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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

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## **MASSACHUSETTS FOCUSES ON IMPROVING END-OF-LIFE CARE**

**Massachusetts Coalition for Serious Illness Care wants to improve end-of-life care in the state.** Representatives from fifty-eight organizations met on May 12 for the launch of the effort. “The coalition is chaired by Atul Gawande, executive director of Ariadne Labs, a joint center of Brigham and Women’s Hospital and Harvard T.H. Chan School of Public Health and author of *Being Mortal: Medicine and What Matters in the End*, and by Maureen Bisognano, former president and CEO of the Institute for Healthcare Improvement.”

**Outcomes of a statewide survey of 1851 citizens were revealed at the May 12 meeting. Among the findings of the survey:**

Fifteen percent of respondents had talked with healthcare providers about their wishes in end-of-life care.

Eighty five percent of respondents believe these conversations with healthcare providers should happen.

In terms of how loved one’s wishes were honored at the end of life, 52% responded that the wishes are followed “very much.”

Of respondents, 45% have named a healthcare agent. Eighty-six percent of those have discussed their wishes with their agents.

Twenty percent of those who had a loved one die in the past year reported that their end-of-life care was fair or poor.

**The coalitions has goals** of encouraging patients and physicians to have these important discussions about patients’ wishes, to be sure that people name a healthcare “decision maker,” and to make certain that patients’ preferences are honored. The coalition will also focus on assuring that physicians are trained to have these important conversations, and to see “that systems are in place to document and carry out patients’ wishes.” To help the coalition reach its goals, Blue Cross and RxFoundation will support the coalition with up to \$200,000 per year. Some of the funding will cover repeating the survey “to measure the campaign’s effectiveness.” Each of the coalition’s member organizations will have a task and/or goal for its work.

“**People have priorities in their lives besides just living longer,**” Gawande said in a statement. “They have goals and aims for the quality of their life, too. This survey shines a light on the need to ask people about what those priorities are— and then to ensure that they are honored.” **“When people voice their wishes and doctors honor them, Gawande said, patients spend less time in intensive care and more time at home, suffer less at the end of life, and even live longer.”** (*Boston Globe*, 5/11, <https://www.bostonglobe.com/metro/2016/05/11/wishes-for-end-life-care-often-ignored-survey->

[finds/Pna4jQN3V1MqxYKTJWLFaP/story.html](https://www.masslive.com/politics/index.ssf/2016/05/end-of-life_care_coalition_lau.html); *MassLive*, 5/12, [http://www.masslive.com/politics/index.ssf/2016/05/end-of-life\\_care\\_coalition\\_lau.html](http://www.masslive.com/politics/index.ssf/2016/05/end-of-life_care_coalition_lau.html); *Boston Globe*, 5/13, <https://www.bostonglobe.com/metro/2016/05/12/new-coalition-confronts-fear-distrust-end-life-care/LNIdb2PY1yvGTUdISdlyHK/story.html>)

## **“COMPASSION FATIGUE” IMPACTS QUALITY OF CARE**

**Janet Abraham, MD, FACP, with the division of adult palliative care at Harvard Medical School, offered a presentation at the American College of Physicians Internal Medicine Meeting.** Abraham explained that physicians who frequently talk to patients about end-of-life issues suffer from “compassion fatigue” because what is hoped for and what happens are troublingly different. Doctors often do not recognize or process their own grief. This can feed a sense of failure and frustration that is sometimes “accompanied by stress-related medical problems, anxiety and depression, substance abuse and family disruption.” Compassion fatigue can also impact the care of other patients, as physicians may detach and depersonalize patients as a way to cope with burn out.

Sometimes, she says, **“Patients and their families can accuse physicians of ‘taking away’ their hope, which can have a significant effect on their professional identity.”** There are moments when doctors feel thrown off balance by something a patient has said, or feel that their identity as a healer has been questioned. At these times, Abraham encourages physicians to “recognize that’s a hit on your identity, and you need to stop. You might need to pretend your beeper went off, and go out on the roof for a second, and regather yourself, because it can affect your judgment, and it can affect the things you offer the patient.”

Abraham says that one way to combat these difficult feelings is in “specifically identifying patients with 1 to 2 years to live, putting them on a palliative care list, finding their healthcare proxies and ensuring their families understand their loved one’s disease is incurable, making the prognosis clear and supporting family members in this distress.” Debriefing and sharing about difficult patients and situations with colleagues is also a helpful practice. (*Healio*, 05/07, [www.healio.com/family-medicine/hospice-and-palliative-care/news/online/%7B0daf3f5e-49d3-41fa-9ded-e2b02f7a4b36%7D/avoiding-compassion-fatigue-in-palliative-end-of-life-care](http://www.healio.com/family-medicine/hospice-and-palliative-care/news/online/%7B0daf3f5e-49d3-41fa-9ded-e2b02f7a4b36%7D/avoiding-compassion-fatigue-in-palliative-end-of-life-care))

## **HOSPICE NOTES**

**\* Leaders from Compassion and Choices applaud the Medicare pilot project that allows some hospice beneficiaries to receive hospice and curative therapies concurrently.** The Medicare Choices Model program has over 140 hospices in 39 states. Barbara Mancini, nurse and consultant for Compassion & Choices, and Mark Dann, federal affairs director for Compassion & Choices, quote Dr. Diane Meier as saying that patients who receive both palliative and curative care simultaneously live longer than those who get only “life-prolonging treatment alone.” “It makes sense. People aren’t in excruciating pain, they’re not depressed and their families feel confident in their ability to care for their loved one.” (*The Cap Times*, 5/15, [http://host.madison.com/ct/opinion/column/barbara-mancini-and-mark-dann-a-better-model-for-hospice/article\\_50a19e39-8a3c-5f81-8a19-eafcdc067952.html](http://host.madison.com/ct/opinion/column/barbara-mancini-and-mark-dann-a-better-model-for-hospice/article_50a19e39-8a3c-5f81-8a19-eafcdc067952.html))

**\* We Honor Veterans, an NHPCO program, is part of the care offered at SSM Health at Home Hospice in St. Louis.** The program serves veterans by thanking them for their service and connecting patients who are veterans with services they need. Often this recognition allows veterans an opportunity to talk about their experiences in a way they have not done before. The program coordinator, Richard Dederer, a veteran himself, explains, “When a veteran is given a terminal diagnosis, a lot of the previous wounds of service come bubbling to the surface. The program gives us an opportunity to talk about that, and gives the veteran avenues to process that.” (*Hospitals and Health Networks*, 05/11, [www.hhnmag.com/articles/7196-veteran-takes-end-of-life-care-to-a-new-level?utm\\_campaign=051116&utm\\_medium=email&utm\\_source=hhndaily&utm\\_source=hhndaily&utm\\_medium=email&utm\\_campaign=051116&eid=256211848&bid=1401262](http://www.hhnmag.com/articles/7196-veteran-takes-end-of-life-care-to-a-new-level?utm_campaign=051116&utm_medium=email&utm_source=hhndaily&utm_source=hhndaily&utm_medium=email&utm_campaign=051116&eid=256211848&bid=1401262))

**\* Elaine McIntosh, president and CEO of Kansas City Hospice, and Dr. Ann Allegre, recently retired medical director for the hospice, discuss the changes they have seen in hospice and end-of-life care.** Both long-term hospice leaders “acknowledge that more work is needed to ease the pain and suffering of the most ailing patients.” The *KCUR* radio program is available online. (*KCUR*, 5/11, <http://kcur.org/post/hospice-and-palliative-care-continues-evolve#stream/0>)

**\* Florida’s Covenant Hospice has changed its name to Covenant Care, signaling its “commitment to expand its service offerings beyond its core hospice services.”** Covenant acquired Peoples Home Health. “Our rebranding signaled the beginning of our transformation to an integrated, comprehensive post-acute provider,” said Jeff Mislevy, Covenant Care’s President and CEO. “That platform shift is in direct response to the revolutionary changes occurring throughout healthcare.” (*Business Wire*, 5/9, <http://www.businesswire.com/news/home/20160509006465/en/Covenant-Care-Acquires-Peoples-Home-Health>)

**\* A study in the *Journal of American Geriatrics Society* examines the rates at which physicians utilize hospice for themselves as they near life’s end.** The study discovered that “US physicians are more likely to use hospice and intensive or critical care units in the last months of life than non-physicians. Hospitalization rates were similar.” (*Wiley Online Library*, 5/16, <http://onlinelibrary.wiley.com/doi/10.1111/jgs.14112/abstract?campaign=wolearlyview>)

**\* The National Partnership for Hospice Innovation (NPHI) is a coalition of not-for-profit hospices that work together “to influence the future of hospice and advanced illness care through innovation and collaboration.”** An article in *The Davis Enterprise*, in California, published an article about an April Senate Briefing held in DC. Highlights from the event, “30+ Years of Person-Centered Care: Innovations in Hospice and the Future,” are covered in the article. (*The Davis Enterprise*, 5/15, <http://www.davisenterprise.com/local-news/news-columns/yolo-hospice-caring-voices-from-capitol-hill/>)

**\* California’s Ann Marie Chiasson is a hospice physician who says she will not participate in physician-assisted suicide. What she will do, she offers, is help her patients understand that they can control when they die, by deciding to refuse food and water.** Says Chiasson, “While legislators decide what is legal and not legal, and while doctors decide if they will or won’t write suicide prescriptions, if you are at the end of your life and you want more control,

just turn off the IV. Say no to the food, yes to ice chips, and then rest. Turn on some music; look out the window. The body knows how to die. You know how to die. It is gentle and easy. This I will help my patients do.” As of 5/16, there are several online responses to Chiasson, and all disagree with her stance. (*Los Angeles Times*, 5/12, <http://www.latimes.com/opinion/op-ed/la-oe-chiasson-physician-assisted-suicide-20160511-story.html>; *Los Angeles Times*, 5/16, <http://www.latimes.com/opinion/readersreact/la-le-0515-sunday-end-of-life-law-dying-20160515-story.html>)

## PALLIATIVE CARE NOTES

\* **A study in *Journal of Palliative Medicine* looked at demographic and psychological predictors of trust in the medical profession among cancer patients receiving palliative care.** The researchers found that high levels of trust were associated with older, less depressed, and more hopeful patients. They also found “that a single 0–10 item trust scale was found to perform adequately compared with a multiple-item questionnaire.” (*Journal of Palliative Medicine*, 05/05, [online.liebertpub.com/doi/abs/10.1089/jpm.2016.0089#utm\\_source=FastTrack&utm\\_medium=email&utm\\_campaign=jpm](http://online.liebertpub.com/doi/abs/10.1089/jpm.2016.0089#utm_source=FastTrack&utm_medium=email&utm_campaign=jpm))

\* **Researchers asked parents of young children who were referred to palliative care about the religious and spiritual care they received.** In the results, published in *Journal of Palliative Medicine*, the majority of parents wanted the medical team to speak to them about their religious or spiritual needs, but fewer than half had that conversation. Those who did have their spiritual needs assessed reported feeling a higher level of care from the palliative care team. Those who used hospital-based religious resources reported increased spiritual comfort. (*Journal of Palliative Medicine*, 05/02, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0509#utm\\_source=FastTrack&utm\\_medium=email&utm\\_campaign=jpm](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0509#utm_source=FastTrack&utm_medium=email&utm_campaign=jpm))

## OTHER NOTES

\* **“On Mother’s Day My Mom Asked Me to Help Her End Her Life” tells the story of Alex Schlempp and his mother, Giuliana.** Told that her cancer leaves only four to six months to live, she asked Schlempp to help her end her life before the cancer did. Schlempp feels conflicted about her decision and his role in it, but ultimately decides it is moral. They consider several options in the United States and Europe, and end up in Switzerland where his mother is able to take her own life in a clinic. (*Enquirer*, 05/05, [www.esquire.com/news-politics/a44491/assisted-suicide-mothers-day/](http://www.esquire.com/news-politics/a44491/assisted-suicide-mothers-day/); *MRC Newsbusters*, 05/10, [newsbusters.org/blogs/culture/katie-yoder/2016/05/10/esquire-cosmo-promote-story-sons-gift-death-mom](http://newsbusters.org/blogs/culture/katie-yoder/2016/05/10/esquire-cosmo-promote-story-sons-gift-death-mom))

\* **DeadSocial is “an online service that helps people prepare their "digital legacy" that will remain online after they've died.”** The site allows users to schedule posts to be published on their social media accounts after they have died. While it is currently free, people do have to sign up during specific enrollment periods. DeadSocial also offers resources about how to make decisions about social media for family and loved ones. (*Tech Insider*, 05/10,

[www.techinsider.io/what-is-dead-social-2016-5](http://www.techinsider.io/what-is-dead-social-2016-5))

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