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# HOSPICE NEWS NETWORK

*What the Media Said about End-of-Life Care This Week*

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## CMS PILOT PROGRAM COULD REPRESENT SHIFT FOR HOSPICE

**In an interview published in *Kaiser Health News*, Diane Meier speaks about the pilot program recently launched by Medicare.** The program will explore the potential impact of providing patients with access to life-prolonging procedures while at the same time receiving the benefit of hospice care. If successful, this trial program could be expanded to seriously ill Americans in general, encouraging individuals to elect hospice without having to immediately choose between comfort care and life-extending treatments.

**Diane Meier, director of the Center to Advance Palliative Care, begins her interview with *Kaiser Health Network* by explaining that there is still great confusion surrounding the relationship between palliative care and hospice.** Meier clarifies that while all hospice care is palliative care, not all palliative care is hospice. The emphasis of palliative care is on relieving pain, regardless of prognosis. The question of how long a patient might live is largely irrelevant.

**This is in contrast to the Medicare hospice benefit, which for the last 25 years has existed under federal guidelines that require a specific prognosis and an expectation (certified by two physicians) that the patient would likely not survive more than six months.** “The patient or family members,” additionally, “need to sign a paper giving up on regular insurance coverage for disease treatment in order to get access to hospice, a forced either/or choice between life-prolonging treatment and palliative care.” **While this represented an attempt by federal regulators to save money, this way of regulating the Medicare hospice benefit has serious downsides.**

Meier speaks out of her own experience counseling individuals with life-limiting illness, “I can tell you it is very painful to tell people they have to sign away their rights to treatment. It’s like hitting a man when they’re down.” **Most people want both life-prolonging and palliative medicine, and by forcing patients and families into a stark binary choice, many individuals may feel pressure to forgo hospice care until the last days of life, when death is clearly imminent.** In the meantime, they may suffer more than is necessary, not having access to the full range of palliative care that hospice offers.

**In this context, Meier expresses her optimism at the newly launched Medicare Choices Model, a program created under the Affordable Care Act, which allows hospice patients with advanced cancer, chronic obstructive pulmonary disease, congestive heart failure and HIV/AIDS to receive both hospice treatment and curative care concurrently.** Meier believes that this experiment signals “a noteworthy change in approach toward caring for dying patients.”

**On the other hand, Meier believes that it is unfortunate that this new benefit is targeted only at those who are already eligible for hospice. “People tend to be pretty damn sick by the time they become eligible for hospice. I’m not really sure what access to curative care means in that context. If these patients could have been ‘cured’ they wouldn’t be eligible for hospice.” Nevertheless, much of “curative” care is, in fact, life-extending in nature, and often represents a form of palliative treatment. “If you have emphysema and I give you broncodilators and steroids to open up your airways, it will prolong your life, and it will also make you feel better.”**

**While the pilot seems very promising in many ways, there are potential downsides. One of these is the prospect of hospices being greatly stretched in their ability to provide care and still balance their budgets. Some hospices have said that they will not participate in the program, because the CMS pilot rate of \$400 is not enough to cover costs.** Meier acknowledges that the patients in these programs “are the sickest patients in our health care system. They need a lot of hand holding. Availability and responsiveness are key and that’s expensive.” **Nevertheless, Meier is optimistic about the resiliency and creativity of the hospice industry.** “I think it’s going to be challenging but I think it will lead to some really creative solutions. Hospice organizations may look to build out a more comprehensive safety net by partnering with other community providers like Meals on Wheels or local aging services or transportation providers.”

**If CMS and hospices can make this program work, the potential benefits are great. Meier cites studies that “show that patients who receive both palliative care and life-prolonging care can actually live longer than those who receive life-prolonging care alone.”** It turns out that, when people are happier and more comfortable, they tend to stick around longer. “They’re not getting less life-prolonging treatment with palliative care, they’re having less crisis. They reduce emergency care use because they don’t need it and that saves money.” **Meier makes a prediction, saying, “It will actually be less expensive to provide both approaches at the same time precisely because it will lead to less need for costly emergency and crisis care.”** (*Kaiser Health News*, 7/29, [www.kaiserhealthnews.org/Stories/2014/July/29/Medicare-Experiment-Could-Signal-Sea-Change-For-Hospice.aspx](http://www.kaiserhealthnews.org/Stories/2014/July/29/Medicare-Experiment-Could-Signal-Sea-Change-For-Hospice.aspx); *NPR*, 7/29, [www.npr.org/blogs/health/2014/07/28/336120433/getting-hospice-care-shouldnt-have-to-mean-giving-up](http://www.npr.org/blogs/health/2014/07/28/336120433/getting-hospice-care-shouldnt-have-to-mean-giving-up); *Palliative In Practice*, 7/30, [palliativeinpractice.org/2014/07/30/capc-news-bites-14/](http://palliativeinpractice.org/2014/07/30/capc-news-bites-14/))

## **HOSPICE NURSE DEMONSTRATES FRANK APPROACH TO THE END OF LIFE**

**In an article and short video documentary posted by the *Pittsburgh Post-Gazette*, readers are led through the experience of 75-year-old former hospice nurse Joan Baldwin-Branch, as she herself faces the end of life, and what this means for her and her family.** “Widely admired as an educator since making a midlife decision to become a nurse, Joan was the one coaxing others out of denial of her terminal illness. ... In her final months, which she sometimes referred to with one of her ever-present laughs as “Joan’s Journey,” she sought to leave a legacy that’s unusual in America despite that high volume of daily mortality all around us.”

Though Baldwin-Branch had frequently been exposed to death and dying in her work as a critical care nurse and personal care home operator, and later accompanied hundreds of

individuals through their final weeks as a hospice nurse, nothing could truly prepare her for the moment when she learned that she was dying. Describing it as being “whacked by a 2-by-4,” she received a diagnosis of a highly lethal ovarian cancer in 2012. Despite attempts to remove and treat the cancer, it eventually became clear that death from the disease was becoming a near certainty.

This spring, Joan Baldwin-Branch was faced with a choice. Physicians suggest an extensive surgery that might provide her with an additional year of life. She eventually decided against the surgery, having become convinced that her body was no longer strong enough to handle the stress of such a far-ranging operation. She enrolled in hospice care on March 20th.

For most of her time as a hospice patient, socializing helped Baldwin-Branch avoid dwelling too much on the pain and fear. She even kept up a blog, musing on the process of cancer treatment and end-of-life care. **Despite her rock-solid focus on communicating with and caring for others, however, Baldwin-Branch was surprised by great anxiety in her last days of life. Just a week before her death, Joan experienced a panic attack. She came face to face with her own fear of death, apparently for the first time.** A friend recalls that Baldwin-Branch, “implied that she was feeling what she had never allowed herself to feel before. I think she’s now seeing the finality, the ‘Oh my God, is this really happening’ part of it.”

Gateway Hospice social worker Candy Pulaski remembers that Baldwin-Branch “spent so much time in the business of thinking it was her job to get everyone ready to lose her, that she didn’t take time to think about what it would mean for her to lose everyone.” Above all, Joan Baldwin-Branch wanted to leave a legacy, sharing four essential things for those who are dying to keep in mind: “Provide forgiveness. Ask for forgiveness. Say ‘I love you.’ Say ‘Goodbye.’ ... Those are very hard things to say.” (*Post-Gazette*, 6/8, [www.post-gazette.com/news/health/2014/06/08/Lifes-journey-a-better-end-A-nurse-s-frank-approach-to-end-of-life/stories/201406080108](http://www.post-gazette.com/news/health/2014/06/08/Lifes-journey-a-better-end-A-nurse-s-frank-approach-to-end-of-life/stories/201406080108))

## HOSPICE AND END-OF-LIFE NOTES

\* **CMS posted the final rule on “Medicare Program; FY 2015 Hospice Wage Index and Payment Rate Update; Hospice Quality Reporting Requirements and Process and Appeals for Part D Payment for Drugs for Beneficiaries Enrolled in Hospice.”** The document will be posted in the *Federal Register* on 8/22 and is now available online now. (*CMS*, 8/4, <https://s3.amazonaws.com/public-inspection.federalregister.gov/2014-18506.pdf>; *Federal Register*, 8/22, <https://www.federalregister.gov/articles/2014/08/22/2014-18506/hospice-wage-index-and-payment-rate-update-fy-2015-hospice-quality-reporting-requirements-and>)

\* **The National Association for Home Care and Hospice and its affiliates have sent a letter to CMS regarding the hospice cost report. The letter “strongly urges” CMS to provide at least nine months for hospices to comply with the final hospice cost report revisions, when they are made public.** “If providers are not afforded the lead time necessary to adapt to the new cost reporting requirements, the opportunity to vastly improve the available detail and quality of data related to hospice costs will not be realized.” (*NAHC*, 7/25, [www.nahc.org/NAHCReport/nr140724\\_2/](http://www.nahc.org/NAHCReport/nr140724_2/))

\* **While many tools exist to help introduce people to the concept of advance care planning, these tools “vary widely in what they offer and how accessible they are.”** According to a study recently released in *The Annals of Internal Medicine*, “‘Decision aids’ have proliferated in many areas of medicine but have yet to really take off in the area of advance directives...”

(*Reuters*, 7/29, [www.reuters.com/article/2014/07/29/us-advance-directives-health-idUSKBN0FY1VV20140729](http://www.reuters.com/article/2014/07/29/us-advance-directives-health-idUSKBN0FY1VV20140729); *MedPage Today*, 7/28, [www.medpagetoday.com/PracticeManagement/Medicolegal/46974](http://www.medpagetoday.com/PracticeManagement/Medicolegal/46974))

\* **A new poll indicates that 24% of older Americans “say that either they or a family member have experienced excessive or unwanted medical treatment.”** The poll was sponsored by Compassion & Choices, whose national and federal programs director Daniel Wilson commented, “Twenty-five million Americans receiving excessive or unwanted medical treatment is 25 million Americans too many. This survey demonstrates that older Americans clearly trust their doctors, but they also expect them to honor their end-of-life medical wishes.” (*Health News Digest*, 7/29, [www.healthnewsdigest.com/news/National\\_30/25-Million-Older-Americans-Have-Experienced-Unwanted-or-Excessive-Medical-Treatment.shtml](http://www.healthnewsdigest.com/news/National_30/25-Million-Older-Americans-Have-Experienced-Unwanted-or-Excessive-Medical-Treatment.shtml))

\* **“Undergraduate nursing education inconsistently prepares students for their role in providing end-of-life care,” finds to a new study published in *The Journal of Hospice & Palliative Nursing*.** The study reports, “An online death and dying course can positively impact nursing students’ attitude toward death and care of the dying.” (*The Journal of Hospice & Palliative Nursing*, 8/2014,

[journals.lww.com/jhpn/Abstract/2014/08000/Nursing\\_Student\\_End\\_of\\_Life\\_Care\\_Attitudes\\_After.10.aspx](http://journals.lww.com/jhpn/Abstract/2014/08000/Nursing_Student_End_of_Life_Care_Attitudes_After.10.aspx))

\* **How are you going to die? A video featured on NPR gives a look into the disparities in living (and dying) conditions across the world.** “Depending on where you live on Earth, cooking dinner, having sex and going to the bathroom are either three of life’s many pleasures, or they’re the riskiest things you can do.” (*NPR*, 7/31,

[www.npr.org/blogs/goatsandsoda/2014/07/31/336369873/how-will-you-die?utm\\_campaign=storyshare&utm\\_source=facebook.com&utm\\_medium=social](http://www.npr.org/blogs/goatsandsoda/2014/07/31/336369873/how-will-you-die?utm_campaign=storyshare&utm_source=facebook.com&utm_medium=social))

\* **Carolyn McLanahan, writing for *Forbes*, shares the “nuts and bolts” about hospices’ expectations of caregivers and “what the caretakers can expect from hospice care at home.”** Specifically, she addresses the reality that hospice patients still need a strong support system. For those who are dying, she recommends that friends and family members: be present; feed loved ones; help with toileting; and help administer medications. (*Forbes*, 8/1, [www.forbes.com/sites/carolynmclanahan/2014/08/01/nuts-and-bolts-of-end-of-life-care/](http://www.forbes.com/sites/carolynmclanahan/2014/08/01/nuts-and-bolts-of-end-of-life-care/))

## PALLIATIVE CARE NOTES

\* **Paul C. Rousseau, MD, reminds physicians that sitting at the bedside and hearing the stories of patients is a crucial part of care that often goes neglected.** “We all have a story, and we all want to tell that story. We want it to be heard, and we want it to resonate. It helps with healing, and it helps when the burden is too heavy to carry alone. The doctors of old understood this, for they had no antibiotics, morphine, or other modern medicaments. They only had the

bedside, where they sat, held hands, waited, and in the end, listened.” (*The Journal of Palliative Medicine*, 7/3, [online.liebertpub.com/doi/abs/10.1089/jpm.2014.0059](http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0059))

\* **Writers for *Health Affairs Blog* examine disparities in palliative care.** “Racial and ethnic disparities in health care have been well documented among minority groups with respect to access to care, receipt of care, and quality of care. As a result of these disparities, minority populations are often diagnosed with late stage illness and have inferior outcomes likely leading to increased suffering.” (*Health Affairs Blog*, 7/30, [healthaffairs.org/blog/2014/07/30/disparities-in-access-to-palliative-care/](http://healthaffairs.org/blog/2014/07/30/disparities-in-access-to-palliative-care/))

\* **Do we really know what “DNR” means?** Robert Macauley, MD, notes that individuals with DNR orders are less likely to receive care not related to resuscitation. “It’s time to... stop using an ambiguous and oft-misunderstood term, especially when the stakes are so high.” (*The Journal of Palliative Medicine*, 7/3, [online.liebertpub.com/doi/abs/10.1089/jpm.2014.0059](http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0059))

\* **NIH has announced a funding opportunity for clinical studies “to provide an evidence base for the use of arts in palliative care for symptom management.”** Details are online. (NIH, <http://grants1.nih.gov/grants/guide/pa-files/PAR-14-294.html>)

## OTHER NOTES

\* **The FDA has approved a new extended-release oxycodone with abuse-deterrent properties.** “Targiniq ER has properties that are expected to deter, but not totally prevent, abuse of the drug by snorting and injection. When crushed and snorted, or crushed, dissolved and injected, the naloxone in Targiniq ER blocks the euphoric effects of oxycodone, making it less liked by abusers than oxycodone alone.” The drug can still be abused when taken orally, which is still the most common form of abuse. (FDA, 7/23, [www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm406407.htm](http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm406407.htm))

\* **French families are challenging an emergency physician and palliative specialist who gave a lethal dose of sedatives to comatose patients on at least seven occasions.** “All this he admitted freely in court, saying he was moved by a sense of duty to act outside the law, to spare his colleagues and his patients’ loved ones the strain of so weighty a choice.” A jury found him not guilty of the poisoning charges he faced. (*The New York Times*, 8/1, [www.nytimes.com/2014/08/01/world/europe/french-families-challenge-doctors-on-wrenching-end-of-life-decisions-medicalized-hospital-deaths.html?\\_r=1](http://www.nytimes.com/2014/08/01/world/europe/french-families-challenge-doctors-on-wrenching-end-of-life-decisions-medicalized-hospital-deaths.html?_r=1))

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