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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

**Volume 20, Number 9 March 8, 2016**  
**A Service of State Hospice Organizations**

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## **RESEARCHERS IDENTIFY ISSUES AT END OF LIFE**

**Pain management, depression, and confusion remain problematic during the last year of life.** One study, published in *Annals of Internal Medicine* in 2015, examined the experiences of patients over age 51 during their last year of life. “Between 1998 and 2010, reports of pain increased 11.9 percent, reports of depression rose 26.6 percent and periodic confusion increased 31.3 percent.”

**Researchers, looking to explain these changes, have pointed to several factors.** Hospice stays are shorter, while use of intensive care has increased. Dr. Karl Lorenz, an author of the 2015 study, explains, “Although we don’t know for certain the cause of worsening outcomes, we do know that more care is not always better care for end-of-life patients. While there has been growth in the number of services for the very ill, patients are not getting the right services at the right time.”

**Doctors, and other medical professionals, must become more familiar with and comfortable in talking with patients about palliative care options in order to address troubling symptoms at the end of life.** “Physicians rightfully have a culture of healing and don’t always know the best way to shepherd the dying process in a healthy and satisfying way for patients and their families,” says Adam Singer, researcher and Adjunct Policy Analyst at the RAND Corporation. The article also says that doctors need to ask their patients about their pain so that they do not risk it not get mentioned and addressed. (*MD News*, 03/01, [www.mdnews.com/news/2016\\_03/study-raises-questions-about-protocols-for-end-of-life-care.aspx](http://www.mdnews.com/news/2016_03/study-raises-questions-about-protocols-for-end-of-life-care.aspx))

## **PHYSICIAN AUTHORS BOOK ABOUT END-OF-LIFE CONVERSATIONS AND QUALITY OF CARE**

**Physician Margaret Overton has published a book titled “Hope for a Cool Pillow.”** The book grew from Overton’s experiences in caring for her dying patients. Unlike most Americans, her father spoke openly and frequently about his end-of-life wishes. Overton examines her unusual familial experience with her time working as a physician, and she reflects on experiences of seeing patients who had not had those important conversations with their loved ones.

Her parents made their wishes clear. Even so, she says, in caring for her parents she often

thought, “Something is wrong with this picture. I've spent a lifetime in medicine — why can't dying be better than this?” **Her hope is that her book will lead more people to have conversations with family members about their wishes for end-of-life care.**

**Overton argues that patients and doctors need to have more conversations about outcomes, and to discuss whether treatment will actually improve quality of life for a patient with a terminal prognosis.** “The researchers said they know from experience — as all of us do in eldercare — that doctors often operate to fix something that will not save a dying patient, and in doing so avoid the difficult conversations with patients and caregivers about their prognosis and what they want,” she writes. (*Chicago Tribune*, 03/03, [www.chicagotribune.com/lifestyles/books/ct-prj-margaret-overton-hope-for-a-cool-pillow-20160303-story.html](http://www.chicagotribune.com/lifestyles/books/ct-prj-margaret-overton-hope-for-a-cool-pillow-20160303-story.html))

## END-OF-LIFE NOTES

**\* Research published in the *American Journal of Nursing* has found that end-of-life care for inmates in American prisons is not uniform or standardized.** While hospice care is becoming more common as the prison population ages, determination of who provides care and what kind of care is given at the end of life varies widely between prisons. The attitudes of prison staff towards prisoners receiving hospice care vary greatly. While some view hospice negatively, those those who had had more exposure to hospice care felt more positive. The number of designated hospice beds also varies significantly. Researchers say, “More research is needed to better understand how healthcare providers’ approach EOL care and to determine how patients, prison administrators and external hospice providers view the quality of EOL care delivered by healthcare professionals in prisons.” (*Psych Central*, 02/28, [psychcentral.com/news/2016/02/28/how-do-prisons-handle-end-of-life-care-for-inmates/99727.html](http://psychcentral.com/news/2016/02/28/how-do-prisons-handle-end-of-life-care-for-inmates/99727.html))

**\* The Pew Charitable Trusts and the Coalition to Transform Advanced Care hosted a Congressional briefing about the Care Planning Act of 2015.** The bill would “ earmark funds to create a clear structure for end-of-life care, including the creation of metrics to measure the effectiveness of such care.” Key components of the bill include: “\$5 million for the Secretary of Health & Human Services to assess existing quality measures and create new ones; \$15 million for grants to raise public awareness for advance care planning and advance illness care; Establishment of a Medicare benefit to cover team-based planning processes; A 5-year pilot project in which patients struggling with two or more disease-related activities can opt into Advanced Illness Coordination Services (AICS) -- a benefit that includes formal and informal supports, medication review and in-home support services;” and, “Improving the portability of advanced (sic) directives.” (*Medpage Today*, 03/01, [www.medpagetoday.com/PublicHealthPolicy/PublicHealth/56477](http://www.medpagetoday.com/PublicHealthPolicy/PublicHealth/56477))

**\* Doctors desire more training in counseling patients about end-of-life decisions, a practice that will become more common now that Medicare is covering such conversations.** A Kaiser Family Foundation survey, completed in 2015, revealed that 89% of physicians who were surveyed said they wanted to engage patients in end-of-life care discussions, while only 17% of them actually did so. Another survey found that 56% of physicians would welcome additional

training in end-of-life counseling. (*Hospital and Health Networks*, 03/01, [www.hhnmag.com/articles/6976-physicians-want-to-know-more-about-end-of-life-counseling](http://www.hhnmag.com/articles/6976-physicians-want-to-know-more-about-end-of-life-counseling))

\* **Karen M. Wyatt argues in *Huffington Post* that those advocating for better care at the end of life can learn important lessons from the natural birth movement.** She says, “Like childbirth in the 1930's, dying in current times is viewed as a ‘pathological process’ that requires medical intervention and control.” To change this view, she says, advocates will need, like the natural birth movement, to have a unified message, based on the importance of education, and to create a coalition around the issues. (*Huffington Post*, 03/02, [www.huffingtonpost.com/karen-m-wyatt-md/what-the-end-of-life-movement-can-learn-from-the-natural-childbirth-movement\\_b\\_9352650.html](http://www.huffingtonpost.com/karen-m-wyatt-md/what-the-end-of-life-movement-can-learn-from-the-natural-childbirth-movement_b_9352650.html))

\* **Brandy Schillace writes in *Long Term Living* an article entitled “How did you die?”** “Death ought to be near us, even dear to us. But we are not familiar. We do not embrace death. We cannot even talk about it when it matters most.” She thinks that people should become more comfortable talking to others about death and about making decisions around it. (*Long Term Living*, 03/01, [www.ltlmagazine.com/article/how-did-you-die](http://www.ltlmagazine.com/article/how-did-you-die))

\* **ReachMD has posted five videos based on the Institute of Medicine report *Dying in America*.** The videos explore “the various aspects of end of life care from the perspective of experts in the field.” They also cover “the importance of palliative care, interdisciplinary teamwork, advance care planning, policies and payment systems, and more.” The videos are available, at no charge, at the link below and (*ReachMD*, 03/2016, [reachmd.com/programs/dying-in-america-series/?&utm\\_source=Radio\\_Promo&utm\\_medium=Radio&utm\\_campaign=Dying\\_in\\_America\\_Radio\\_Promo\\_2016](http://reachmd.com/programs/dying-in-america-series/?&utm_source=Radio_Promo&utm_medium=Radio&utm_campaign=Dying_in_America_Radio_Promo_2016); *PRWeb*, 03/05, [www.prweb.com/releases/2016/03/prweb13249194.htm](http://www.prweb.com/releases/2016/03/prweb13249194.htm))

\* **Karla Erikson, writing in *US News and World Report*, contemplates the growing cost of end-of-life care and medical interventions.** She argues, “While this level of spending is unsustainable, there are greater costs – constantly fighting against death's inevitability is also deeply unsatisfying.” She is also concerned that death-delaying treatment is often pursued at the expense of easing discomfort and helping the dying person through non-medical means. Erikson stresses the importance of connecting with loved ones while they are dying, and avoiding regrets for spending too much time and energy focused on treatment. She says, “The friends and family members who are most proud of how they helped their loved ones often talk about little tokens” of love and remembrance between them and their loved one. (*US News and World Report*, 02/29, [www.usnews.com/opinion/blogs/policy-dose/articles/2016-02-29/what-we-miss-by-delaying-death-with-expensive-end-of-life-care](http://www.usnews.com/opinion/blogs/policy-dose/articles/2016-02-29/what-we-miss-by-delaying-death-with-expensive-end-of-life-care))

## PALLIATIVE CARE NOTES

\* **Researchers presented at the Biophysical Society’s Sixtieth Annual Meeting in Los Angeles about the promising potential for ProTx-II, a peptide toxin extracted from the venom of the Peruvian green velvet tarantula, to treat pain.** Sonia Troeira Henriques, one of the researchers, explains how the toxin works. “It binds to the pain receptor located within the membrane of neuronal cells, but the precise peptide-receptor binding site and the importance of

the cell membrane in the inhibitory activity of ProTx-II is unknown.” (*Medical Daily*, 02/29, [www.medicaldaily.com/tarantula-venom-less-addictive-painkiller-375457](http://www.medicaldaily.com/tarantula-venom-less-addictive-painkiller-375457))

\* ***Journal of Palliative Medicine* published a study that exams a hospital-based palliative care program and the use of life-sustaining therapies in each state.** The report “examined the relationship between state-level palliative care programs (PCP) prevalence and commonly used treatments for critically ill patients as well as other public health metrics.” Looking at demographic information, they found, “State-level poverty rates were negatively correlated with the percent of hospitals with PCPs.” States which had more hospital-based PCPs had “significantly lower rates of prolonged acute mechanical ventilation, tracheostomies, and hemodialysis but higher rates of nutritional support than states with fewer PCPs.” (*Journal of Palliative*, 03/2016, [online.liebertpub.com/doi/pdf/10.1089/jpm.2015.0233](http://online.liebertpub.com/doi/pdf/10.1089/jpm.2015.0233))

\* **A study in *JAMA Oncology* looked at the outcomes of emergency room patients who were randomly assigned to either standard care or care that included a palliative care consultation initiated by emergency department staff.** The palliative care consultation included “assessment of symptoms, spiritual and/or social needs, and goals of care.” Twelve weeks after the emergency room visit, the researchers found that “quality of life, as measured by a change in FACT-G score from enrollment to 12 weeks, was significantly higher in patients randomized to the intervention group.” There was not a significant difference between the control group and the intervention group when the researchers measured depression. The researchers concluded that “Emergency department–initiated palliative care consultation in advanced cancer improves quality of life in patients with advanced cancer and does not seem to shorten survival; the impact on health care utilization and depression is less clear and warrants further study.” (*JAMA Oncology*, 01/14, [oncology.jamanetwork.com/article.aspx?articleid=2481021](http://oncology.jamanetwork.com/article.aspx?articleid=2481021))

\* **Dr. Robert Califf, new commissioner of the Food and Drug Administration, committed his agency to doing their part in helping to develop pain-killing drugs that are harder to abuse.** He said that the FDA would do “everything possible under our authority to prevent abuse, save lives and treat dependence.” The FDA has approved five abuse-deterrent drugs since 2010, with another thirty in the works. Califf also pointed out that recalling opioids is too difficult and costly to be feasible. (*NBC News*, 03/01, [www.nbcnews.com/health/health-news/new-fda-head-pledges-painkiller-reform-n529461](http://www.nbcnews.com/health/health-news/new-fda-head-pledges-painkiller-reform-n529461))

\* **Hospitals are beginning to try new ways to address prescription pain killer addiction.** Gundersen Heath System, Wisconsin, has been working on the issue since 2008, when pain medication specialists began training primary care physicians about the issues faced by patients with chronic pain, and helped initiate guidelines for treatment. Medical training up to this point has relied heavily on pharmaceutical solutions for pain management. (*Hospital and Health Networks*, 03/02, [www.hhnmag.com/articles/6924-how-hospitals-are-fighting-on-the-frontlines-of-the-opioid-crisis?utm\\_source=opioids&utm\\_medium=email&utm\\_campaign=HHN](http://www.hhnmag.com/articles/6924-how-hospitals-are-fighting-on-the-frontlines-of-the-opioid-crisis?utm_source=opioids&utm_medium=email&utm_campaign=HHN))

\* **While some families may want to shield their loved ones from hearing a poor or terminal diagnosis, it is the medical professional's role to let the patient make the decision about how much information they want to have?** Dr. Brian Carlisle, writing in *KevinMD*, says, “We learn in medical school that patient autonomy trumps all. In the end, the decision falls to the individual patient to decide how much or how little they wish to hear about their diagnosis.” (*KevinMD*,

03/02, [www.kevinmd.com/blog/2016/03/shielding-patients-from-difficult-diagnoses-undermines-their-autonomy.html](http://www.kevinmd.com/blog/2016/03/shielding-patients-from-difficult-diagnoses-undermines-their-autonomy.html))

**\* Two cost analyses relating to palliative and end-of-life care were presented at the American Society of Clinical Oncology's Quality Care Symposium.** One found that the cost for advanced cancer patients being treated at academic medical centers was significantly higher than for patients in other locations. And the costs increased as the disease progressed, suggesting that academic medical centers are more aggressively treating cancers. A second cost analysis found that “offering patients palliative care in a palliative care unit significantly attenuates the usual cost of hospital care.” (*Medscape Multispeciality*, 03/02, [www.medscape.com/viewarticle/859696](http://www.medscape.com/viewarticle/859696))

## PHYSICIAN-ASSISTED SUICIDE NOTES

**\* A research letter in *JAMA Internal Medicine* reports that the numbers of physician-assisted suicides in Europe are increasing. And, there are more PAS deaths there than in the US states where PAS is legal.** The researchers believe the reason for this is that the laws allowing PAS in the United States differ significantly than in Europe. A video discussing “the study findings, the differences in physician-assisted death between the U.S. and Europe, and how the growing acceptance of these practices should prompt what the perspective described as an international call to action” can be found on *Medpage Today*. (*Medpage Today*, 03/01, [www.medpagetoday.com/Geriatrics/GeneralGeriatrics/56482](http://www.medpagetoday.com/Geriatrics/GeneralGeriatrics/56482))

**\* The sponsor of a physician-assisted suicide bill in the Maryland Senate withdrew the bill from consideration before a committee vote in which it was likely to be voted down.** A similar bill failed to pass last year. A House committee is considering a similar bill, but it would have to pass through the same Senate committee and the full Senate before becoming law. (*Washington Post*, 03/03, [www.washingtonpost.com/local/md-politics/effort-to-legalize-assisted-suicide-in-maryland-fails/2016/03/03/fe92ea74-e14b-11e5-846c-10191d1fc4ec\\_story.html?wpisrc=nl\\_buzz](http://www.washingtonpost.com/local/md-politics/effort-to-legalize-assisted-suicide-in-maryland-fails/2016/03/03/fe92ea74-e14b-11e5-846c-10191d1fc4ec_story.html?wpisrc=nl_buzz))

Thanks to Don Pendley for contributions.

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