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# HOSPICE NEWS NETWORK

*Recent News On End-of-Life Care*

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## NEJM EXAMINES HISTORY OF THE END-OF-LIFE CARE

In forty years of working to improve end-of-life care, progress has been “incremental.” There are still many difficulties yet to overcome in order to provide patient-centered care to those who most need it. **According to an article published in *The New England Journal of Medicine*, we are still in the midst of an historical transition to comprehensive reform of the health care system, ensuring that all patients are extended the benefits of high-quality care at the end of life.**

**The study’s authors note that, despite forty years of intensive work, “aligning care with patients’ needs and preferences in order to ease the dying process is surprisingly difficult.”**

Early on in this process, there was great optimism about establishing patients’ rights to make decisions for their own care. With the passage of time, however, this rosy vision has dimmed somewhat, replaced by a greater recognition of the depth of the challenge - “sobering data showing that declaring these rights [is] not enough to alter treatment patterns and that systemic issues [loom] large.”

**The *NEJM* report provides a brief overview of the history of the end-of-life care movement, dividing the last four decades years into three distinct periods. The history begins with the “Securing Rights” period from 1976-1994.** This first period of end-of-life reform, lasting until 1994, was focused on establishing the legal rights of patients. This early stage began with the decision by the New Jersey Supreme Court, which established that a comatose patient had a “right of choice” to discontinue medical treatment, which could be carried out by her surrogate - in this case, her father. “Many cases followed in which courts recognized the constitutional and common law rights of patients to refuse life-sustaining treatment and the authority of surrogate decision makers for patients who lacked decision-making capacity.”

It was during this time period that many legal rights that we take for granted today were established, including the Medicare Hospice Benefit and the passage of Oregon’s “Death with Dignity” law, allowing physicians to assist terminally-ill patients in ending their lives. In the 1990 case of Nancy Cruzan, the US Supreme Court recognized the right of patients to refuse life-sustaining treatments, such as artificial nutrition and hydration. (The Supreme Court also indicated that designated surrogates had better legal standing if patients had stated their wishes in advance, in writing, which led to a greater movement to promote the use of advance directives.)

**Beginning in 1994, we entered into a second phase, which the article’s authors call the “Facing Clinical Realities” period. During this time, the legal rights framework developed**

**in the 70s and 80s was found to be inadequate in the face of actual practice in clinical settings.** In 1995, investigators found that “documented treatment preferences, even when championed by a nurse advocate, failed to change clinical practice.” As one commentator explained, “Improving the quality of care generally requires changes in the organization and the culture of the hospital and the active support of hospital leaders.”

**During this time period, palliative care came to the forefront of end-of-life efforts.** Relieving pain and promoting patient comfort became a major focus, and one that could be applied to any clinical setting, not just hospice care. During this same time frame, focus grew on how to take into account various subsets of the terminally ill population. In 2002, the IOM published “When Children Die,” exploring how parents can make medical decisions for their children. Around this time, there was also growing controversy over decisions to end life-sustaining treatment for individuals on the basis of long-term disability. “People with disabilities raised concerns that such decisions were sometimes based on inappropriate assumptions about quality of life.”

**Toward the end of this second period, the politics of end-of-life care became more divisive.** In 2009, opponents of the Affordable Care Act (ACA) seized hold of the fact that the ACA as originally composed would have provided for reimbursement of physicians who preformed voluntary counseling with patients about end-of-life issues. Opponents of the ACA spread false information about the bill, insisting that these voluntary consultations would amount to “death panels,” whose intention was to “kill grandma” to save money. Under intense political pressure, the provision was removed from the final bill that was approved by Congress.

**The passage of the ACA in 2010 marked the beginning of a third historical phase in the movement for improved end-of-life care: the “Reforming End-of-Life Care Systems” period.** Within the new regulatory environment created by the ACA, “efforts to improve end-of-life care have become increasingly focused on health care institutions, systems, and finance.” In 2014, the IOM released its ground-breaking report, “Dying in America,” which analyzed current financial incentives, finding that they “do not support ready access to the care patients want and need near the end of life.”

**Our current period is marked by an incomplete progress.** Despite ample evidence of benefit, the full integration of palliative care is at best partial. Although hospice usage has increased markedly in recent years, “Medicare data reveal patterns of treatment escalation before enrollment.” As the Boomer generation ages, America faces a sharp uptick in a variety of end-of-life-related challenges, including the meteoric rise of Alzheimer’s disease.

**In the midst of numerous pressures, the ACA is driving changes in systems, renewing efforts to improve end-of-life care at a systems level.** For example, there is growing funding for concurrent hospice and curative efforts for seriously ill children, and new efforts to fund patient/physician end-of-life conversations are underway.

**The systems-focus in policy initiatives is mirrored by a similar approach to ethics.** “In 2013, the Hastings Center produced a revised, expanded edition of the 1987 guidelines, addressing not only individual rights and the clinical realities of decision making but also institutional and systemic issues such as transfers between institutions, end-of-life care in the context of large and complex health care organizations, the role of cost in decisions, and health care access for

uninsured people.” **These new guidelines, combined with the recent IOM report, reframe the care of dying people as “patient centered, family oriented.”**

**Having recounted a brief history of end-of-life care from 1976 to present, the authors draw out a number of lessons from this period of important, incremental growth.** They highlight the importance of training clinicians to support and inform decision makers. **To facilitate end-of-life conversations, the authors specifically call for more and better training in communication for physicians.**

**Equally important is the growth of systemic improvements, which can be designed to assist all professions involved in caring for patients at the end of life.** The authors say, “Clinicians should have at least generalist palliative care training” and be trained to collaborate with other health care workers in providing such care.

In addition to clinician training in communication and palliative care, the authors highlight the need for systemic and financing reforms across the board. **At present, they say, “Misaligned financial incentives work against dying patients’ choices, interests, and safety.” They point out that the 2014 IOM report recommends devising financial incentives for advance care planning and shared decision-making.**

**The article concludes by recognizing that much work remains to be done.** “More work is needed at all levels — to protect patients’ rights to choose care options, to improve the quality of clinical care and clinicians’ responsiveness to patients and families, and to create well-functioning health care finance and delivery systems that make high-quality care genuinely available.” (*NEJM*, 2/12, [www.nejm.org/doi/full/10.1056/NEJMms1410321](http://www.nejm.org/doi/full/10.1056/NEJMms1410321); [www.nejm.org/doi/full/10.1056/NEJMp1413167](http://www.nejm.org/doi/full/10.1056/NEJMp1413167); [www.nejm.org/doi/full/10.1056/NEJMp1411717](http://www.nejm.org/doi/full/10.1056/NEJMp1411717); *EurekaAlert*, 2/11, [www.eurekaalert.org/pub\\_releases/2015-02/thc-iec021115.php](http://www.eurekaalert.org/pub_releases/2015-02/thc-iec021115.php); *Medscape*, 2/11, [www.medscape.com/viewarticle/839629](http://www.medscape.com/viewarticle/839629); *Yahoo! News*, 2/11, [news.yahoo.com/doctors-own-end-life-planning-221754474.html](http://news.yahoo.com/doctors-own-end-life-planning-221754474.html))

## **WHICH PHYSICIAN IS BEST TO COUNSEL PATIENTS NEARING THE END OF LIFE?**

*The New England Journal of Medicine* recently published a clinical decision vignette about a 59-year-old breast cancer patient. After sharing the details and history of the woman’s illness, readers are asked to respond with their ideas about who should talk with the woman about her goals and plans for care? Should it be the primary care physician, the oncology team, or a palliative care physician? Several days from the publication, one hundred and nine responders wrote opinions, with 53 responding to each of the three choices. Covering the responses in *NEJM*, *Reuters* published, “Which doctors should ‘own’ end-of-life planning?”

Susan Tolle, developer of the POLST paradigm, believes the task of these difficult conversations should go the primary care physician. Tolle “maintains that without widespread intervention of primary providers, patients will be less likely to ensure their end of life wishes are honored.” Dr. Anthony Black, an oncologist, believes the task belongs to an oncologist, while

Dr. Diane Meier, Center for Advancing Palliative Care, says the conversation is the job of the palliative care specialist.

The case vignette and responses are online. (*NEJM*, 2/12, <http://www.nejm.org/doi/full/10.1056/NEJMc1411152>; *Reuters*, 2/11, <http://www.reuters.com/article/2015/02/11/us-end-of-life-planning-idUSKBN0LF2KW20150211>)

## **PBS FRONTLINE FEATURES GAWANDE AND END-OF-LIFE ISSUES**

**“If you knew you were dying, what would you do with the time you have left?” asks PBS *FRONTLINE* in a collection of online content released this week. *FRONTLINE* explores end-of-life issues, enlisting the help of Atul Gwanade, whose best-selling book, “Being Mortal”, explores many issues that physicians face caring for patients and families at the end of life. **PBS includes a feature article on how to talk with your doctor and loved ones about end-of-life issues.** They also include an interview with Dr. Gawande, a documentary short featuring the story of one family’s experience of end-of-life conversations, and an opportunity to participate in a live chat on the subject, “How would you spend your last days?”**

**For Dr. Atul Gawande, the subject of end-of-life care and conversations is personal.** As a practicing physician, Gawande remembers how the choice to engage in open and compassionate end-of-life conversations allowed his father “to make critical decisions about his treatment, and to focus on what mattered the most to him during the last few years of his life.” Such conversations are aided by the rise of palliative care medicine, which helps physicians to manage and incorporate conversations into the type of care that patients receive at the end-of-life.

**The first article released by PBS *FRONTLINE* focuses not only on the abstract importance of these conversations, but also provides a framework for how they can take place.** The most important thing is simply to have the conversation, and have it early. **“I think one mistake we often make is only having these difficult conversations when something’s going wrong,”** says Dr. Jennifer Temel, clinical doctor of thoracic oncology at Massachusetts General Hospital. But the most effective end-of-life conversations occur long before a crisis, allowing individuals and their families to have a clearer sense about general attitudes towards death and dying, and the kind of treatment each person would like to receive.

**“At the heart of these conversations is the question: What matters most to you?”** For many, it’s spending time with family. For others, independent living is the top goal. Some prefer being treated in the hospital, while many others want to stay at home as much as possible. Some individuals may prefer no treatment at all.

**Whatever the particular preferences of each individual, the *FRONTLINE* article emphasizes the importance of clear conversations, allowing people to express their hopes and fears, and to consider the limits and trade-offs of any decision that is made.** The article explicitly mentions hospice care, explaining how hospice is distinct from palliative care, and why it might be a good choice for many.

In an interview with *FRONTLINE*, Atul Gawande explains the importance of advance care planning for end-of-life care. **While it’s understandable that most of us don’t prefer to talk**

**about death, it's important that we have these difficult conversations so that we have a plan in place for the best possible experience at the end of life. In Gawande's words, "Hope is not a plan."**

**Dr. Gawande says that far too often, many crucial questions are going unasked.** Questions like: "What are your priorities if your time is limited? What are your goals for treatment? What are your fears? And what trade-offs are you willing to accept as a result of your care?" Above all, he says, the goal is to be governed not by fear, but instead by clear thinking and a solid understanding of what your end-of-life wishes really are.

For this kind of open and honest discernment to take place, the role of doctors is indispensable. **Unfortunately, Gawande says, many physicians are deeply uncomfortable with these difficult conversations, and especially the expression of strong emotions by patients and families.** "When people can cry or get angry... we don't know what to do with that." Dr. Gawande highlights the need for a palliative care consciousness to take hold in the medical community, encouraging doctors to be sensitive stewards of these crucial end-of-life discussions. **"Having this kind of conversation is radical because... in order to have that conversation, the doctor is spending more than half of the time listening rather than talking."**

**In an online video released on YouTube, *FRONTLINE* demonstrates what these conversations can look like.** In the documentary video "Debbie's dying wish," PBS portrays the end-of-life care that Debbie Whitmore and her family receive as she struggles with cancer over a period of several years. Viewers are given an inside look into the kind of frank, compassionate end-of-life conversations that she has with her oncologist, Dr. Jeff Meyerhardt.

**"The discussion is getting her to whatever quality of life we could get her to," says Meyerhardt in a video interview.** Later, after explaining the diminishing returns that they are seeing from aggressive cancer treatment, he asks Debbie directly, "What do you want to do?" When Debbie begins by saying, "Well, I guess I could do another round of treatment," Dr. Meyerhardt emphasizes that he is not asking her to do another round, he's asking her what she really wants. **In the words of her husband, "Do you want to endure another treatment? That's what it comes down to."** After considering it, Debbie does decide to proceed with another round of treatment.

**The video portrays the decisions that Debbie and her family make about fulfilling her fondest wish: Taking a family trip with her children to Disney World. Debbie is able to accomplish this wish, though her body begins shutting down before the trip is over and she is forced to return home. She spends her last days in hospice care.** (*FRONTLINE*, 2/10, [www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/facing-mortality-how-to-talk-to-your-doctor/](http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/facing-mortality-how-to-talk-to-your-doctor/); [www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/dr-atul-gawande-hope-is-not-a-plan-when-doctors-patients-talk-death/](http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/dr-atul-gawande-hope-is-not-a-plan-when-doctors-patients-talk-death/); [www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/what-matters-most-to-you-in-the-end/](http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/what-matters-most-to-you-in-the-end/); 2/11, [www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/how-would-you-spend-your-last-days-live-chat-3-p-m-et-on-thursday-212/](http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/how-would-you-spend-your-last-days-live-chat-3-p-m-et-on-thursday-212/))

## HOSPICE NOTES

\* **Several hospices have recently come to settlements with the US Department of Justice.** The settlements resolve allegations that these hospices submitted false claims for patients who were not terminally ill. The settlements for the hospice groups ranged from \$4 million to \$6.9 million. (DOJ, 2/10, [www.justice.gov/opa/pr/owner-miami-home-health-company-pleads-guilty-role-69-million-medicare-fraud-scheme](http://www.justice.gov/opa/pr/owner-miami-home-health-company-pleads-guilty-role-69-million-medicare-fraud-scheme); [www.justice.gov/opa/pr/iowa-home-care-company-pay-563-million-settle-false-claims-act-allegations](http://www.justice.gov/opa/pr/iowa-home-care-company-pay-563-million-settle-false-claims-act-allegations); *eNews Park Forest*, 2/6, [www.enevspf.com/latest-news/law-and-order/federal-and-international/58975-united-states-settles-false-claims-act-suit-against-good-shepherd-hospice-inc-and-related-entities.html](http://www.enevspf.com/latest-news/law-and-order/federal-and-international/58975-united-states-settles-false-claims-act-suit-against-good-shepherd-hospice-inc-and-related-entities.html); *Muskogee Phoenix*, 2/7, [www.muskogee phoenix.com/news/local\\_news/hospice-group-settles-allegations-for-m/article\\_49c57a28-ae87-11e4-81fe-17e38fd52c50.html](http://www.muskogee phoenix.com/news/local_news/hospice-group-settles-allegations-for-m/article_49c57a28-ae87-11e4-81fe-17e38fd52c50.html))

\* **NHPCO has formed a council to address the lack of hospice care utilization in diverse communities.** “As Americans celebrate Black History Month, hospice professionals acknowledge that hospice utilization within African American communities is disproportionately low. To help address this disparity in end-of-life care, the National Hospice and Palliative Care Organization has created a Diversity Advisory Council – a group of hospice and healthcare professionals and experts who will work to increase access to hospice and palliative care services.” (NHPCO, 2/11, [www.nhpco.org/press-room/press-releases/nhpco-announces-diversity-advisory-council](http://www.nhpco.org/press-room/press-releases/nhpco-announces-diversity-advisory-council))

\* **The Bloom Project is making sure that unsold flowers become bouquets for hospice patients this Valentine’s Day.** “Once complete, the flower bouquets will be delivered to hospice patients, brightening up what could be an otherwise dreary setting just in time for Valentine’s Day.” **Check out the video story online.** (*Oregon Live*, 2/11, [www.oregonlive.com/window-shop/index.ssf/2015/02/the\\_bloom\\_project\\_unsold\\_flowe.html](http://www.oregonlive.com/window-shop/index.ssf/2015/02/the_bloom_project_unsold_flowe.html))

## END-OF-LIFE NOTES

\* **Facebook users in the US can now designate a surrogate decision-maker for their digital profile.** Facebook has announced the “legacy contact” feature, which allows users to designate an individual who can manage a loved one’s Facebook account in the case of death or incapacitation. (*The Wall Street Journal*, 2/12, <http://www.wsj.com/articles/facebook-heir-time-to-choose-who-manages-your-account-when-you-die-1423738802>)

\* **Medicare spending peaks at age 96. A new study has found that Medicare per capita spending increases steadily with age, peaking just shy of the century mark.** (*The Wall Street Journal*, 2/10, [blogs.wsj.com/washwire/2015/02/10/medicare-spending-peaks-at-age-96/](http://blogs.wsj.com/washwire/2015/02/10/medicare-spending-peaks-at-age-96/))

\* **Oregon Health & Science University students are learning about - and practicing - end-of-life care conversations as a part of their coursework.** “At OHSU, the medical students meet six times with their patient, who’s called a teacher. But both people learn from each other.” (*Oregon Live*, 2/12, [www.oregonlive.com/health/index.ssf/2015/02/ohsu\\_prepares\\_students\\_for\\_end.html#incart\\_river](http://www.oregonlive.com/health/index.ssf/2015/02/ohsu_prepares_students_for_end.html#incart_river))

**\*How can you tell when a person is about to die from cancer?** Researchers at the University of Texas MD Anderson Cancer Center provide eight signs of imminent death from cancer, including nonreactive pupils, grunting, and gastrointestinal bleeding. (*Digest Club*, 2/8, [digest.club/article/c0ea2e77a17d15e4b44b15b3a522b320/](http://digest.club/article/c0ea2e77a17d15e4b44b15b3a522b320/); *Physicians Briefing*, 2/9, [www.physiciansbriefing.com/Article.asp?AID=696326](http://www.physiciansbriefing.com/Article.asp?AID=696326))

**\* The loved ones of brain-injured veterans may face health risks of their own.** “The caregivers reported having levels of grief that were similar to those of people who have lost a loved one.” (*HealthDay*, 2/9, [consumer.healthday.com/senior-citizen-information-31/caregiving-news-728/some-who-care-for-veterans-with-brain-injuries-face-health-risks-study-696184.html](http://consumer.healthday.com/senior-citizen-information-31/caregiving-news-728/some-who-care-for-veterans-with-brain-injuries-face-health-risks-study-696184.html))

**\* The iSAGE program at Stanford University is helping to educate Indian-American elders on end-of-life care.** “We should be more active physically, take care of our diets, exercise and interact more with seniors, but I feel we need more help from doctors, families and society also,” says Chandra Lakhini. (*New America Media*, 2/10, [newamericamedia.org/2015/02/stanford-program-educates-indian-american-elders-on-end-of-life-care.php](http://newamericamedia.org/2015/02/stanford-program-educates-indian-american-elders-on-end-of-life-care.php))

**\* Angelo Volandes asks, “Why Isn’t Healthcare More Like Starbucks?”** Starbucks honors consumer wishes and needs, says Volandes, and healthcare providers need to do the same. “The first, essential step toward a remedy lies with a return to the oldest tool in medicine’s proverbial black bag: talking with patients about their wishes for how they want to live their remaining time.” (*Forbes*, 2/12, [www.forbes.com/sites/matthewherper/2015/02/12/the-un-starbucks-success-to-american-health-care/](http://www.forbes.com/sites/matthewherper/2015/02/12/the-un-starbucks-success-to-american-health-care/))

**\* Palliative care is showing clear benefits for patients with advanced pancreatic cancer.** “Patients with advanced pancreatic cancer who received palliative care underwent less aggressive end-of-life treatment, required fewer hospital admissions and survived longer than those who did not receive palliative care, according to study results.” (*Healio*, 2/5, [www.healio.com/hematology-oncology/palliative-care/news/online/%7B38771139-3c0a-4e16-876f-2a139bebe4f3%7D/palliative-care-benefited-patients-with-advanced-pancreatic-cancer](http://www.healio.com/hematology-oncology/palliative-care/news/online/%7B38771139-3c0a-4e16-876f-2a139bebe4f3%7D/palliative-care-benefited-patients-with-advanced-pancreatic-cancer))

**\* Physician Jessica Nutik Zitter penned an opinion for *The New York Times*. Zitter shares about the inadequacy of many advanced directives by sharing the experiences of an ill patient who moved often between his nursing home and the hospital.** She graphically shares the horror of his experiences due, in part, to his own advance directive that asked for every intervention to keep him alive as long as possible. That was the course that was followed and, she says, “**I am sure that this poor man could not have known that his last days would look as they did. I, an I.C.U. physician, wouldn’t have imagined it in my worst nightmare.**” (*The New York Times*, 2/7, [http://opinionator.blogs.nytimes.com/2015/02/07/when-doing-everything-is-way-too-much/?emc=eta1&\\_r=1](http://opinionator.blogs.nytimes.com/2015/02/07/when-doing-everything-is-way-too-much/?emc=eta1&_r=1))

## PAS NOTES

**\* Lawmakers in Colorado have voted down a bill that would have legalized physician-assisted suicide in that state.** “By an 8-to-5 bipartisan vote, the so-called “Death with Dignity”

bill was rejected by the Public Health and Human Services Committee in the state's House of Representatives.” (Reuters, 2/7, [www.reuters.com/article/2015/02/07/us-usa-colorado-suicide-idUSKBN0LB07L20150207](http://www.reuters.com/article/2015/02/07/us-usa-colorado-suicide-idUSKBN0LB07L20150207))

**\* Legislation has been introduced in the Alaska House of Representatives that would allow terminally ill patients to end their own lives with the help of a physician. Re. Harriet Drummond (D) says it's not a question of suicide, but rather the right for terminally ill patients and their families' peace of mind.** (Wane, 2/10, [wane.com/2015/02/10/alaska-bill-would-let-terminally-ill-make-decision-to-die/](http://wane.com/2015/02/10/alaska-bill-would-let-terminally-ill-make-decision-to-die/))

\* Physician Aaron Kheriaty says, **“The debates on physician-assisted suicide have largely ignored what research in psychiatry and the social sciences has demonstrated about suicide.”** Kheriaty examines those research findings and the efforts to reduce suicides. “Social acceptance of physician-assisted suicide,” he says, “will undermine these efforts and place vulnerable individuals at risk.” (Orange County Register, California, 2/12, <http://www.ocregister.com/articles/suicide-651078-assisted-death.html>)

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