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# HOSPICE NEWS NETWORK

*Recent News On End-of-Life Care*

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## PATIENTS TEACH DOCTOR HOW TO GIVE END OF LIFE CARE

An article in *New America Media* highlights the experience of Dr. V.J. Periyakoil, who is a “leading voice in the movement to reconceptualize end-of-life care from limited hospice treatment in the last six months of life to comprehensive treatment for profoundly ill people.” “Much of my work has been on the importance of dignity in health care,” Dr. Periyakoil says. Contrary to conventional wisdom, Periyakoil has found that “most patients don’t simply want every medical intervention that may or may not prolong their lives.” Ultimately, most people “want appropriate care sensitive to their quality of life and enabling them to experience their final days as fully as possible with minimal stress for their families.”

**Periyakoil’s personal observation is backed up by research, as well.** A 2012 report by the California Health Care Foundation, notes that patients “didn’t want their families burdened by the cost of their care, or by having to struggle with troubling decisions about their treatment.” The study found significant differences between ethnic groups, with the majority (56%) of Latinos expressing that prolonging life was their top priority, while only 18% of Asians did. Whites and African Americans fell in the middle, with 25% and 43% of these groups, respectively, answering that they prioritized prolonging life above all.

**For most patients, says Periyakoil, there are more immediate concerns than overall length of life.** Many care “more about concrete things – “Treat my pain first, take care of me first - then you can treat me with respect.” She notes that this translates for patients to “good pain care and symptom management, which is good palliative care.”

**Dr. Periyakoil has been through quite a journey to arrive at this perspective. In the 25 years between her time in medical school in India and her current role as director of Stanford University’s palliative care fellowship program, she has learned to listen deeply to her patients, hearing what their concerns and needs truly are.** By learning from them, Periyakoil has come to a practice of medicine that looks beyond the simple goal of extending life, to the matters that are most important to those she serves.

**Periyakoil believes that “palliative care should be woven seamlessly into treatment,” regardless of whether patients are aware of the term.** “It should be something that is given to you when and where you need it because it is the standard practice.”

**A part of effective palliative and end-of-life care is being sensitive to the needs of a variety of cultural groups.** With so many widely varying conceptions about death and dying, holistic end-of-life care must take these into account. Periyakoil describes her experience of learning that

many in the Chinese Buddhist community she serves “believe that the soul lingers in the body for some time after death. So they do not touch the body nor vocally express grief as this might disrupt the passage of the dying person’s soul.” Acting with this knowledge, she is able to deliver better care to families experiencing the loss of a loved one. (*New America Media*, 4/3, [newamericamedia.org/trending/2013/04/patients-teach-doctor-how-to-heal-at-the-end-of-life.php](http://newamericamedia.org/trending/2013/04/patients-teach-doctor-how-to-heal-at-the-end-of-life.php))

## **PARALYZED HUNTER CHOOSES TO END LIFE SUPPORT**

**An Indiana man who suffered catastrophic spinal injuries during a hunting accident consciously chose to take himself off of life support shortly after being awakened in the ICU.** The *Associated Press* reports that Tim Bowers, 32, was hunting for deer when he fell 16 feet from a tree and sustained injuries that left him paralyzed from the shoulders down. Doctors believed that he would probably never breathe again without assistance.

**What is remarkable about this case is not that Bowers was ultimately taken off life support, but rather the fact that he himself made the decision.** “Courts have long upheld the rights of patients to refuse life support. But Bowers’ case was unusual because it’s often family members or surrogates, not the patient, who make end-of-life decisions.”

**Physicians informed family members that he would be paralyzed and could require a ventilator for the rest of his life. One day after the accident, the family requested that Bowers be brought out of sedation and asked what he wanted to do.** Though unable to speak because of ventilation, Bowers indicated that he did not want to continue to live this way.

**Although medical ethicists say it’s uncommon for a patient to decide to be removed from life support, especially so soon after an injury, “standard medical practice is to grant more autonomy to patients.”** After confirming this decision with Bowers, medical staff removed the ventilator unit, allowing the patient to speak again - but almost certainly to die, as well.

“I just remember him saying so many times that he loved us all and that he lived a great life,” said one sibling. “At one point he was saying, ‘I’m ready. I’m ready.’” Tim Bowers died about five hours after ventilation was removed. The story was broadly covered. The link below leads to one version of the story and many responsive comments as well. (*ABC News*, 11/5, [abcnews.go.com/US/wireStory/injured-indiana-hunter-chooses-end-life-support-20791392](http://abcnews.go.com/US/wireStory/injured-indiana-hunter-chooses-end-life-support-20791392))

## **ACCESS TO END-OF-LIFE CARE A GROWING CONCERN FOR FILIPINO AMERICANS**

**An article published in *New America Media* highlights the growing needs of the Filipino American community with regards to palliative medicine, end-of-life care, and hospice.** While the Filipino community in the United States has a “rising number of elders, as well as high incidences of serious illnesses among them,” Filipinos over 65 are less likely to enroll in hospice care. **The article explores the nature of palliative care, its uneven application among ethnic**

**groups, and the particular importance that palliative medicine will have for the aging Filipino American population.**

**The Filipino community in the United States is steadily growing its elderly population**, with individuals over 65 making up almost 10% of the approximately 2.6 million Filipino Americans. Add to that the fact that roughly 35% of those individuals are disabled, and one can expect to see greater need in coming years for palliative services. **Debilitating diseases are even more frequent among Asian Americans, perhaps because of a pattern of forgoing screening for diseases such as colorectal cancer.** Such diseases, more common among this population, “often require intensive care, making palliative care all the more relevant.”

**A major barrier to the diffusion of palliative care among this population is a resistance among some - especially newer immigrants - to talk about serious illness.** The usual response from such patients is to involve family members in decision-making. **Fortunately, Filipino Americans and their family members seem generally open to advance directives and POLST forms.** Overall, increasing awareness of and information about palliative care will be crucial for ensuring that Filipino Americans get access to quality palliative care. (*New America Media*, 9/18, [newamericamedia.org/2013/09/more-filipino-americans-will-need-palliative-care.php](http://newamericamedia.org/2013/09/more-filipino-americans-will-need-palliative-care.php))

## HOSPICE NOTES

**\* A Colorado hospice, now closed, is criticized for alleged financial mismanagement and faulty care of patients.** “The once well-respected charity health care organization became cash-strapped and was forced to shut down at the end of August.” (*9News*, 11/7, [www.9news.com/news/local/article/363398/222/Closed-hospice-criticized-for-spending-care](http://www.9news.com/news/local/article/363398/222/Closed-hospice-criticized-for-spending-care))

**\* An article by a local ABC News station highlights the therapeutic role that hospice care can have, not only for patients, but for their loved ones, as well.** (*WFAA*, 11/5, [www.wfaa.com/news/health/Until-Gods-Mercy-230717011.html](http://www.wfaa.com/news/health/Until-Gods-Mercy-230717011.html))

**\* Hospice Buffalo is beneficiary of a \$2 million gift from the estate of a local pharmacist and business owner.** The gift from William M. Bender’s estate helps the hospice organization move to \$9.5 million of the goal for its \$10 million capital campaign. (*Metro WNY*, 11/3, [www.metrowny.com/news/659-Hospice-receives-2-million-gift-from-Buffalo-entrepreneur.html](http://www.metrowny.com/news/659-Hospice-receives-2-million-gift-from-Buffalo-entrepreneur.html))

## END-OF-LIFE NOTES

**\* When considering the costs and benefits of heroic measures at the end of life, “sometimes it’s our patients who can teach us the most,”** writes Dr. Mikkael Sekeres. *Writing for The New York Times* blog, Sekeres details cases, including that of an Amish man who factors the costs of futile care in his decision to forego care. The high costs of care and the low returns of heroic measures at the end of life were of concern to the man. “We should pause to consider that a critical component to true health care reform is in changing our core expectations about the use of heroic measures at the end of life and whether to treat illnesses that are likely incurable. In this

respect, sometimes it's our patients who can teach us the most." (*The New York Times*, 11/7, [well.blogs.nytimes.com/2013/11/07/what-our-patients-can-teach-us/?\\_r=0](http://well.blogs.nytimes.com/2013/11/07/what-our-patients-can-teach-us/?_r=0))

\* **Former Senator and heart transplant surgeon Bill Frist writes for *The Tennessean*, sharing on the importance of making plans for end-of-life care.** "Experts have told us that if end-of-life care is to improve, whole communities need to change." (*The Tennessean*, 11/3, [www.tennessean.com/article/20131103/OPINION03/311030095/2071?gcheck=1](http://www.tennessean.com/article/20131103/OPINION03/311030095/2071?gcheck=1))

\* **The *US News Hospital of Tomorrow* conference included a session entitled "Fixing End-of-Life Care."** "Experts discussed how patients could live well during their final days or months, and how health care professionals could intervene in ways outside the hospital." (*US News*, 11/5, [health.usnews.com/health-news/hospital-of-tomorrow/articles/2013/11/05/fixing-end-of-life-care](http://health.usnews.com/health-news/hospital-of-tomorrow/articles/2013/11/05/fixing-end-of-life-care))

\* **The holidays are the perfect time to "talk turkey" about end-of-life care wishes.** The article cited below highlights the work that Compassion & Choices is doing to encourage conversations about end-of-life decisions among family members this holiday season. (*Digital Journal*, 11/7, [www.digitaljournal.com/pr/1573274](http://www.digitaljournal.com/pr/1573274))

\* **Using Nelson Mandela as an example, an article published in *The Atlanta Black Star* encourages readers to consider and plan for their end-of-life wishes.** (*The Atlanta Black Star*, 11/5, [atlantablackstar.com/2013/11/05/make-sure-end-life-plan-action/](http://atlantablackstar.com/2013/11/05/make-sure-end-life-plan-action/))

## PALLIATIVE CARE NOTES

\* **The Discovery Channel will be featuring a new documentary, *Pain Matters*.** The program will explore "what chronic pain is, its individual and societal impact, and the future of pain management through the stories and struggles of six individuals living with chronic pain and their loved ones, as well as perspective from leading national experts in pain management." *Pain Matters* premieres on November 16th. More information is available online. (*Painmatters*, November 2013, [painmattersfilm.com](http://painmattersfilm.com))

\* **The American Academy of Pediatrics has released a policy statement, "Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations."** The full report is online at the link below. (*Pediatrics*, 10/28, <http://pediatrics.aappublications.org/content/132/5/966.full>)

\* **At a recent talk, Jennifer Ballentine, executive director of the Life Quality Institute, detailed Medieval European conceptions about death, dying and spiritual redemption.** She drew attention to the *Ars Morendi*, "a pair of 15th-century texts that served as a guide for dealing with death and dying in one of the Western world's darkest eras." (*The Aurora Sentinel*, 11/7, [www.aurorasentinel.com/guide/palliative-care-doesnt-make-death-take-holiday-make-better-end-life/](http://www.aurorasentinel.com/guide/palliative-care-doesnt-make-death-take-holiday-make-better-end-life/))

\* **A study released recently in *The Journal of Palliative Medicine* finds that patient safety issues in home hospice care are similar to those in other care areas.** The study concludes by

saying, “Further research and consensus building of the definition of patient safety incidents and patient safety incidents in this setting is recommended.” (*The Journal of Palliative Medicine*, online ahead of print 10/26, [online.liebertpub.com/doi/abs/10.1089/jpm.2013.0104](http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0104))

\* **An article in *The Philadelphia Enquirer* highlights the importance of palliative care. “If palliative care were a new cancer drug, it would be hailed as a breakthrough,” according to Diane Meier.** (*The Philadelphia Enquirer*, 11/2, [articles.philly.com/2013-11-02/news/43595370\\_1\\_palliative-care-cancer-patients-palliative-medicine](http://articles.philly.com/2013-11-02/news/43595370_1_palliative-care-cancer-patients-palliative-medicine))

## VETERANS NOTES

\* **An oral history project seeks to allow future relatives to hear the voices of their veteran ancestors.** “In the future, 100 years from now, if the great-grandchildren want to listen to their great-grandfather talk, they just call the Library of Congress and give his name.” (*The North & South Brunswick Sentinel*, 11/7, [mnsb.gmnews.com/news/2013-11-07/Front\\_Page/Project\\_ensures\\_veterans\\_stories\\_will\\_not\\_be\\_forgo.html](http://mnsb.gmnews.com/news/2013-11-07/Front_Page/Project_ensures_veterans_stories_will_not_be_forgo.html))

\* **In a letter to the editor, JoAnne Ruden, Vice President of Holy Redeemer HomeCare & Hospice, writes to express her organization’s solidarity with “Pennsylvania’s more than 964,000 veterans.”** According to the NHPCO, one in four dying Americans is a veteran. (*Mainline Media News*, 11/5, [mainlinemedianews.com/articles/2013/11/05/main\\_line\\_suburban\\_life/opinion/doc5279510055f2c298923882.txt](http://mainlinemedianews.com/articles/2013/11/05/main_line_suburban_life/opinion/doc5279510055f2c298923882.txt))

## OTHER NOTES

\* **Hospitals in Washington State may soon face new disclosure rules.** Seeking to address religious control of health services, proposed regulations would require hospitals to publish online their policies on end-of-life and reproductive-health services. (*The Seattle Times*, 11/4, [seattletimes.com/html/localnews/2022192738\\_hospitalrulesxml.html](http://seattletimes.com/html/localnews/2022192738_hospitalrulesxml.html))

\* **The “space burial company,” Elysium Space, hopes to launch the remains of loved ones into space.** They even plan to offer an app that tracks the location of the remains in low earth orbit. (*NBC News*, 11/5, [www.nbcnews.com/science/launch-your-loved-one-heaven-or-least-their-ashes-8C11538531](http://www.nbcnews.com/science/launch-your-loved-one-heaven-or-least-their-ashes-8C11538531))

\* **IOM issued recommendations: Improving the Quality of Cancer Care in an Aging Population.** According to the IOM report, “The United States has entered into a new era in cancer care.” (*JAMA*, 2013;310(17):1795-1796, [jama.jamanetwork.com/article.aspx?articleID=1764058&utm\\_source=Silverchair%20Information%20Systems&utm\\_medium=email&utm\\_campaign=MASTER:JAMALatestIssueTOCNotification11/05/2013](http://jama.jamanetwork.com/article.aspx?articleID=1764058&utm_source=Silverchair%20Information%20Systems&utm_medium=email&utm_campaign=MASTER:JAMALatestIssueTOCNotification11/05/2013))

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