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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

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## **AUTHOR EXPLORES THE IMPORTANCE OF “GETTING IT”**

**James C. Salwitz, an oncologist, writes on *KevinMD* about the importance of healthcare professionals who “get it” when it comes to hospice care.** Hospice professionals easily spot those who don’t “get it,” says Salwitz. These are the physicians, he says, who “despite death lurking, just another complication away,” treat their patients “with maximal, aggressive, unrestrained care.” These physicians, he says, don’t “get it,” and fail to provide good care. Instead, such healthcare professionals “maximize suffering, compound confusion, amplify futile intervention and guarantee out-of-control costs that will bankrupt the family.” The family will bear the costs, says Salwitz, and care like this has “set up a ridiculous, unethical and incredibly common system of care.”

**There is a second set of physicians who are “just beginning to ‘get it.’”** And more and more physicians are falling into this group. These physicians, unlike those who do not “get it” at all, are engaged in more end-of-life consultations. They know patients die, but they “are not sure what to do about it.” These physicians are far more likely to refer patients out for palliative care and hospice consultations.

**Physicians who “get it” offer frank and honest feedback to their patients and respect their patients’ rights to make their own choices.** Says Salwitz, “It is your life. As your doctor, my job is to guide, not order or command. It is about you, not me. You are the patient. I am the teacher and healer.” Because patients face increasingly available and confusing choices in care, he says, it is ever more important that physicians “get it.”

**The ability to receive truth, and to be enabled and guided in making our own healthcare decisions is critical.** Salwitz concludes, “Only by seizing those precious moments, deciding our own fate, can we hope for quality, comfort and dignity.” (*Kevin MD*, 5/24, <http://www.kevinmd.com/blog/2016/05/the-enemy-is-not-death-the-enemy-is-needless-suffering.html>)

## **USE OF ADVANCE CARE VIDEO DECISION AIDS HAS MULTIPLE OUTCOMES**

**The *Journal of General Internal Medicine* published an article that explores the use of video decision aides in promoting advance care planning.** Lead by Angelo E. Volandes, MD, MPH, Massachusetts General Hospital, the research study is set in Hilo, Hawaii, which has one hospital

and one hospice. The study's authors say, "Although ACP has been promoted as a promising avenue to improve the delivery of care at the end of life, scalable and cost-effective methods have not previously been examined."

**Simply put, the researchers utilized "a single, 1- to 4-h training and access to the ACP video decision aids.** The training focused on the use of video decision aids in supporting – not replacing—ACP conversations." Before the intervention, ACP documentation rate for inpatients with late-stage diseases was 3/2%. The number of ACP documentations, after the intervention, moved from 3.2% to 39.9%. Overall, after the intervention, Hilo had a 37% completion of ACP for these patients, compared with 25.6% elsewhere in the state.

There was more good news. **Hospital rates declined in patients over 65. Prior to 2012, 5.1% was the in-hospital death rate for these patients. After the intervention, however, that number dropped to 4/3%.** And, says the study, "Primary care providers in the intervention had an ACP completion rate for patients over 75 years of 37.0 % (1,437/3,888) compared to control providers, who had an average of 25.6 % (10,760/42,099) ( $P < 0.001$ )."

**Improvement was also reported in terms of hospice utilization.** Before the intervention, the hospital-to-hospice discharge rate was 5.7% for "patients with late-state disease." After the intervention, the discharge to hospice rate rose to 13.8%. Hospice of Hilo reported growth in admission rates at a rate higher than state and national averages.

**Costs of care were also improved.** "The average total insurance cost for the last month of life among Hilo patients was \$3,458 (95 % CI \$3,051 to 3,865) lower per patient after the intervention when compared to the control region."

**The study demonstrates, it says, "that the success of the intervention shows how clinicians and patients can be empowered to engage in ACP and potentially reduce undesired treatment in our healthcare system."**

**Overall, the one-time intervention is associated with an improvement in hospice utilization, increase in completed advance directives, and a decrease in costs of care during the last month of life.** The complete report is available online. (*Journal of General Internal Medicine*, 5/16, [http://download.springer.com/static/pdf/905/art%253A10.1007%252Fs11606-016-3730-2.pdf?originUrl=http%3A%2F%2Flink.springer.com%2Farticle%2F10.1007%2Fs11606-016-3730-2&token2=exp=1464467701~acl=%2Fstatic%2Fpdf%2F905%2Fart%25253A10.1007%25252Fs11606-016-3730-2.pdf%3ForiginUrl%3Dhttp%253A%252F%252Flink.springer.com%252Farticle%252F10.1007%252Fs11606-016-3730-2\\*~hmac=c41c5e674361b111443b1871d56fccb6ff0b907796c93084645f1bb20ccf89e7](http://download.springer.com/static/pdf/905/art%253A10.1007%252Fs11606-016-3730-2.pdf?originUrl=http%3A%2F%2Flink.springer.com%2Farticle%2F10.1007%2Fs11606-016-3730-2&token2=exp=1464467701~acl=%2Fstatic%2Fpdf%2F905%2Fart%25253A10.1007%25252Fs11606-016-3730-2.pdf%3ForiginUrl%3Dhttp%253A%252F%252Flink.springer.com%252Farticle%252F10.1007%252Fs11606-016-3730-2*~hmac=c41c5e674361b111443b1871d56fccb6ff0b907796c93084645f1bb20ccf89e7))

## HOSPICE NOTES

\* Three leaders of Kokua Mau, Hawaii's Hospice and Palliative Care Organization, including executive director Jeannete Koijane, wrote "Palliative and hospice care a critical

**need at end-of-life stage” published in the *Honolulu Star Advertiser*.** The authors recognize the difficulties faced when living with serious illness. They remind Hawaiians that hospice and palliative care specialists “help restore quality of life through active medical, emotional, social, psychological and spiritual care, while honoring an individuals’ values and wishes” The article notes that “aid in dying,” or “physician-assisted suicide,” was recently proposed as an option in Hawaii. KoKua Mau takes a neutral stand on this issue and, the authors note, “People of compassion and integrity hold diverse views on this sensitive topic, including our own members.” The authors pose several questions for Hawaiians to consider as the state deliberates the issue. What the authors do assure Hawaiians of is that they want community members to understand hospice and palliative care, and to receive the best care possible when living with life-limiting and terminal illnesses. (*Honolulu Star-Advertiser*, 5/26)

**\* An article in *Salon* profiles the work of Journey Songs, a choir that sings for elderly and terminally ill persons.** The article says that Journey Songs, which sings on an invitation only basis, is “one of a growing number of hospice choirs across the country.” (*Salon*, 5/23, [http://www.salon.com/2016/05/23/songs\\_for\\_the\\_dying\\_hospice\\_choirs\\_provide\\_peace\\_comfort/](http://www.salon.com/2016/05/23/songs_for_the_dying_hospice_choirs_provide_peace_comfort/))

**\* Kristy Allan is a hospice patient in California.** In an article she wrote for *The Mercury News*, she says, “Death doesn't scare me because we're spiritual beings. It's just that I'm quite fond of my life and don't want it to end.” Nevertheless, she is grateful that the California physician-assisted suicide law will be available to her as of June 9. She gave up futile treatment last October and would be grateful for curative treatment. “Unfortunately, the reality is –based on exhaustive research—that there are no treatments or medicine existing to cure this aggressive cancer.” Allan shares poignantly about the changes in her life since her diagnosis. While she welcomes the “empowerment to make my own end-of-life care decisions, she says, “Nonetheless it brings me to tears when I think of actually getting to that point in time.” (*The Mercury News* (San Jose), 5/19, [http://www.mercurynews.com/opinion/ci\\_29909051/allan-cancer-patient-explains-end-life-decision](http://www.mercurynews.com/opinion/ci_29909051/allan-cancer-patient-explains-end-life-decision))

**\* An article in *The New York Times* profiles the care offered by Rosary Hill Home in Hawthorne, NY.** Photographer Gillian Laub took her mother-in-law there when she was suffering with terminal cancer and could not afford the 24-hour care she needed. Catholic nuns, who accept no payment from any of the incurable cancer patients whom they treat, run Rosary Hill Home, which was founded in 1901. Laub photographed the nuns as they cared for her mother-in-law, and returned later to do portraits of the nuns. “She asked the nuns to sit for portraits, in which she stripped away the background to show their eyes and faces in clear focus. ‘I wanted them to be quiet,’ she said, ‘so their power could come through.’” “‘This is how dying should be,’ Laub says. ‘It doesn’t feel like a place of death. It feels like a place of living.’” The article and photos are online. (*The New York Times*, 5/12, <http://www.nytimes.com/2016/05/15/magazine/the-sisters-who-treat-the-untreatable.html>)

**\* The federal government says it will appeal a hospice fraud case “in which a judge ruled that disagreements between doctors over patients’ eligibility for hospice care do not prove fraud.”** In March, a federal judge ruled that when two physicians look at “the very same medical records and disagree about whether the medical records support hospice eligibility, the opinion of one medical expert alone cannot prove falsity without further evidence of an objective

falsehood.” The federal government says it will appeal the ruling, as well as some of the ways the case was handled. (*Modern Healthcare*, 5/27, <http://www.modernhealthcare.com/article/20160527/NEWS/160529914>)

## PALLIATIVE CARE NOTES

**A new study, published in the *Journal of Palliative Medicine*, examined the utilization of hospice and palliative care of nearly 12,000 veterans who are living cancer.** Utilizing 2012 data, the study revealed that “only about half” of the elderly cancer patients received palliative care. And, of those who did receive it, it was often offered much later in their diseases than guidelines recommend. The same study says that, of these patients served by VA, “58.5% received hospice care for at least the last 3 days of life, and 64.9% died while under hospice care.” Patients in the VA system “received hospice a median of 14 days before death; for those with VA-purchased care, it was a median of 28 days, and for Medicare beneficiaries, it was 16 days.” More hospice patients being served by the VA received “active therapy” when compared with patients served by Medicare. The study shows, the authors say, “Palliative and hospice care are not being utilized enough.” (*Journal of Palliative Medicine*, 5/26, <http://online.liebertpub.com/doi/10.1089/jpm.2015.0514>; *Medscape*, 5/27, [http://www.medscape.com/viewarticle/863878#vp\\_2](http://www.medscape.com/viewarticle/863878#vp_2); *UPI*, 5/27, [http://www.upi.com/Health\\_News/2016/05/27/Palliative-hospice-care-not-used-enough-for-cancer-patients-study-says/1551464369518/](http://www.upi.com/Health_News/2016/05/27/Palliative-hospice-care-not-used-enough-for-cancer-patients-study-says/1551464369518/); *Stanford Medicine New Center*, 5/26, <http://med.stanford.edu/news/all-news/2016/05/palliative-hospice-care-lacking-among-dying-cancer-patients.html>)

\* **An article posted on the website of *The California State University* encourages community partnerships in offering palliative care.** The article says that “doing it on your own” is not the best idea, encourages utilization of good data, and urges skillful advance care planning. (*The California State University*, May 2016, <https://csupalliativecare.org/helen-may-2016/>)

\* **Physicians are calling for palliative care discussions with heart patients who have implanted devices.** A physician survey revealed “a low rate of formal inclusion of palliative care consultation in institutional protocols.” The American Heart Association guidelines recommend that patients know that turning off a device may sometimes be the best choice. (*Medical Research*, 5/24, <http://medicalresearch.com/author-interviews/too-few-patients-with-end-stage-heart-disease-receive-palliative-care-discussion/24632/>; *Medpage Today*, 5/26, <http://www.medpagetoday.com/Geriatrics/CHF/58144>)

## ADVANCE CARE PLANNING NOTES

\* **An article in *The Philadelphia Inquirer* reports on the work of Scott Halpern, a critical care medicine physician with Penn Medicine.** Halpern, in an earlier *New England Journal of Medicine* article, criticized some of the better-known programs that aid people in making end-of-life choices. Says Halpern, “FIELDS is the country’s only program devoted to applying the principles of behavioral economics, in essence the study of how people make choices.” Halpern believes patients make the best healthcare choices once they are dealing with serious illness.

Along with others, Halpern plans to utilize electronic medical records to query oncologists about outcomes for patients, and encourage them to consider hospice and palliative care. He also plans to give “report cards” to physicians in order to make them aware of how often their patients are given chemotherapy during the last two weeks of life, and to compare their numbers to those of their colleagues. His long-term goal is “to measure quality of end-of-life care. But using typical outcomes such as survival is obviously problematic.” (*The Philadelphia Inquirer*, 5/22, [http://www.philly.com/philly/health/20160522\\_Making\\_end-of-life\\_care\\_more\\_scientific.html](http://www.philly.com/philly/health/20160522_Making_end-of-life_care_more_scientific.html))

\* **A survey reported in the *Journal of Palliative Medicine* notes that advance directives are “Useful, Needed, and Elusive” for emergency physicians.** The survey of ED physicians found only 31% felt extremely confident that they could locate advance care planning documents when needed. Of that 31%, 55% felt they were very confident that they could follow the patient’s wishes. “ED physicians wanted highly visible ACP information, ‘on the main screen.’” The authors conclude, “EMR systems are not optimized to provide critical ACP information to ED physicians who lack confidence finding or using ACP EMR documentation to care for patients.” (*Journal of Palliative Medicine*, 5/20, <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0486>)

## PHYSICIAN-ASSISTED SUICIDE NOTES

\***Physician Paul C. Rousseau considers “the muddled contradiction that legally separates aid in dying and palliative sedation.”** He describes the pain of a suffering patient who is near life’s end. Rousseau ponders how he, they physician, was prohibited from ordering medication to help end her life, even as she lay begging for him to do so. Instead, he did what he could do, by offering to sedate her. When this offer was made, she “frantically nodded in agreement.” Says Rousseau, “The incongruity seemed absurd.” Rousseau does not agree with the premise that there is a difference between sedation and physician-assisted suicide. Both, he says are intended to “relieve suffering and symptoms, both use sedative medications, and both end in death – it’s just that one takes a little longer.” For this patient, the journey to death took eleven more days after sedation. He recognizes the concerns that many have about physician-assisted suicide. But, he worries, too, about the agony of family members and the “emotional anguish” of watching their loved ones “wither away.” (*Journal of Palliative Medicine*, 5/16, <http://online.liebertpub.com/doi/abs/10.1089/jpm.2016.0055>)

\* **New York’s Assembly Health Committee approved the Medical Aid in Dying Act (A.10059/S.7579) on 5/23.** Sponsor of the act, Assemblywoman Amy Paulin (D) says that 77 percent of new Yorkers support “this end of life option.” New Yorkers for Constitutional Freedoms opposes the act saying, “It could pose a danger to patients, persons with disabilities and New York’s most vulnerable population.” The act will require that: “Two doctors must determine an adult has 6 months or less to live; There must also be two witnesses present; Misuse of the law could result in criminal prosecution; and, No hospital or doctor would be forced to participate in aid in dying.” (*The Legislative Gazette* (Albany), 5/24, <http://legislativegazette.com/archives/3349>; *New York State Assembly*, 5/23, [http://assembly.state.ny.us/leg/?default\\_fld=&leg\\_video=&bn=A10059&term=2015&Summary=Y&Actions=Y&Committee%2](http://assembly.state.ny.us/leg/?default_fld=&leg_video=&bn=A10059&term=2015&Summary=Y&Actions=Y&Committee%2))

6nbspVotes=Y&Floor%26nbspVotes=Y&Memo=Y&Text=Y; *WIBV.com*, 5/24,  
<http://wivb.com/2016/05/24/end-of-life-options-act-moves-forward-in-assembly/>)

\* *Medical Daily* published a lengthy article entitled “**Suicide Tourism: Traveling For The Right To Die, And The Ethical And Legal Dilemmas That Come With It.**” The article considers numerous aspects of this issue and is online for review. (*Medical Daily*, 5/25, <http://www.medicaldaily.com/assisted-suicide-tourism-right-die-387577>)

## OTHER NOTES

\* **A study in *The Journal of Clinical Oncology* reports that few advanced cancer patients understand their medical conditions and are in need of better communication from their physicians about their prognoses.** “Results of this study demonstrate how poorly patients with advanced cancer understand their prognoses and how effective recent prognostic discussions are to improve illness understanding by patients... A small minority [5%] of patients accurately, and completely, understood the gravity of their illnesses...” (*BioEdge*, 5/29, <http://www.bioedge.org/bioethics/patients-dont-know-their-life-is-ending-new-study/11890>)

\* **An article in the *John Hopkins Magazine* lauds the value of therapeutic humor.** The article notes that humor does not change clinical outcomes. Humor can, however, says author Rachel Wallach, “help patients better navigate the processes of illness, recovery and even dying.” (*John Hopkins Magazine*, Summer 2016, <http://hub.jhu.edu/magazine/2016/summer/humor-therapy-nursing-medicine>)

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