
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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“VOICING MY CHOICES” HELPS YOUNGER PATIENTS

Two years ago, *Aging with Dignity* published, “*Voicing My Choices*,” a guide for very ill young patients that allows them to be engaged in their own medical decisions. “While there are end-of-life workbooks for young children and their parents,” says the article, “as well as planning guides for older adults, this is the first guide crafted for—and largely by—adolescent and young adult patients.” *The New York Times* describes the guide, and shares the stories of several teenagers and young adults who have used it. Journalist Jan Hoffman examines what the guide has meant for the patients, their families, and their healthcare providers.

“Adolescents are competent enough to discuss their end-of-life preferences, said Pamela S. Hinds, a contributor on pediatrics” for the 2014 NIH *Dying in America* report. While these conversations provide “a huge opportunity,” the move to bring these conversations out in the open has “met some resistance.” Physicians are not trained for these conversations, and some families and younger patients are not interested.

“Until recently, most clinical teams believed that adolescents would not understand the implications of end-of-life planning and that they might be psychologically harmed by such talk.” “Research,” however, “shows that avoiding these talks exacerbates the teenage patient’s fear and sense of isolation.” Dr. Chris Feudtner, a pediatric palliative care physician and ethicist at the Children’s Hospital of Philadelphia, says, “Teenage patients can guide, even lead, their medical care.” And, doing so, he notes, helps them feel less alone and more connected with others.

The *Times* article gives detailed accounts of patients who have been helped by completing “*Voicing My Choices*.” Ashleigh McHale’s mother Ronda said that, at the time of Ashleigh’s death, “I don’t know what I would have done if I’d had to make these decisions during our extreme grief. But she did it all for me. Even though she got to where she couldn’t speak, Ashleigh had her say.”

Karly Koch, who is featured in an online video at the site below, completed her copy of the document awhile back. She says, “Now, looking at it, I think I’d like to add some things.” The article, video, pictures and more details are online. In addition to the link below, a version of the story was also featured on page 1A of *The New York Times* on 3/29/15. (*New York Times*, 3/28, <http://well.blogs.nytimes.com/2015/03/28/teen-advance-directive-end-of-life-care/>)

GEORGE WASHINGTON UNIVERSITY EXPERT SAYS HEALTH INNOVATION MUST INCLUDE BETTER DEATHS

What does it mean to experience a “good death”? Dale Lupu, nursing researcher at George Washington University says that **answering this question, and then making it happen for patients, is critical for the development of a fully mature health care system.** She is convinced that too many Americans don't receive the quality care that they deserve. Too often, persons experience unhelpful and unwanted medical interventions that prolong suffering and often result in greatly reduced quality of life.

So how can our medical system ensure that more patients have the kind of death that they desire? It starts by asking the right questions. “We've spent a lot of money on people for what they don't even want because we didn't ask about their preference or values,” says Lupu, who is an associate research professor at GWU's nursing school. She is one of many hospice and palliative care experts who are working to simplify how this question is answered, boiling it down to a top-10 list of recommendations for how end-of-life care can be improved.

The list of recommendations was created with the help of the American Academy of Hospice and Palliative Care Medicine, and the Hospice and Palliative Nurses Association. Recently published in *The Journal of Pain and Symptom Management*, **the committee recommends that palliative care and hospice workers “measure how often patients are screened for pain, shortness of breath, nausea and constipation during their admission at a health care facility and how often they receive treatment for those symptoms within 24 hours.”** The report also recommends that organizations measure whether they're having structured end-of-life conversations with those whom they serve. **“The critical measure is, ‘have their wishes been followed?’”** (*Washington Business Journal*, 3/20, www.bizjournals.com/washington/blog/2015/03/george-washington-university-expert-innovation-in.html?page=all)

DYING IS A “VEXING PROBLEM” FOR PHYSICIANS

Writing for KevinMD, radiologist Saurabh Jha explores the present-day struggles of physicians who look to extend life while avoiding an overmedicalized end that few desire for themselves or others. Learning from the writings of Dr. Atul Gawande, Dr. Jha points out that our response to death and dying is deeply cultural. “It would be easy to blame doctors, their incentives, and egotism” for the poor quality of life at the end of life that many experience. Jha is learning from Gawande that the problem goes much deeper than attitudes on the part of physicians.

We in the United States have a particular way of engaging with the end of life, one that is sometimes incompatible with the need for acceptance of limitations, and ultimately loss of function and life. “In our lexicon, life is a constant war against the grim reaper. We say inactivity kills; screening saves lives... by giving cancer moral agency – we wage war on cancer – we imply that death is an anomaly that must be fought.” This is a war that we fight in the hospitals and hospices, in homes and emergency rooms, says Jha.

“Dying is a vexing problem for the medical profession.” **When doctors and other medical staff combine the “can do” optimism so prevalent in American culture with a “won't give up” tenacity, the results can be unfortunate for patients** who might be better served by a focus on greatest health and well-being at the end of life, rather than strictly seeking longevity and a sometimes quixotic fight to avoid death.

If we're ready to embrace a cultural shift, there are ways that physicians can make death less medical and more personal. But they can't do this by themselves. “Doctors alone can't beat culture. Modern society obsesses about not dying. When physician Ezekiel Emanuel wrote that he wouldn't seek medical care after 75, some readers, including physicians, were offended. “Some interpreted his writing that an unproductive life is a life not worth saving.”

Such “paranoia” must be overcome, says Jha. “Where demagogues rush, doctors fear to tread.” Growth towards a medical system that has a healthier, more realistic view of death must be a matter of cultural renewal, not just advances in medical know-how. (*KevinMD*, 3/21, www.kevinmd.com/blog/2015/03/the-vexing-problem-of-dying-for-the-medical-profession.html)

MOTHER OF FOUR IS AN INSPIRATION TO MANY IN HER LIVING WITH AND DYING FROM CANCER

Kara Tippetts was a woman who lived her last days out loud. A 38-year-old mother of four, she and her family shared Tippetts' experience of the end of life, including hospice care, as she struggled with terminal cancer. Through her blog, *Mundane Faithfulness*, Tippetts and her family became an inspiration for many who are looking for a way to face the end of life with love, dignity, and courage.

Ann Voskamp, also a blogger, writes about her personal relationship with Kara Tippetts. “Kara taught us all... how to have an imagination for the grace that will meet us, how to unwrap the gift of wonder over the infinite, all this that has no finite end – how to travel well, right through to the end... to the end that ushers us into the beginning forever.” One of the great pieces of insight that Tippetts gave to Voskamp is this: “When you come to the end of yourself, that's when something else can begin.” Another time Tippetts told her, “We must always have an imagination for the grace that will meet us.”

“Kara recovered for us the lost art of dying well,” she says. “Because she'd recovered the art of living well – she had an imagination to trust that the love and beauty she had found in life would be the love and beauty that would meet her in the end.”

* *Christianity Today* also featured an article about Tippetts. “Far from pulling back from this world and those she loved in the face of death,” says the article, “she pressed into love more fully.” (*A Holy Experience*, 3/2015, www.aholyexperience.com/2015/03/how-to-recover-the-lost-art-of-dying-well-what-kara-tippetts-taught-us/; *Mundane Faithfulness*, www.mundanefaithfulness.com; *Christianity Today*, 3/22, www.christianitytoday.com/women/2015/march/remembering-kara-tippetts-and-her-inspiring-mundane-faithfu.html?paging=off)

HOSPICE NOTES

* **Medicare fraud – including by hospice organizations - is all too common, says Patrick Miles Jr., the US Attorney for the Western District of Michigan.** “There are a lot of bad apples, practitioners who are billing for unnecessary services, perhaps even services that aren’t even performed.” (*ABC10*, 3/25, abc10up.com/u-s-district-attorney-talks-medicare-fraud/)

* **The Mississippi legislature has passed a bill that would extend the moratorium on new hospice licenses in that state.** The bill is headed to the Governor's desk for signature. (*The Clarion-Ledger*, 3/22)

* **The State of New York is considering legislation that would extend up to 12 weeks of paid family leave to workers.** This leave would have an impact on hospice care, as working family members could be freed up to provide care for dying loved ones. (*Register-Star*, 3/20, www.registerstar.com/news/article_d5c7d8c8-cea7-11e4-9249-6f9c73ff398b.html)

END-OF-LIFE NOTES

* **Discontinuing the use of statins in the final stages of life does not seem to cause any problems, according to researchers Anees Daud, MD, and James Jiang.** (*2 Minute Medicine*, 3/25, <http://www.2minutemedicine.com/discontinuing-statins-near-end-of-life-not-associated-with-adverse-outcomes/>)

* **Atul Gawande and Charles Munger explain why more health care isn't necessarily better.** “American health care is obsessed with more.” (*Forbes*, 3/19, www.forbes.com/sites/robertpearl/2015/03/19/atul-gawande-charles-munger/)

* **“Everyone You Love Will Die,” is the name of a new children's book by Dr. Daniel Crosby, illustrated by Naomi Win.** Kay Campbell writes about the book saying, “So: Hurrah for Death? Well maybe not that far, but a gut-deep, new awareness of the fact of Death does help me remember, as Daniel's book says, ‘Yes, everyone you love will die / but you're here today and so am I.’” (*Alabama*, 3/19, www.al.com/opinion/index.ssf/2015/03/fear_not_death.html)

* **The Alzheimer’s Association says that there are benefits in physicians sharing their diagnosis of Alzheimer’s with patients, even though they are not legally obliged to do so.** When given an honest diagnosis, patients are allowed to “maximize their quality of life.” In examining Medicare records, a survey found that less than half of Alzheimer’s patients “received the tough news.” Now, the Alzheimer’s Association will work to change this and “has the resources to help.” (*Associations Now*, http://associationsnow.com/2015/03/doctors-dont-deliver-alzheimers-diagnosis-half-patients-report-says/?utm_source=AN%2BDaily%2BNews&utm_medium=email&utm_campaign=20150327%2BFriday)

* **UMASSmedNOW writes about the UMass Medical School report calling for “awareness of end-of-life care options.”** The article summarizes the “MA Panel on End of Life Report – Looking Forward: 2014 and Beyond,” and reviews the recommendations. (*UMASSmedNow*,

3/26, www.umassmed.edu/news/news-archives/2015/03/umass-medical-school-report-cites-need-for-awareness-of-end-of-life-care-options/;

* **Physician-assisted suicide gained an important endorsement when US Senator Dianne Feinstein (D-California) announced her support for California's End of Life Option Act.** The bill, modeled after Oregon's Death with Dignity law, would allow terminally ill patients to end their lives with physician-prescribed medication. (*Times-Herald*, 3/17, www.timesheraldonline.com/20150317/feinstein-announces-support-for-end-of-life-option-act; *David Vanguard*, 3/20, www.davisvanguard.org/2015/03/senator-feinstein-endorses-california-end-of-life-option-act/)

* **“Right to die” groups are quietly offering help to those who want to die in California, where physician-assisted suicide is actively under debate.** As California lawmakers prepare to debate a “right to die” bill, volunteers are already providing illegal aid to those who want to die on their own terms, regardless of state law. (*San Jose Mercury News*, 3/25, www.mercurynews.com/science/ci_27778797/right-die-group-offers-aid-secret-california-legislation)

PALLIATIVE CARE NOTES

* **How does palliative care knowledge of nursing home staff impact the care that residents receive?** A recently published study in *The Journal of Palliative Medicine* finds that policies promoting palliative care knowledge among staff members have the potential to improve resident care and reduce hospital and ER admissions. (*The Journal of Palliative Medicine*, online 3/16, online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393#utm_source=FastTrack&utm_medium=email&utm_campaign=jpm; *Medical Xpress*, 3/20, medicalxpress.com/news/2015-03-futile-end-of-life-palliative-knowledge-greater.html; *NY Mag*, 3/24, nymag.com/scienceofus/2015/03/many-nursing-homes-fall-short-at-palliative-care.html)

* **A recent survey has found that 88% of patients believe that the DEA's decision to crack down on hydrocodone prescriptions “denies chronic pain patients their right to adequate pain treatment, and 72% say it is harmful to pain patients.”** “Prescription drug abuse is a massive problem and we have to deal with it, but I’d also to see more consideration given to the person in pain in the dialogue going forward,” says Dr. Steve Passik, chief spokesperson for the survey. (*National Pain Report*, 3/24, nationalpainreport.com/are-pain-patients-being-heard-on-impact-of-dea-ruling-8825857.html)

OTHER NOTES

* **“In a rare moment of bipartisanship bringing House Speaker John Boehner and House Minority Leader Nancy Pelosi together, the House passed the so called “doc fix.”** The House passed it overwhelmingly, 392-37.” The bill permanently fixes Medicare reimbursements for doctors, and it includes a two-year extension for a popular children's health insurance and funding for community health centers. (*CNN*, 3/26, www.cnn.com/2015/03/26/politics/doc-fix-house-medicare/)

*** Pennsylvania is considering legalization of medical marijuana.** “A joint public hearing on the legalization of the medical use of cannabis in Pennsylvania was held Tuesday at Pennsylvania Hospital, one of Penn Medicine’s medical facilities. The first of three hearings related to the use of medical marijuana, the session focused on the potential medical implications of legalizing medical marijuana, as well as the science behind the use of marijuana in treating various maladies.” (*The Daily Pennsylvanian*, 3/25, www.thedp.com/article/2015/03/medical-marijuana-first-public-hearing)

*** Physician James C. Salwitz reflects on “our quandary as we expand the use of electronic decision-making tools, artificial intelligence if you will, into the daily care of patients.”** Admitting that technology has an important place in healthcare, Salwitz asks, however, **“Where does machine stop and man begin?”** (*KevinMD*, 3/26, <http://www.kevinmd.com/blog/2015/03/where-does-the-doctor-stop-and-computer-begin.html>)

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