NURSE ARGUES THAT AMERICANS NEED END-OF-LIFE OPTIONS

Barbara Mancini is a former ER nurse. She now works as a consultant for Compassion & Choices, which is the nation’s largest end-of-life choice advocacy organization. Mancini says, “I was charged with aiding an attempted suicide, a second-degree felony, for handing my dying 93-year-old father, who was in great pain, his legally prescribed morphine.” She recently wrote an editorial published in York Dispatch about her experience of her father’s death, and the current climate around end-of-life options.

Mancini describes how she handed her father’s morphine to him, and how he took a lethal dose. The article says, “The home hospice provider and the police invalidated his legal advance directive, and he suffered greatly for four more days, enduring unwanted medical treatment that prolonged his agonizing dying process before succumbing to pneumonia.” Before he died, she had been arrested, and her father was in great distress about it. A year later, a judge dismissed Mancini’s case.

From her experience, Mancini has become a supporter of medical aid-in-dying laws. She says, “My ordeal, and the tragic end of my father’s life, have led me to become a supporter of the option of medical aid in dying for mentally sound, terminally ill adults with a prognosis of six months or less to live.” Mancini writes of her support of Pennsylvania’s Senate and House bills that would make it legal for a physician to provide lethal medication to competent adults who have less than six months to live. The current bill is modeled after the law in Oregon, and Mancini rejects the idea that the law would lead to abuse. She quotes The Journal of Palliative Medicine as saying, “Oregon Death with Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care and has thus increased hospice referrals and reduced potentially concerning patterns of hospice use in the state.”

She also points to a recent article in American Journal of Geriatric Psychiatry that found what mattered most to people at the end of life was “‘having control over their dying process followed by being pain-free, and having their emotional and spiritual needs met.’” She argues, “Using medical aid in dying is not an act of desperation, but a rational decision that is made after a careful evaluation process that contains strict safeguards to keep it open, transparent and safe.” (York Dispatch, 04/12, www.yorkdispatch.com/story/opinion/contributors/2016/04/11/oped-medical-aid-dying-must-end--life-option/82892062/)
FDA COMMITED TO ADDRESSING OPIOID ABUSE

“A Proactive Response to Prescription Opioid Abuse” is a special report from the FDA that is published in The New England Journal of Medicine. The FDA expresses its commitment to partnering with medical professionals, drug manufacturers, and communities to combat the misuse and abuse of opioids.

The FDA writes that the one hundred million Americans who suffer from short term or chronic pain “should benefit from skillful and appropriate pain management, which may include the judicious use of opioid medicines in conjunction with other methods of treatment or in circumstances in which nonaddictive therapies are insufficient to control pain.” The agency calls for a balanced strategy. “The United States must deal aggressively with opioid misuse and addiction.” At the same time, says the FDA, the US “must protect the well-being of people experiencing the devastating effects of acute or chronic pain.”

The FDA hopes to coordinate with other federal agencies, prescribers, and key stakeholders in order “to ensure that all available effective tools are brought to bear on this epidemic and that the evidence base for proper pain management and appropriate opioid use is optimized and translated into practice.” As a part of an intensive review of opioids, the FDA has asked the National Academy of Medicine to develop “a regulatory framework for opioid review, approval, and monitoring that balances individual need for pain control with considerations of the broader public health consequences of abuse and misuse.”

Labeling of opioids will also be reviewed in order to see if they adequately convey the risks. Postmarketing studies of the effects of the drugs will also be expanded. The FDA also continues to support mandatory training for prescribers, and education about the best practices in preventing opioid abuse and effectively curbing pain. Additionally, they encourage drug manufacturers and clinicians to develop non-opioid ways of addressing pain effectively. They are committed to moving medicinal solutions through the approval process as quickly as they can safely do so in order to give doctors more tools against pain. The need for different ways to address pain is particularly acute for children. The FDA now requires that studies be done on the effects of opioids on children instead of assuming that the drugs will work the same way that the do in adults.

Finally, the FDA highlights the needs for more evidence-based solutions and more research funding. The FDA relies on a growing body of scientific knowledge about the effects of opioids and the risk of abuse and addiction. They encourage the continuation of this research, noting that the pain management crisis is acute. (The New England Journal of Medicine, 04/14, www.nejm.org/doi/full/10.1056/NEJMsr1601307)

HOSPICE NOTES

* The Des Moines Register’s editorial board published an opinion piece that critiques the state’s lack of mandatory licensing and infrequent inspections of hospice facilities.
Previously in Iowa, says the article, hospices were inspected only every twenty years, though the federal government now requires inspections every three years. The governor has argued that
tighter government controls are not needed, despite cases of hospices being accused of providing substandard care. The newspaper, however, argues that this new inspection regimen has uncovered “not just isolated instances of inadequate care, but systemic problems that affect many patients and should have been addressed years ago.” According to the article, there are currently twenty-three hospice providers in Iowa who have not been inspected in the last three years, and seventy-four out of eighty-three are not licensed. (The Des Moines Register, 04/08, www.desmoinesregister.com/story/opinion/editorials/2016/04/08/editorial-iowas-lax-oversight-hospice-care-scandal/82714028/)

* The Department of Justice announced that five major political donors pleaded guilty for their roles in a $33 million Medicare fraud scheme involving home health and hospice companies in the Detroit area. These five people included two doctors and three hospice owners. Barbara L. McQuade, US Attorney for the Eastern District of Michigan, said, “We hope cases like these will alert doctors, pharmacists and other providers that criminal investigators are scrutinizing billing records so that we can detect fraud and hold wrongdoers accountable.” (Home Health Care News, 04/05, homehealthcarenews.com/2016/04/political-donors-plead-guilty-in-33-million-medicare-fraud/)

* A study in Journal of the American Geriatrics Society considered the costs for nursing home residents who died with and without hospice care. They found that “use of hospice did not increase costs in the last 6 months of life. Evidence supporting cost savings is sensitive to analyses that vary the time period before death.” The data showed that “hospice users had lower total Medicare costs for all time periods up to and including 90 days before death. For dually eligible beneficiaries, overall costs and Medicare costs were significantly lower for hospice users up to 30 days before death.” (Wiley Online Library, 04/05, onlinelibrary.wiley.com/doi/10.1111/jgs.14070/abstract?campaign=wolearlyview)

* The Toledo Blade published an editorial that says hospice fraud is too common. The article says that, according to an OIG investigation, many patients have higher levels of care and longer stays than are appropriate. “Ohio’s record is worse than the nation’s, according to Jodi Nudelman and Nancy T. Harrison, two federal inspectors who led the investigation. They spoke to The Blade last week. Of 33 cases sampled in Ohio, 18 of them involved inappropriate lengths of inpatient stays.” (The Toledo Blade, 04/12, www.toledoblade.com/Featured-Editorial-Home/2016/04/12/Vital-hospice-must-be-done-right.html)

* Pikes Peak Hospice & Palliative Care announced that it will affiliate with Care Synergy, “a not-for-profit organization created to support, sustain and grow preeminent not-for-profit, community-based, legacy hospice providers along Colorado’s Front Range.” Tim Bowen, President and CEO of Care Synergy, explained that “In affiliating with The Denver Hospice, Halcyon Hospice and Pathways Hospice, Pikes Peak Hospice will maintain its local identity while joining in a not-for-profit, values-based, mission driven organization committed to providing care, comfort and compassion to the individuals, families and communities we each are honored and privileged to serve.” (Ehospice, 04/13, www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/18979/language/en-GB/View.aspx; KTVN, 04/13, www.ktvn.com/story/31712229/pikes-peak-hospice-palliative-care-joins-care-synergy)

* In order to celebrate National Volunteer Week (April 10-16), National Hospice and
Palliative Care Organizations released some statistics on hospice volunteering in the US. They report says that there are over 430,000 hospice volunteers in the country, and that they provide 19 million volunteer hours each year. (*Ehospice*, 04/12, www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/18969/language/en-GB/View.aspx)

* Dan Hogan of National Association of Home Care and Hospice argues that hospice is now more important than ever, from both a financial and quality-of-care perspective. He says, “Hospice is not a bleak sentence; it’s a healthy option preferred by patients and their families.” Patients and families, Hogan writes, need to understand their options for end-of-life care and, he says, hospice is a good choice for many. (*National Association of Home Care and Hospice*, 04/2016, www.nahc.org/news/why-hospice-is-more-important-today-than-ever-before/)

* Barbara Mancini and Mark Dann of Compassion and Choices argue that Medicare should cover both hospice and curative treatments of a patient at the same time. The pilot program Medicare Choices Model is now testing the provision of concurrent care at one hundred forty test sites across the country. Compassion and Choices recommends that Medicare make this an option for all patients at the end of life. (*Pittsburgh Post-Gazette*, 04/12, www.post-gazette.com/opinion/Op-Ed/2016/04/12/Hospice-plus-treatment/stories/201604120025)

* The Rural Access to Hospice Act, S. 2786, has been introduced in the US Senate. The bill “would allow primary care providers at Rural Health Clinics and Federally Qualified Health Centers to serve as the hospice attending physician.” The bill would allow physicians and nurses from Rural Health Clinics (RHCs) and Federally Qualified Health Centers (FQHCs) “to bill for hospice attending physician services.” NHPCO encourages hospice advocates to contact their Senators and urge them to cosponsor the bill. (*NHPCO NewsBriefs*, 04/14; *Ehospice*, 04/14, www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/18993/language/en-GB/View.aspx)

* A recent study from the Department of Health and Human Services found more than $250 million in inappropriate Medicare charges for hospice care in 2012, with the issues focused on general inpatient care. Now, hospice organizations are pressing for clearer rules on billing. Industry groups are cautioning against jeopardizing access to needed care because of onerousness regulation. The National Association of Home Care and Hospice explained, “Congress must closely monitor the impact of the payment reform changes implemented by CMS and any future activities to ensure that changes do not reduce access to quality hospice services for Medicare beneficiaries during the final stages of life.” NHPCO released a statement expressing their concerns, comments, and commitment to assuring quality care. “NHPCO will continue to work with member organizations, policymakers, and other stakeholders to ensure that hospice claims are billed appropriately, and that beneficiaries experience high quality, compassionate care at the end-of-life.” (*Associations Now*, 04/13, associationsnow.com/2016/04/after-hospice-overbilling-report-associations-urge-more-clarity-on-care-rules/; *NHPCO*, 4/4, http://www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/18882/language/en-GB/View.aspx)
* The Pew Charitable Trusts and the Coalition to Transform Advanced Care (C-TAC) co-sponsored a briefing to highlight the growing bipartisan consensus around improving care for patients at the end of life. Several members of Congress, who spoke at the briefing, shared about their work and their personal experiences that have shown them the importance of good end-of-life care. There was also discussion about the Care Planning Act, which would “prioritize and fund the development of quality measures that encourage clinicians, health systems, and insurers to improve end-of-life care and to test new models for delivering health services to those with advanced illnesses.” (The Pew Charitable Trusts, 03/29, www.pewtrusts.org/en/research-and-analysis/analysis/2016/03/29/serious-illness-and-end-of-life-care-gains-bipartisan-support)

* There are a growing number of death doulas offering guidance and wisdom to those who are near the end of life, much like doulas do for birth. While they offer similar kinds of support to hospice providers, they are able to spend more time with the patient and family. One death doula explains, “The death doula philosophy focuses on the idea of a ‘conscious death,’ where ‘people have the death they really want.’” She says, “We want to make it so families have more time to be in a loving, fear-free experience.” (Stat, 04/07, www.statnews.com/2016/04/07/death-doulas-end-of-life/)

* An editorial in Intensive Care Medicine argues for an increased understanding of the role that uncertainty plays in end-of-life care. Often, there is a need to consider a complex milieu of personal values and beliefs, where tensions between patient autonomy, sanctity of life, quality of life, and social justice abound.” This makes it difficult to come to a consensus about what should be done in any particular situation. (Paperity, 04/2016, paperity.org/p/75859939/addressing-uncertainty-what-is-the-role-of-consensus-in-end-of-life-care)

* When Breath Becomes Air, by Dr. Paul Kalanithi, is the latest in a series of best-selling books about death and end-of-life care. While many people still avoid talking about death, the growing popularity of books like this one allow people to consider the issues before they or a loved one are close to death. This seems to be part of a shift towards more open conversation, including steps such as Medicare reimbursing doctors for advance care planning, and the growth of nonprofits like the Conversation Project. (New York Magazine, 04/06, nymag.com/scienceofus/2016/04/americans-suddenly-really-like-reading-about-death.html)

* In a two-part series, The Washington Post reports that death rates for middle-aged whites, particularly women, have risen since the turn of the century. They explain that this is particularly true in rural areas and among the lower middle class. The spike, seems to be due to increases in risky behavior and mental health declines. (The Washington Post, 04/08, www.washingtonpost.com/sf/national/2016/04/08/we-dont-know-why-it-came-to-this/; The Washington Post, 04/10, www.washingtonpost.com/sf/national/2016/04/10/a-new-divide-in-american-death/)

* Dr. Kristine Scruggs explains that people should be more informed about what resuscitation at the hospital entails so that they can make informed decisions about their care. She explains that details about what resuscitation is, and the possible side effects, are often
not explained. Therefore, patients or family members misunderstand what they are consenting to. She encourages people to think about their general health and what kind of interventions they would like, and then fill out the right forms and talk to their family. (*Huffington Post, 04/12, www.huffingtonpost.com/kristine-scruggs-md/the-dirty-secret-about-cp_b_9664496.html)

* PLOS ONE published a survey of people who are over ninety-five about their attitudes about death and dying. The researchers found that the respondents are often very willing to talk about death, but are not frequently asked about it. They also tend to focus on enjoying each day, and say that they feel ready to die. They also express concerns about how they would die, preferring to stay at home. However, while some had expressed this to their doctors, few have had conversations with their family members about it. (Health Day, 04/05, consumer.healthday.com/senior-citizen-information-31/misc-death-and-dying-news-172/waiting-to-die-with-no-one-to-talk-to-about-it-709587.html)

* LeadingAge NJ and NJHPCO announced their partnership in the “Being Mortal” Film Project, a series of community education events about end-of-life decisions. Beginning in June, the two organizations will be showing screenings of the PBS film version of “Being Mortal,” a film based on Dr. Atul Gawande’s work. The film will act as a starting point for people to have further conversations about end-of-life planning. (EconoTimes, 04/14, www.econotimes.com/LeadingAge-New-Jersey-and-New-Jersey-Hospice-Palliative-Care-Organization-Announce-%E2%80%9CBeing-Mortal%E2%80%9D-Film-Project-195182)

**PALLIATIVE CARE NOTES**

* Iowa First District Congressman Rod Blum has announced that he’ll co-sponsor a federal bill to help train health care workers who treat chronically ill patients in palliative care. As a part of his announcement, he met with hospice workers, doctors, and the American Cancer Society to learn more about palliative care. The bill would require the Department of Health and Human Services to award grants or contracts for palliative care and hospice education centers for nurses training, workforce development, and research on palliative care. (*KCRG TV9*, 03/31, www.kcrg.com/content/news/Congressman-Rod-Blum-to-Co-Sponsor-Palliative-Care-Bill-374202631.html)

* A new study published in Proceedings of the National Academy of Sciences suggests that unconscious biases and misinformation are the causes of African-Americans’ pain being undertreated compared to whites. The researchers found that many medical residents held false beliefs. One is that African-Americans have less nerve endings than whites. These same medical professionals also rated black pain as lower than white, and were less likely to suggest proper treatment. (*The Washington Post, 04/04, www.washingtonpost.com/news/to-your-health/wp/2016/04/04/do-blacks-feel-less-pain-than-whites-their-doctors-may-think-so/)

* Patient advocate and medical educator Dr. Ira Byock, of the Providence Institute for Human Caring, spoke to *State of the Reform* about his work to develop “value-based, whole-person care, rooted in palliative care, [that] is scalable across many different clinical settings.” He says, “This notion that we can’t afford whole-person, goal-aligned care is nonsense. It no longer holds water. And we can’t allow unfounded financial concerns to become
an excuse for not digging down and doing the hard work of getting this right.” Byock’s talk to the 2016 Northern California State of Reform Health Policy Conference can be watched online. (State of Reform, 03/23, stateofreform.com/news/industry/healthcare-providers/2016/03/30203/; State of the Reform, 04/08, stateofreform.com/news/states/2016/04/2016-northern-california-state-of-reform-morning-keynote-with-dr-ira-byock/)

* **TribLive explains the importance of palliative care, especially at the end of life.** They quote a 2015 Kaiser Family Foundation poll that found, “Eighty-nine percent of people say doctors should discuss end-of-life care issues with patients, while only about seventeen percent say they have had those talks with their doctors or other health care workers.” This kind of care can be provided both by specialists and by other healthcare professionals who are trained in palliative care. (TribLive, 04/11, triblive.com/news/healthnow/10210091-74/care-palliative-doctors)

* The Drug Enforcement Administration has announced that it will address the legal status of marijuana by July, possibly opening the way to move forward to more research on the medical benefits of the drug. Currently the drug is considered a Schedule 1 substance with dangerous effects and no medical value. But with marijuana now legal for medical or recreational use in several states, researchers want to be able to run studies that address questions about the plant. The DEA may change the classification of marijuana to a Schedule 2 drug. (New Scientist, 04/12, www.newscientist.com/article/2084036-dea-mellowing-out-on-cannabis-would-make-medical-research-easier/)

* **Journal of Palliative Medicine** published a study that surveyed experts about the “challenges to and potential solutions for promoting, adopting, and implementing policies that would support or expand high-quality palliative care.” There was consensus found around the main challenges, including “knowledge about PC in the health care setting, cultural beliefs about PC, payment/reimbursement for PC services, and public understanding of PC.” However, the solutions to these challenges are diverse and diffuse. The researchers suggested that this points to the need for more consensus building in the field. (Journal of Palliative Medicine, 04/01, online.liebertpub.com/doi/full/10.1089/jpm.2015.0296)

**PHYSICIAN ASSISTED SUICIDE NOTES**

* **New Hampshire Public Radio hosted an hour-long program on the debate around physician-assisted suicide after a terminally ill local man asked Hillary Clinton about the issue last month.** The program can be heard on their website. The New Hampshire legislature is once again considering a bill that would form a committee to study the topic. Governor Hassan has vetoed two similar bills. (NHPR, 03/06, nhpr.org/post/debating-physician-assisted-suicide-risks-vs-right-choose)

* **Oncologists at the Gastrointestinal Cancers Symposium in San Francisco were asked to consider a case study in which a patient’s prognosis is poor, and where the patient expresses a desire to stop treatment.** A discussion about the doctor’s role in talking about palliative care, hospice care, and physician-assisted suicide found differences in what the physicians thought they should do. One panelist explained the importance of the conversation saying “For those who haven't thought about this [physician-assisted suicide], or even if you don't live in a state where it
is legal, you may well have to grapple with it soon.” (Medscape Multispecialty, 04/05, www.medscape.com/viewarticle/861481#vp_1)

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