
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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ARTICLES ABOUT END-OF-LIFE TWEETING DRAW STRONG RESPONSE

***New York Times'* Op-Ed columnist Bill Keller and his wife Emma Keller have drawn heavy fire for articles they have written critiquing the dying process of one prolific social media user.** The controversy began with an article by Emma Keller published in *The Guardian*, in which she questions the tweeting of Lisa Adams, a 40-something mother of three who is publically chronicling her fight with terminal cancer. Following intense criticism of Keller's article, her husband, former *New York Times* editor and current Op-Ed columnist Bill Keller, wrote his own piece on Lisa Adams, published in *The New York Times*. Keller framed the issue in terms of his father-in-law's death and what it means to die with peace and dignity. Rather than calming the media storm, the piece stoked only more controversy, as more commenters, bloggers and journalists questioned the motivations and integrity of both Kellers.

Emma Keller question Adams' extremely active use of social media (she has tweeted more than 165,000 times), asking whether "her tweets [are] a grim equivalent of deathbed selfies, one step further than funeral selfies?" **In her article, Keller labels Adams' social media use as "compulsive," and questions whether Adam's saga represents a disturbing new trend, a "new way of death."** At times, she seems to question whether Adam's care might be too expensive. "[Adams] describes a fantastic set up [at her hospital], where she can order what she wants to eat at any time of day or night and get as much pain medication as she needs from a dedicated and compassionate "team," but there is no mention of the cost."

The article published in *The Guardian* drew such furious reaction from readers that it was taken down just days after it was published. At first, the explanation given was that *Guardian* staff had deemed it "inconsistent" with its "editorial code." Soon, however, this explanation was replaced with a more ominous note: **"This post has been removed pending investigation."** **The Washington Post reports that, "Keller quoted an exchange of direct messages with Adams without Adams' knowledge or permission, a violation of journalism ethics."**

In an update to her original article, **Keller acknowledged that when she communicated with Adams she did not reveal that she was working on a newspaper article, nor that their communications would be made public.** The *Washington Post* quotes her as writing, **"Given her health, I could have given [Adams] advance warning about the article and should have told her that I planned to quote from our conversations. I regret not doing so."**

As controversy continued to unfold around the *Guardian* piece, husband Bill Keller published his own editorial on Lisa Adams. In his piece, Keller compares Adams' battle against cancer to the end-of-life experience of his father-in-law, who died in a "calm" manner. Keller questions the benefit of Adams' decision to "treat her terminal disease as a military campaign."

He quotes Steven Goodman, associate dean of the Stanford University School of Medicine, who Keller says "cringes at the combat metaphor, because it suggests that those who choose not to spend their final days in battle, using every weapon in the high-tech medical arsenal, lack character or willpower." **Keller quotes Goodman, after examining Adams' blog, "I'm sure it has brought meaning, a deserved sense of accomplishment. But it shouldn't be unduly praised. Equal praise is due to those who accept an inevitable fate with grace and courage."**

With both Kellers now having published articles questioning the wisdom of a dying mother's end-of-life decisions, both writers are drawing fury from both left and right. John Nolte excoriates Bill and Emma Keller in a piece for the conservative blog, *Breitbart.com*. Nolte argues, "The Kellers are engaging in *life shaming*... What the Kellers appear to be doing is worse than lobbying for euthanasia, which at the very least is a personal decision. From their elite perches, the Kellers are tag-teaming a woman hospitalized with Stage IV cancer as a selfish and narcissistic financial drain..." **Nolte brandishes the Keller's articles as further evidence of an Obamacare mindset gone amok.** "The left's mask of compassion slipped late last year as they attempted to dismiss millions losing their health insurance as an overall positive. And now the Kellers have given us another chilling example of those who are all too eager to sacrifice a few to serve some cold robotic vision of a cold robotic Utopia."

On the other end of the ideological spectrum, Katie Halper writes an essay for *Feministing.com*, entitled, "Former NYT editor mansplains to cancer patient to shut up and die the right way." In spite of the title, Halper criticizes both Kellers, rehashing the original *Guardian* article that ignited the controversy, before turning to Bill Keller's piece in *The New York Times*, concluding, "Bill would be wise to stop playing doctor..."

In an opinion piece published by *Reuters*, Anne Taylor Fleming takes issue with the tone of Emma Keller's essay. "For starters," she writes, "Do you really want to be hip and clever by tossing around the word 'selfie' when talking about someone dying? Death, after all, can be pretty personal." **Fleming sees a difference between Emma Keller's essay and that of her husband, however.** While the former "may sound a bit mean-spirited... Her husband's remarks, more sober and big picture, are aiming at something larger... He is examining one of today's hot topics: How to Die." **Unfortunately, says Fleming, while the issues that Bill Keller is seeking to engage are important and worthwhile, "the problem is that he is doing it over Adam's failing body. He's got the wrong person, the wrong patient."**

As for Adams herself, the tweets continue. To Bill Keller she tweeted, "The main thing is that I am alive. Do not write me off and make statements about how my life ends TIL IT DOES, SIR." (*The New York Times*, 1/12, www.nytimes.com/2014/01/13/opinion/keller-heroic-measures.html?partner=rssnyt&emc=rss&_r=1; *The Washington Post*, 1/13, www.washingtonpost.com/lifestyle/style/former-nyt-editor-bill-keller-and-his-wife-under-fire-for-commentary-on-cancer-patient/2014/01/13/d40a0ac4-7ca0-11e3-93c1-0e888170b723_story.html; *Reuters*, 1/15, www.reuters.com/article/2014/01/15/fleming-death

idUSL2N0KP1GI20140115?feedType=RSS&feedName=rbssHealthcareNews; *The Guardian*, 1/8, web.archive.org/web/20140109033020/http://www.theguardian.com/commentisfree/2014/jan/08/lisa-adams-tweeting-cancer-ethics [archived]; *Breibert*, 1/14, www.breitbart.com/Big-Journalism/2014/01/14/ex-NY-Times-editor-to-cancer-patient-go-gently-save-us-money; *Feministing*, 1/14, feministing.com/2014/01/14/former-nyt-editor-mansplains-to-cancer-patient-to-shut-up-and-die-the-right-way/; *Slate*, 1/14, http://www.slate.com/articles/double_x/doublex/2014/01/bill_keller_on_lisa_adams_tweeting_and_blogging_her_cancer_all_wrong.html)

HOSPICE NOTES

* **MEDPac’s website has the Dec. 13, 2013, presentation on “Assessing payment adequacy and updating payments: hospice services.”** The presentation reports that in 2012: Hospices served 1.27 million persons; Medicare spent \$15 billion on hospice; Average length of stay is up from 86 days in 2011 to 88 days in 2012; and Margins average 8.7%. *Mondaq* noted that Medicare expenditures on hospice are “a small fraction of the Medicare spend,” and “**MEDPac staff recommended no 2015 payment adjustment.**” The complete presentation is on the MEDPac website. (*Mondaq*, 1/15,

<http://www.mondaq.com/unitedstates/x/286114/Healthcare/MEDPacs+View+Of+The+Hospice+Benefit+December+Meeting+Update>; *MEDPac Website*, 12/2013, http://www.medpac.gov/meeting_search.cfm?SelectedDate=12/12/2013&t=m&month=2013-12)

* **Why do Latinos use hospice and palliative care in lower proportions than whites?** An article in *Reflejos* notes the continuing disparity among Latinos in end-of-life care and examines the cultural and economic roots of this problem. (*Reflejos*, 1/12, www.reflejos.com/en/stories/health/article/14-01-12/los_latinos_en_eeuu_no_usan_los_servicios_paliativos.aspx)

* **What happens to undocumented immigrants who become terminally ill?** *New America Media* highlights the difficulties faced by undocumented individuals who are facing the end of life. (*New America Media*, 1/6, newamericamedia.org/2014/01/undocumented-and-dying-latinos-may-find-comfort-in-final-journey-home.php)

* **When is it appropriate to treat terminally ill patients with antibiotics?** “The role of antibiotics in hospice is far from clear cut,” writes Alex Smith for *Geripal*, who calls for researchers to bring greater clarity to this area of medicine. (*Geripal*, 1/15, www.geripal.org/2014/01/antibiotics-in-hospice.html)

* **Hospitalization is often avoidable in gastrointestinal cancers, writes Charles Bankhead for *Medpage Today*.** “An oncologist’s advice to consider hospice care significantly increased the likelihood of avoidable hospitalization among patients with advanced gastrointestinal (GI) cancers.” (*Medpage Today*, 1/14, www.medpagetoday.com/HospitalBasedMedicine/GeneralHospitalPractice/43808)

* **Dr. Ira Byock is featured in an article in *The Union Leader*, which highlights the importance of earlier admission into hospice care.** “Nearly half... of [New Hampshire] patients were in the hospital for fewer than 30 days, and 28 percent received care for less than one week.” (*The Union Leader*, 1/12, www.unionleader.com/article/20140112/NEWS12/140119839/0/FRONTPAGE)

* **All hospice patients are not the same, reports a study published in *The Journal of Palliative Medicine*.** The report examines variables that “could help hospices to better anticipate patient needs and staff workload, and could be used to guide strategic planning as hospices take part in accountable care organizations.” (*The Journal of Palliative Medicine*, 12/10 [online], online.liebertpub.com/doi/abs/10.1089/jpm.2013.0109#utm_source=FastTrack&utm_medium=email&utm_campaign=jpm)

* **A recent article shares how one hospice works to get all staff engaged in financial concerns.** The leaders of Hospice by the Bay describe how the organization promoted good collaboration between the clinical and financial divisions of the organization. “Working on those relationships... enables staff to practice hospice values of respect, service excellence and teamwork in daily jobs.” (*Health Resources Publishing*, 1/13, healthrespubs.com/hospice-and-palliative-care-news/2014/01/13/money-matters-helps-bridge-gaps-between-hospice-clinicians-and-finance)

* **High school students learn about hospice care, receive training and then serve as volunteers.** An article in *The Fay Observer* highlights the positive experience of high school students participating in programs that aim to teach youth about “the process of death and dying and to be able to help those in hospice care.” (*The Fay Observer*, 1/8, www.fayobserver.com/living/article_c33bc1a6-e97b-53f1-a302-ca5c1536db9e.html?mode=jqm)

END-OF-LIFE NOTES

* **NBC News features a nightly news segment on how to have end-of-life conversations.** Dr. Nancy Snyderman interviews her own parents, describing the process of taking increasing care for them as they grow older. The TV segment is in video format, but also includes text online. The website includes links to numerous resources. (*NBC News*, 1/16, dailynightly.nbcnews.com/news/2014/01/16/22328150-resources-how-to-start-conversations-about-end-of-life-issues?lite)

* **How do we define death? According to Sharon Kaufman, PhD: Very ambivalently.** Writing for *The Huffington Post*, Kaufman examines the difficulties that we face in knowing when someone in a vegetative state is effectively deceased, or whether they are merely seriously ill. (*The Huffington Post*, 1/17, www.huffingtonpost.com/american-anthropological-association/defining-death-four-decades-of-ambivalence_b_4617991.html)

* **What are the ethics of saving a life that is nearing its natural end?** David Baker speaks of his experience as a physician, caring for patients who are in the last stages of life and wondering how much really ought to be done. (*Lompoc Record*, 1/17,

www.lompocrecord.com/news/opinion/editorial/commentary/the-ethics-of-saving-a-life-nearing-its-natural-end/article_7c316986-7f3f-11e3-862d-0019bb2963f4.html)

* **End-of-life care would benefit from a national dialogue, writes John Schiller, Esq., for *Managed Health Care Executive*.** Schiller hopes the issue will get the attention needed and that “policies will be refined and developed that will move our country forward to a more sensible, consistent, compassionate and cost-effective approach to end-of-life care.” (*Managed Health Care Executive*, 12/16, managedhealthcareexecutive.modernmedicine.com/managed-healthcare-executive/news/end-life-care-third-rail-healthcare-policy)

* **Hilary Young of the Huffington Post encourages her readers to begin thinking about end-of-life care.** Young describes the process of advance care planning, explaining the importance of investing time and effort into expressing and documenting wishes for the end-of-life. (*The Huffington Post*, 1/14, www.huffingtonpost.com/hilary-young/are-you-thinking-about-end-of-life-care_b_4590795.html)

PALLIATIVE CARE NOTES

* **It doesn’t make sense to imagine palliative care patients as “rational consumers.”** “Consumerism in health care defines patients as self-determined, rational customers. Yet, it is questionable whether vulnerable patients, such as the terminally ill, also fulfill these criteria,” explains a report published in *The Journal of Palliative Medicine*. “Self-determination must be understood in relational terms, regardless of whether the customer or patient role is preferred.” (*The Journal of Palliative Medicine*, 1/10, online.liebertpub.com/doi/abs/10.1089/jpm.2013.0141#utm_source=ETOC&utm_medium=email&utm_campaign=jpm)

* **“The Colorado Board of Health unanimously approved a definition and set of standards for palliative care for the health care community.”** The process of reaching this point of standardization began in 2009, and was spearheaded by the Colorado Center for Hospice and Palliative Care. (*Colorado Hospice*, 1/17, www.coloradohospice.org/2014/01/17/palliative-care-standards-approved-by-board-of-health/)

* **An article in *The St. Louis American* highlights the benefits of palliative care for those suffering serious illness.** “A campaign just launched by the National Institute of Nursing Research... aims to increase the use of palliative care for children with serious illness.” (*The St. Louis American*, 1/16, www.stlamerican.com/your_health_matters/health_news/article_f56e1f24-7e6d-11e3-9db5-0019bb2963f4.html)

* ***The Miami Herald* highlights the work of “a pioneering palliative care program,” at Miami’s Broward Health.** “We call it ‘walking alongside the patient,’” explains Dr. Pamela Sutton, who established the program in 1994. (*The Miami Herald*, 1/13, www.miamiherald.com/2014/01/13/3870391/a-pioneering-palliative-care-program.html)

OTHER NOTES

* **New Mexico's Judge Nan Nash has ruled, "The ability of competent, terminally ill patients to choose aid in dying is a fundamental right under the state constitution."** (*KRQE*, 1/13, www.krqe.com/news/local/judge-allows-physician-assisted-death)

* *Medscape* **highlights the issue of waste in the ICU, and suggests what can be done to decrease it.** The article suggests that it is unreasonable to expect ICU doctors to spend unlimited funds on each patient. "Rationing is unavoidable. You cannot reconcile boundless needs to bounded funds." **In order to reduce waste, *Medscape* lists five specific practices that should be avoided to save resources in critical care.** (*Medscape*, 1/13, www.medscape.com/viewarticle/819057)

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