
HOSPICE NEWS NETWORK

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

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APPLYING THE NEW YORK FAMILY HEALTH CARE DECISIONS ACT TO HOSPICE PATIENTS

Kathy McMahon, President and CEO of the Hospice and Palliative Care Association of New York State, has written an article on New York State's Family Health Care Decisions Act (FHCDA). The article appears in the latest issue of the New York State Bar Association's (NYSBA) *Health Law Journal*. First introduced in 1993, the law finally passed in 2010. It establishes the rules for decision-making for patients who do not have the capacity to do so for themselves and who have not designated a proxy or established advance directives. As written, however, the law only applies to surrogate decision-making in hospitals and long-term care facilities, not to hospices.

McMahon briefly discusses hospice, and illustrates the less-than-optimal end-of-life care received by a cancer patient when his wife was not allowed to elect hospice for him. **McMahon points out that hospices fit into the FHCDA structure, as they are highly regulated and certified by both state and federal organizations. They can meet FHCDA standards pertaining to ethics committees, processes for determining capacity, process and procedures for making decisions at the end of life, and decision-making for patients who lack capacity but have no one who fits the listed FHCDA hierarchy.**

McMahon concludes, **"We are now in year eighteen of the struggle for a health care decision-making process that supports access to hospice. Will 2011 be the year? We certainly hope so. The Task Force on Life and Law is to be commended for their comprehensive report and thoughtful consideration of the issues. The Legislature should act quickly to adopt the Task Force's recommendations, and apply the FHCDA to decisions relating to hospice."**

The publication also contains a letter to New York legislators from Beth E. Roxland, Executive Director of the New York State Task Force on Life and the Law. The letter accompanies the Task Force's recommendations regarding FHCDA and Hospice. The recommendations document discusses FHCDA, the provision of hospice in the state, and barriers to surrogate decision making regarding hospice.

The task force recommends amending the FHCDA to 1) Allow hospice-eligible patients who cannot make decisions on their own the ability to have a surrogate appointed to make hospice decisions; 2) Apply presumptions and procedures similar to those currently in the FHCDA in determining whether a potential hospice patient lacks the capacity for decision-making, and to the selection of the surrogate; 3) Allow surrogates to elect hospice care for patients regardless of the patient's place of residence; and, 4) Authorize the surrogate to

make decisions for all care in hospice, using standards and oversight mechanisms similar to those in FHCDA. (*Health Law Journal*, NYSBA, Spring/2011,16(1):49-50)

SHARED DECISION-MAKING IMPORTANT IN EOL CARE

At Dartmouth College's annual "Law Day," a panel of experts discussed the benefits of shared decision-making, "a process that includes collaborative patient-physician discussion regarding the multitude of health care options." Elliot Fisher, professor of community and family medicine at Dartmouth Medical School, said that shared decision-making "has become important in discussions of patients' rights to end-of-life care."

The director of the Center for Informed Choice for The Dartmouth Institute for Health Policy and Clinical Practice said, "Shared decision making operates under the assumption that not only do informed patients make better decisions, but that patients should have a say in medical decisions."

Ben Moulton, professor at the Harvard School of Public Health, cited public belief that only physicians should mediate medicine as one barrier to shared decision-making, and the tendency of health systems to reward action rather than "watchful waiting" as another.

Fisher and others think that the states will mandate shared decision-making before the federal government gets around to it. California has already done so, in the aftermath of a patient's horrendous death and the family lawsuit against his health care personnel for not treating his pain adequately.

Fisher also said that shared decision-making lets facilities cut costs even while honoring patient preferences. "It's not about death panels," he said. "Shared decision making and health care reform has to be implemented because the current system is bankrupting states. There's an ethical imperative to allow patients to make informed decisions." (*The Dartmouth*, 5/2, thedartmouth.com/2011/05/02/news/panel)

SPECIAL DISASTER RELIEF NOTE

* Through May 15, Hospice Foundation of America will match all individual or corporate contributions up to \$100 made to HFA for the Alabama Hospice Organization disaster relief effort. Contact them at www.hospicefoundation.org/donate. The National Hospice Foundation is also making funds available to the Alabama Hospice Organization. See www.nationalhospicefoundation.org/i4a/forms/form.cfm?id=60&pageid=436&showTitle=0 to make donations. (*Hospice Foundation of America*, www.hospicefoundation.org/; *National Hospice Foundation E-mail*, 5/4)

PAIN & MEDICAL MARIJUANA NOTES

* Presenters at the 2011 American Academy of Pain Medicine meeting reported that human chorionic gonadotropin gave relief to eight of twelve patients with intractable pain. The eight patients continued their doses for over a year, and reported no side-effects. They reported "increased energy, improved mental concentration and memory, less depression, and fewer pain

flares. Seven of the 8 (87.5%) reduced their opioid use by 30 to 50%.” (*American Academy of Pain Medicine*, www.painmed.org/library/posters/poster-164/)

* **Mike Hyde was watching his two-year-old son Cash die before his very eyes, not only from the brain tumor that could only be 10% resected, but from the 40 days of pain, the drugs to kill the pain which didn’t work, and the vomiting. Desperate, Mike got some cannabis oil, which was fed to Cash in tiny amounts through his feeding tube.** Immediately, he was hungry, and did his last round of chemo with no nausea medication. No doctors or nurses would agree to talk to *KXLY* about medical marijuana for a child that young, but Mike Hyde “doesn’t care about the controversy or the political battle over this drug. He cares that his son survived and is convinced not only did the cannabis help Cashy feel better, it prevented long-term damage to his organs. For Mike, the proof is in his vibrant two-year old boy.” Cash has just had a check-up as is cancer-free. (*KXLY*, 4/28, www.kxly.com/news/27706509/detail.html)

* **“Handbook of Pain Relief in Older Adults: An Evidence-Based Approach” is reviewed in a recent *JAMA*. The reviewer says, “In a fascinating way, gerontologist F. Michael Gloth and his interdisciplinary team provide the reader with the opportunity to follow” the development of an “evidence-based foundation for the diagnosis, treatment, and prevention of pain.”** He adds, “The chapter authors show great skill in integrating up-to-date evidence-based information, at times citing relevant guidelines... in such a way that the book becomes a direct source of understandable and detailed recommendations for the attentive reader. However, evidence-based medicine is not presented uncritically, and potential causes of bias are revealed: for example, the conditions under which research data are obtained. The text likewise includes essential background information about what is special in older adults, as well as epidemiologic data.” (*JAMA*, 2011;305(17):1820-1811, dx.doi.org/10.1001/jama.2011.568)

PUBLIC POLICY NOTES

* ***McKnight’s Long-Term Care News* reports that CMS’ proposed Hospice Wage Index for Fiscal Year 2012 would lower Medicare hospice payment rates by \$80 million in 2012.** The proposal, which also includes the implementation of a quality reporting program, contains a 15% BNAF along with the phased-out BNAF, for a total reduction in 2012 of 40%. The rule also revises the face-to-face visit standards when recertifying terminal illnesses. The rule is online at www.ofr.gov/OFRUpload/OFRData/2011-10689_PI.pdf. (*McKnight’s Long-Term Care News*, 5/2, www.mcknights.com/cms-rule-would-lower-hospice-payment-rates-by-80-million/article/201813/)

* **An article in *The New York Times* says that the medical marijuana business is growing as some states attempt to regulate it, and that the federal government is again weighing in with a heavy hand. Supporters of medical marijuana say the Justice Department is “sending mixed signals,” with a 2009 “clear memo” saying that the focus would not be “on individuals whose actions are in clear and unambiguous compliance with existing state laws providing for the medical use of marijuana.”** Recently, however, federal prosecutors have authorized raids and sent “strongly-worded letters” to the governors of several states about the sale of medical marijuana in those states. A Justice Department spokesman says, “This is not a change in policy. It’s a reiteration of the guidance that was handed down in 2009 by the deputy attorney general.” (*The New York Times*, 5/7, www.nytimes.com/2011/05/08/us/08marijuana.html)

HOSPICE & PALLIATIVE CARE NOTES

* **The Hospice of Central Ohio offers a Motherless Daughters Support Group for women who have lost their mothers later in life.** The group's facilitator, Kathy Cox, says that the grief of a young woman losing her mother is different than that of an older daughter. The situation is especially difficult if the two women have not had a close relationship, Cox said, as the grief is more emotional and laden with guilt. Of the loss of her mother, one participant said, "It makes you feel older. It hits you in the face. Mothers seem to be the glue that keeps us (the family) together. Men don't seem to have that." (*Newark Advocate*, 5/8, www.newarkadvocate.com/article/20110508/NEWS01/105080304/Hospice-Central-Ohio-group-helps-women-cope-loss-moms)

* **A group of palliative care specialists at the University of California, San Francisco, are developing a website that will give a "reasonably accurate" prognosis of your life span, given your history and your health. The researchers, "uneasy" about how laypeople might use such a website, are soliciting comments from the public.** They'd like to know the following: "Would you find such a site useful in guiding your own or your elderly parents' care? Would you be angry if it were restricted only to professionals? What would you do with the information? Do you want for us to post the site's name and U.R.L. when it's up and running?" **You can post your answers on *The New York Times* website at the link below.** Scroll down below the article to respond. (*The New York Times*, 5/2, newoldage.blogs.nytimes.com/2011/05/02/figuring-the-odds/)

* **Kenneth J. Doka, Senior Consultant at the Hospice Foundation of America, defines the "end-of-life paradox" as the focus of the elderly on death when their middle-aged children are around. The parents want to "speak about the logistics of death in detail" ... "at the time when it is most difficult emotionally and spiritually for their adult child to listen to such conversations."** He writes, "Middle-aged children struggling with their own awareness of mortality may be deeply threatened by their parents' death and hence avoid such discussion. That same paradox may trouble adult children's end-of-life decision making as they confront the death of an older parent. Only by addressing these issues together can both generations meet their developmental needs." (*The Huffington Post*, 5/7, www.huffingtonpost.com/kenneth-j-doka/end-of-life-paradox_b_858013.html)

* **In "The End-of-Life Memoir," Cristina Nehring, mother of an infant who has survived acute myeloid leukemia, reviews *The Long Goodbye*, Meghan O'Rourke's book about the death of her 55-year-old mother. Nehring says that conventional wisdom holds that those grieving after a death should "let go" and "move on," but she disagrees.** She says, "I'm with O'Rourke when it comes to 'outing' death, lingering with it, feeling it, and failing to minimize its violence. I'm with her when she bristles at the facile way people say that 'at least my mother [is] 'no longer suffering'—as though illnesses were never cured, nor accidents averted. I salute her when she rails against 'a world where there were so few rituals to guide me through this loss.' I endorse her call for ceremony, discussion, indignation—her resistance to that false idol of modernity called closure. For what is closure but another way of telling the departed 'I'm through with you?' The package is sealed, shelved, and forgotten. We owe our dead, and ourselves, better than that." (*The New York Times*, 5/1, nymag.com/arts/books/reviews/the-long-goodbye-meghan-orourke-2011-5/)

RESOURCE NOTES

* **A new, free, online webinar, “Alzheimer’s Disease and Hospice Care,” has been developed by the Hospice Foundation of America.** The program “discusses the impact of advanced Alzheimer’s disease, and how family, professionals and volunteers can manage the demands of caring for someone with end-stage dementia.” The webinar “looks at the specialized care and education that hospice offers to persons with Alzheimer’s and their families.” The program will be available at www.hospicefoundation.org/infocenter -- click on “Professional Education,” then on “Webinar Series.” (PR Newswire, 5/2, <http://www.prnewswire.com/news-releases/new-hospice-foundation-of-america-program-focuses-on-alzheimers-disease-and-hospice-care-121084299.html>)

* **“Missed Opportunities: Use of an End-of-Life Symptom Management Order Protocol among Inpatients Dying Expected Deaths” reported on a study of end-of-life care of patients admitted to the hospital who were expected to die.** Only half were placed on an end-of-life symptom management order (EMSO) protocol. Ninety-five percent of those were placed on an opiate drip. Patients admitted from nursing homes and those being considered for transplants were “significantly less likely to be placed on the EMSO protocol prior to death.” The researchers conclude that “evaluation of implementation of a standardized order set can identify areas for quality improvement and missed opportunities for use.” (*Journal of Palliative Medicine*, 2011,14(4):407-412, www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.0328)

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