
HOSPICE NEWS NETWORK

Recent News on End-of-Life Care | November 2017

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AUTHOR ENCOURAGES READERS TO WRITE THEIR OWN CARE PLANS

By 2030, nearly one fifth of the U.S. population will be over 65 years old. For many nearing retirement, and those in younger demographics who plan ahead, the question, “Who will take care of me when I’m old?” has become a central theme that includes questions about finances, emotional support, and quality of life.

A new book by Joy Loverde published by Da Capo Lifelong Books takes that question as its title. *Who Will Take Care of Me When I’m Old: Plan Now to Safeguard Your Health and Happiness in Old Age* is a collection of tips, worksheets, links, and resources to not just plan for the aging in your life, but to focus on planning for yourself. With the launch of her book, Loverde was interviewed by Alessandra Malito of *MarketWatch* who asks about the challenges of making plans and how, exactly, to be the best advocate for one’s health, financial, and support plans.

“I talked to people who are 90 and 100 years old,” Loverde says, “and they tell me what plagues them day and night is ‘will I run out of money?’ That’s the first thing.” She concedes that the financial component is critical when it comes to securing appropriate care, and this will be increasingly true in the future. “The elephant in the room is there is a caregiver shortage. There are 77 million baby boomers,” she says, and you’ll need to have considerable resources to secure that care.

Loverde also finds that people “wonder what all of this age is for anyway. In other words, one of their greatest needs is the need to be needed by somebody for something so there has to be meaning and purpose in their life.” Loverde’s book addresses this sense of purpose in chapters like “Meet Your Future Self: Discovering who you have yet to become.” She suggests that readers not passively read, but actively “work” the concepts in the book.

For many, the subject of death can be hard to approach. “We all know how the story ends and many times we don’t necessarily want to talk about it,” says Loverde. But she insists that planning “leads to a quality of life, including end of life.” So what does it take for a person to embrace this stage of life? Loverde says it’s about asking a lot of questions and embracing critical thinking. “In the aging industry,” she says, “there’s a lot of talk about the concept of resilience, of bouncing back when something bad happens to you. They say by being resilient, the better off you’ll be. I think resilience is reactive, critical thinking is proactive. **Critical thinking requires that we get out of our comfort zone and we begin to research what the possibilities are as we age.**”

Asking questions that help define your needs and goals can be a way to take on this proactive, critical approach. Questions like, “Who do I need to talk to? Who younger and older do I need to get advice from? How do I weigh all of this information out? Am I open-minded? Am I willing to change midstream?” These questions create a mode of inspection and promote a sense of agency.

Planning ultimately needs to be formed into a concrete plan, so “everything has to be in writing.” This is true for legal documents, including a durable power of attorney. While the most important part is getting a plan in place, she reminds readers that the documents can always be updated along the way. “Look through this document on a regular basis,” she says. “And you may change your mind on who you designate.” (*Market Watch*, 10/30, www.marketwatch.com/story/who-will-take-care-of-you-when-youre-old-its-probably-not-who-you-think-2017-10-30)

VETS LIVING WITH THE PAST AT THE END OF LIFE

April Dembosky’s tells about the plight of many dying veterans in her *KQED News* article “What Vets Want at the End of Life Is Very Different From What Civilians Want.” An audio lead before the story, available online, says that what veterans want may be very different from what others want. **Veterans want honor and respect, says the speaker, more than they want comfort and freedom from pain.**

Ron Fleming, a veteran in Dembosky’s story, says, “I take issue with those who say we lost [the war in Vietnam]. We didn’t lose that war,” says Ron Fleming, who at 21 was a door gunner in Vietnam. He’s now 74 and living at the San Francisco VA medical center. As he has aged, Fleming has dealt with congestive heart failure, arthritis, and asthma attacks that land him in the palliative care team’s purview. Fleming was diagnosed with PTSD a decade ago, but for other veterans, it takes symptoms from terminal illness such as breathlessness to raise issues like flashbacks.

VJ Periyakoil is a palliative care physician at the VA in Palo Alto. She says, “War memories start coming back” for those who are dying. Some vets begin to have nightmares. And adding opioids to manage pain can sometimes compound the problem. “Your defenses that you use to cope with the PTSD, which might help repress a lot of the difficult memories, that coping strategy starts to come apart,” says Periyakoil.

Ron Fleming thinks about death, and says, “I wish it’d get off its ass and come on me. I’m sick of this crap.” It has been hard for him to hold down a job. He never got married or had children. He finds himself hyper vigilant and easy to anger. Yet he does not want to begin taking the antidepressants that his doctors encourage. Says Fleming, “The vets call them the happy pills. I don’t want any of those, because they change you. I don’t want to change.”

“Sometimes I’ve had patients refuse medications that might ease their experiences because they feel that they deserve to suffer,” says Periyakoil. “This is redemptive.” Other patients have told her that they would “much rather tolerate the physical pain, the cancer pain, than take opioids and my defenses crumble.” Periyakoil notes that medical professionals want to ease the pain and suffering. But, **“The best thing to do in these situations can be to stand down, she said. With weeks left to live, there isn’t enough time to resolve the mental anguish, and staff have to let patients set the pace and tone for their care.”**

The article says that it’s Fleming’s pain that connects him to the past. “The loss and grief he experienced in Vietnam are woven into the same memories of victory and glory. He doesn’t want treatment that might make that go away.” (*KQED News*, 11/9, ww2.kqed.org/stateofhealth/2017/11/09/what-vets-want-at-the-end-of-life-is-very-different-from-what-civilians-want)

HOSPICE NOTES

*** “It’s about how you live!” This November, NHPCO has partnered with hundreds of hospice programs around the country to share that message, the theme to its annual push**

to raise awareness about hospice and palliative care. “Every year, nearly 1.5 million people living with a life-limiting illness receive care from hospices in this country,” said Edo Banach, president and CEO of the National Hospice and Palliative Care Organization. “These highly-trained professionals ensure that patients and families find dignity, respect, and love during one of life’s most difficult journeys – it’s really about living.” Supporters are encouraged to share positive and inspirational messages with the hashtag #hospiceawareness throughout the month. (NHPCO, 11/1, www.nhpc.org/press-room/press-releases/raising-awareness-november)

* **Defining Hope, a documentary from Carolyn Jones about hospice and palliative care, is called a “clear-eyed and compassionate conversation starter.”** Reviewer Sheri Linden wrote the review that appeared in *Hollywood Reporter*. The plot follows two nurses, whose “commitment to their work and the sense of fulfillment it gives them come[s] through powerfully in their interviews.” Linden says the film “provides a vision of healthcare reform that often gets lost amid the ongoing debate over insurance and the economics of medicine. ‘Quality of life’ may be a tossed-around phrase, but Jones’ clear-eyed film shows how it can be a guiding principle.” (*Hollywood Reporter*, 11/1, www.hollywoodreporter.com/review/defining-hope-1052750)

END-OF-LIFE NOTES

* **Men account for 40% of all caregivers over 18 years old. AARP calls this the “best-kept secret” of caregiving in America.** The article reports that about 16 million men care for a family member or friend. The statistic comes from a University of Michigan healthy aging poll, sponsored by AARP. Of this caregiving group, more than half perform nursing and medical duties. The article provides five brief profiles of male caregivers around the country. (AARP, 11/2017, www.aarp.org/caregiving/life-balance/info-2017/male-caregivers-increasing-role.html)

* **How do patients with varying terminal diseases feel about their preferred places of care and death (PPOC & PPOD)? How do differing diseases correlate to levels of anxiety among patients?** These two questions are the focus of a study published in the *Journal of Palliative Medicine*. The authors note that previous research often focuses on cancer patients, “most of whom identify home as their PPOC and PPOD.” They wondered if those preferences were mirrored in patients suffering from nonmalignant fatal diseases. **The researchers report, “Patient preferences for PPOC and PPOD vary according to their diagnoses; tailoring palliative needs to patients’ preferences is important regardless of their diagnosis.”** (*Journal of Palliative Medicine*, 11/1, <http://online.liebertpub.com/doi/abs/10.1089/jpm.2017.0082>)

* **“How can we give a diagnosis of terminal illness without being pessimistic?” asks Arefa Cassoobhoy, MD, to panel member Diane E. Meier, MD.** Meier discusses the practice of asking questions, providing an open body language, and allowing time for information to settle in. After gaining permission from the patient to share information, Meier says, “Break the news in one short sentence ... then stop talking. This is the hardest thing in the world for clinicians to do because we want to jump into that space and make it better. The patient is not hearing a word you say after you said that the cancer has progressed, so just be quiet and let them process it. Allow silence and just sit with your hands on your legs with open body language and wait. It sometimes feels like it's a 10-year silence, but it's a 5-second silence.” (*Medscape*, 10/30, www.medscape.com/viewarticle/887503)

PALLIATIVE CARE NOTES

*** For the 600,000 Americans with end-stage renal disease (ESRD), palliative care can help relieve pain and address symptoms and stress, says John Halsey.** “Managing care and treatment for individuals with CKD and ESRD can be a round-the-clock effort that puts enormous physical and emotional strain on both the patient and the family,” he writes. Halsey offers ways that palliative care can offer up additional support. Palliative care, he says, can: manage pain and other related conditions; help with communication with other doctors and evaluating treatment options; explain what to expect throughout the illness; and help patients cope with worry, stress, or depression. (*McKnight's*, 10/30, www.mcknights.com/guest-columns/value-of-palliative-care-for-those-with-end-stage-renal-disease/article/703628)

OTHER NOTES

*** How should we cope if elderly parents' behavior worsens? An article in *The Dallas Morning News* tells the story of Cindy Rubin, and describes the decline of her mother's health and behavior.** The author consults experts like Dallas psychologist Paul Chafetz, author of *Loving Hard-to-Love Parents: A Handbook for Adult Children of Difficult Older Parents*; Courtney Smith, director of the caregiver support program at the Senior Source, a Dallas nonprofit that offers resources on aging; and Dr. Diana Kerwin, chief of geriatrics at Texas Health Dallas and founder of Texas Alzheimer's and Memory Disorders. **These experts provide advice from their respective fields, and the article concludes with a list of seven coping skills including “adopt healthy self-care habits,” “enforce boundaries,” and “tackle your own difficult behaviors.”** (*The Dallas Morning News*, 11/9, www.dallasnews.com/life/aging-1/2017/11/09/caring-hurt-experts-advise-cope-elderly-parents-behavior-changes-worse)

*** “Every practicing physician quickly realizes that communication is everything in health care.”** This is the core message from Suneel Dhand, MD, in her article “10 golden communication tips for doctors. And 3 things they shouldn't do.” Dhand highlights issues of courtesy and demeanor that apply to doctors, but also any professional involved in care for sick or suffering patients. Her 10 sections cover: knock, greeting, sit down, let the patient speak, other techniques, involve the family always, ask open-ended questions, avoid technical jargon, give a chance to ask questions, and ending. What shouldn't doctors do? They shouldn't turn around and look at the computer as they speak, make their time constraints obvious, or treat any problem as if it's trivial. (*KevinMD*, 10/28, www.kevinmd.com/blog/2017/10/10-golden-communication-tips-doctors-3-things-shouldnt.html)