Times New Old Age* blog, Ford Vox and Paula Span explain how action by legislators could make end-of-life conversations an integral part of what physicians are paid to do.**

Writing for *Bloomberg.com*, Ford Vox, MD, argues that medical doctors should bill for consulting with patients on end-of-life decisions. Sharing from his own personal experience as a hospital intern, Vox paints a picture of a medical system where few patients are even aware of the basic terms and concepts of end-of-life care - hospice, palliative care, power of attorney, advance directives, and DNR orders. **Far from being empowered to take control of their own care at the end-of-life, most Americans - including many patients who have been undergoing treatment for serious, chronic illnesses - do not have a grip on what their options are.**

The Care Planning Act, drafted by Senator Mark Warner (D-Virginia) and co-sponsored by Senator Johnny Isakson (R-Georgia), “identifies the need for a detailed, structured discussion between the patient and their health-care providers, family, friends and other support such as faith leaders.” **The proposed legislation would create a billing code for “planning services,” allowing doctors to charge for lengthy and challenging end-of-life conversations with patients and their support networks.** It would also require that the meeting result in a documented end-of-life plan.

This legislation is significant for end-of-life planning in the United States, because patient care options are generally determined by what gets paid for. In our present system, with little or no financial support for end-of-life planning, these physician conversations are much less likely to happen.

Warner and Isakson are not promoting the Care Planning Act as a cost-saving measure, due in large part to the potential political cost of being labeled as promoters of “death panels.” Nevertheless, Vox points out, “This bill would indeed contain costs while providing the care that patients want.” Vox cites a 2009 study of advanced cancer patients that found that “those who participated in end-of-life discussions with their physicians spent 36 percent less on

medical care in their final week and experienced a better death than patients who didn't get the benefit of such counsel."

In a related article, published in *The New York Times*, Paula Span details the efforts of US Representative Earl Blumenauer (D-Oregon) to advance legislation that "would provide for Medicare and Medicaid coverage of voluntary discussion of advance care planning." Though his initial effort was derailed by fierce opposition from those who labeled such end-of-life discussions "death panels," Blumenauer, along with several co-sponsors from both major parties, is again introducing the Personal Your Care Act of 2013.

"This time, Mr. Blumenauer has vowed to meet with all 435 members of the House to explain his idea and seek their support, and has passed the 100-member mark." Nevertheless, he doubts that the bill could pass this year. He hopes that the time may be right by 2014 or 2015.

The time certainly wasn't right three years ago, when Blumenauer made his first attempt to make advance care planning a sponsored part of the Medicare/Medicaid system. At that time, "the political climate was so toxic" that it was suddenly removed from the final version of the Affordable Care Act. "It was the height of the frenzy, and the administration got cold feet and yanked it," said Mr. Blumenauer.

Today, the political conversation around issues of death and dying seems to be somewhat less frenzied. With a bipartisan coalition emerging in both chambers of Congress, the question of equal access to advance care planning is becoming increasingly decoupled from other disagreements in the health care field. **In fact, some of the co-sponsors of the House bill have vowed to overturn the Affordable Care Act. "For this, it doesn't matter where someone stands on Obamacare," explains Blumenauer.** (*Bloomberg.com*, 8/26, www.bloomberg.com/news/2013-08-26/doctors-should-bill-for-life-or-death-decisions.html?goback=%2Egmp_917937%2Egde_917937_member_269598542#%21; *The New York Times*, 8/28, newoldage.blogs.nytimes.com/2013/08/28/death-panels-this-time-maybe-not-so-scary/?_r=1)

NEW HAMPSHIRE PUBLIC RADIO AIRS SERIES ON ADVANCE CARE PLANNING

***New Hampshire Public Radio* featured a three-part series focused on advance care directives.** In order to help listeners most fully understand the issues, the series includes an online glossary of terms related to end-of-life care. **In part one, Health Reporter Todd Bookman offers an update on New Hampshire's legislative efforts to "streamline and simplify the documents."** Clarity and simplicity have been the goals of recent revisions. Advance directives can be difficult to create and difficult to follow. Only about 25% of New Hampshire adults have completed them.

Part 2 of the series includes examination of efforts to increase these numbers and to make these important conversations a bit easier. Bookman says, "End-of-life remains simply a taboo subject in many households." He shares how Dartmouth Hitchcock utilizes volunteers to

help persons develop advance care plans. They also have a team “that works to ensure a patient’s wishes are being followed.” Maplewood Nursing Home is also cited as an example of a facility where “staff do more than just hand out a pamphlet.” The facility works to create opportunities for advance care planning and has nearly 100% participation. Another group working on advance care planning is the TLC Nursing Associates, who are part of the Conversation Project.

In part three of the series, Bookman examines the difficult position that many families and public officials are finding themselves in when the court system is forced to arbitrate end-of-life decisions for incapacitated individuals. In some cases, families of seriously ill individuals who are no longer able to communicate their wishes must navigate a legal process that no one, court officials included, finds ideal.

The radio segment uses the example of Dr. Tim Lahey, a physician who “prefers to spend his days in hospitals and clinics, not courtrooms.” Yet, earlier this year, he found himself before a judge, discussing the case of a patient who had suffered a devastating head injury. The young man had never had a conversation with his family about what his wishes if he should ever be in this kind of situation.

Without any form of legal documentation regarding his end-of-life wishes, the family chose to petition court officials to determine whether they could remove life-sustaining treatment. What ensued was an emotional hearing, one in which Dr. Lahey was asked to testify. **It was an ordeal that could have been avoided entirely, had the patient had an advance directive to guide family members and medical staff.**

For their part, court officials would prefer not to be involved. “I shouldn’t make that decision,” says David King, a 23-year veteran New Hampshire judge. “The decision should be made by the individual when they have capacity to make the decision. Not by a judge who never met the person, in some cases is trying to determine the credibility of siblings... some say dad would want to be kept on life support, others say he wouldn’t. Dad is the one who should make that decision.”

Generally, these questions don’t get answered in court. As long as families are in agreement about how things should play out, there is generally no legal issue. Yet, when there are disagreements, family members are often blindsided. Relatives are often surprised to learn that they don’t get automatic authority to make decisions for their incapacitated loved one. “That’s because New Hampshire is one of only a handful of states without a default surrogate consent statute.” **The absence of an automatic hierarchy of who gets to make care decisions for a patient unable to speak for themselves can lend itself to confusion and conflict.**

For this reason, some New Hampshire lawmakers are collaborating to draft legislation that would codify who gets to make what decisions. Nevertheless, it’s a tricky to resolve who should get a place in front of the line. “If you do a default... what is it, the oldest child? Well, you know families are more complex than a series of hierarchy,” explains State Senator Peggy Gilmour (D-District 12). A new law would also need to take care not to take away the rights and wishes of disabled individuals and those with dementia.

Throughout the series, Bookman includes stories of patients and caregivers, and works to create greater awareness of the need for, and value of, advance care planning. The website includes recordings of each part of the series, a video on advance care planning from the Foundation for Healthy Communities, and the glossary on end-of-life terms. (*New Hampshire Public Radio*, 8/26, <http://nhpr.org/post/plain-language-glossary-terms-end-life-planning>; 8/26, <http://nhpr.org/post/planning-end-new-hampshires-advance-directive-gets-update>; 8/27, <http://nhpr.org/post/planning-end-talking-about-death-often-stands-way>; 8/28, nhpr.org/post/planning-end-when-courts-have-make-medical-decisions; *Foundation for Healthy Communities*, <http://www.healthynh.com/fhc-initiatives/advance-directives-healthcare-decision-coalition.html>)

HOSPICE NOTES

* **Dr. David Casarett, director of hospice care at the Perelman School of Medicine, was interviewed on National Public Radio's *Weekend Edition*.** Dr. Casarett shared about his work as a hospice doctor, helping families to navigate end-of-life care. (*National Public Radio*, 8/25, www.npr.org/2013/08/25/215218100/hospice-doctor-helps-families-navigate-the-end-of-life)

* **Galen Miller, Executive Vice President of the National Hospice and Palliative Care organization, died on Thursday, August 22, 2013, at the end of several weeks of struggle with a severe bacterial infection.** "Galen Miller was a truly dedicated man, a friend to many and will be missed by all." (*National Hospice Foundation*, www.nationalhospicefoundation.org/i4a/pages/index.cfm?pageID=751; *NHPCO*, 8/23, www.nhpco.org/press-room/press-releases/don-schumacher-shares-sad-news-nhpco)

* **A hospice nurse has been arrested for stealing medication from a deceased patient.** The Louisiana man was charged with theft of a control dangerous substance II. (*FOX 8 Live*, 8/28, www.fox8live.com/story/23278761/hospice-nurse-arrested-for-stealing-medication-from-deceased-patient)

END-OF-LIFE NOTES

* **When experiencing the sudden or tragic death of a patient, professional caregivers often experience prolonged grief, or even post-traumatic stress.** A recently released study reveals that caregivers can suffer major trauma from the loss of patients. (*GoodTherapy*, 7/2, www.goodtherapy.org/blog/ptsd-and-prolonged-grief-in-caregivers-0702131)

* **A new film, *Unfinished Song*, tells the story of finding joy at the end of life.** The film is a small scale and deeply personal look at one couple's experience of the end of life. (*The Huffington Post*, 7/9, www.huffingtonpost.com/sophia-stuart/an-unfinishedsong-which-_b_3564706.html)

* **Demographic changes may mean a shortage of caregivers for Baby Boomers at the end of life.** An AARP report looks at the coming challenge for Boomer elders, as the number of potential caregivers for every person over 80 years old goes declines from seven to one in 2010, four to one in 2030, and three to one in 2050. (*AARP*, 8/2013, www.aarp.org/home-

family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html)

PALLIATIVE CARE NOTES

* **“Clinicians who care for critically ill children reported that they often used do-not-resuscitate (DNR) orders as a surrogate for changing the course of treatment toward palliative care,” according to researchers at Boston Children’s hospital.** The study revealed that 33.1% of those surveyed consider DNR orders to be “the threshold for limiting other treatments not pertaining to resuscitation.” (*MedPageToday*, 8/26, www.medpagetoday.com/CriticalCare/GeneralCriticalCare/41201; *Medscape*, 8/26, www.medscape.com/viewarticle/810057; *JAMA Pediatrics*, 8/26, archpedi.jamanetwork.com/article.aspx?articleid=1730533)

* **An article in the *Daily Citizen* highlights the benefits of palliative care in improving the end-of-life experience for terminally ill imprisoned patients.** Though friends and family are often the most important support group for dying individuals, inmates “are faced with a far bleaker situation where family and friends are either unable or unwilling to care for them in their final days. That’s where the palliative care program comes in.” (*The Daily Citizen*, 8/29, www.wiscnews.com/bdc/news/local/article_dffdf106-9cf9-5555-b94e-eafe72395c07.html)

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