
HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

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SPECIAL NEWS OF NOTE

The US House passed the Palliative Care and Hospice Education and Training Act (PCHETA), HR 647. PCHETA now advances to the Senate and advocates are hopeful for swift advancement. (*C-TAC*, 10/28, <https://www.thectac.org/2019/10/palliative-care-and-hospice-education-and-training-act-passed-by-u-s-house/>)

OREGON POLST AIRS ISSUES OF CONCERN

***Oregon POLST* shares program news that addresses numerous updates from POLST. The state of Oregon separated from the POLST Paradigm Office in June of 2017. The decision ultimately came “as a result of the POLST Paradigm decision to liberalize their gift policy.”** *Oregon POLST* explains: “While we share the goal of assuring patient wishes are honored, we disagree on the appropriate standards related to sources of funding. As health care shifts from fee-for-service to value-based care, there is a growing focus on reducing costs of care near the end of life.” *Oregon POLST* states clearly that they are not in agreement that reducing costs is a purpose of the form. Rather, they are focused on the form’s purpose of creating accurate records surrounding a patient’s end-of-life wishes. “Any focus on financial incentives, including the practice of counting POLST form completion rates, opens the door to conflicting influences and can leave patients feeling pressured,” *Oregon POLST* says. “To preserve voluntariness and the public trust, the Oregon POLST Program does not accept gifts from health care industry sources to avoid, either, a real or perceived appearance of conflict of interest.” This stand creates problems and misunderstandings between *Oregon POLST* and the POLST Paradigm office in DC.

***Oregon POLST* now reports that the POLST Paradigm Office has marked Oregon as “unaffiliated” on their October 2019 update to the national map. Previously, Oregon had been designated as having a “mature” POLST program.** *Oregon POLST* argues that this is a mischaracterization of their program. “This new designation suggests that Oregon is less mature than 43 other states in the nation, despite the fact that Oregon developed the POLST Program in the early 1990s and was the first state to earn a ‘mature’ status in 2013,” *Oregon POLST* says. This is not the first time the POLST Paradigm Office has downgraded their status. A previous mischaracterization led to an investigation which deemed *Oregon POLST* as meeting all requirements of a “mature” program.

The designation is important. Oregon POLST has been left out of important development efforts toward the uniform POLST document. They have identified six critical needs for improvement in the proposed uniform POLST. They say these six issues will greatly impede other states working toward “mature” status. “The Oregon POLST Program continues to lead by sharing its innovations and materials freely, while expecting appropriate attribution of Oregon’s ‘mature’ status — both to honor promises made during the separation, and to avoid unnecessary confusion for government agencies and others,” *Oregon POLST* states. The six areas of concern are online at

<https://static1.squarespace.com/static/52dc687be4b032209172e33e/t/5d80131f2898da0a1ac5cc88/1568674592498/2019.09.16+Policy+-+Essential+POLST+Elements-Part+II+FINAL.pdf>.

One element that *Oregon POLST* opposes in the proposed uniform document is the requirement of surrogate signatures. The newsletter includes a personal vignette of Dawn, who, at the end of her husband’s life, found herself too overwhelmed to make the required surrogate signature to make his DNR official. “Studies show that the burden of emotional distress, and lasting symptoms of anxiety and guilt, some family members feel when they are asked to take active steps such as signing a form to withdraw or limit treatment for their loved ones,” *Oregon POLST* says.

Oregon POLST quotes the Oregon POLST Coalition’s October 17th decision to reaffirm their “endorsement of the authority of physician assistants to independently sign POLST orders without the counter signature of their supervising physician.” An image of the proposed uniform document is included to illustrate what they consider “a confusing signature line for the ‘supervising physician.’” Additionally, *Oregon POLST* includes a statement of endorsement from the Oregon ACEP: “The Oregon Chapter of the American College of Emergency Physicians (Oregon ACEP) recommends that Emergency Departments implement a protocol to routinely check for Portable Orders for Life-Sustaining Treatment (POLST) forms for anyone 85 or older, and anyone coming to the ED from a residential care facility.”

Additional information in the newsletter encourages hospices to register patients in the system and provides direction on doing so. Other issues are also addressed and the entire *Oregon POLST* can be read in full at the link below. (*Oregon POLST*, 10/25, <https://centerforethics.activehosted.com/social/fe9fc289c3ff0af142b6d3bead98a923.79>)

ENSURING QUALITY HOSPICE CARE BY VETTING PROVIDERS

Barbara Mancini, RN, MSN, shares advice for ensuring your loved one receives the best hospice care available to them. In a recent podcast with *ElderLawAnswers*, Mancini says, “My biggest regret is that I didn’t do more to research hospice care...Hospice is a vital end-of-life care option. The problem is that hospices vary greatly in the quality of care that they provide.”

Mancini learned the hard way how important it is to make well-informed decisions regarding hospice care. In 2013, she was arrested and charged with “aiding the attempted suicide of her dying 93-year-old father, Joseph Yourshaw,” *ElderLawAnswers* says. Yourshaw had asked his daughter to hand him his prescribed morphine, and she obliged, prompting Yourshaw’s hospice

nurse to call 911. “The hospice nurse and the police ignored Mr. Yourshaw’s written advance directives about the kind of care he wanted at the end of his life, and he was hospitalized and treated in defiance of his wishes,” *ElderLawAnswers* says. “He died at a hospital four days later.” The case against Mancini was eventually dismissed due to insufficient evidence.

The ordeal has inspired Mancini to advocate strongly for improving end-of-life care. She believes that a patient’s goals and needs should be the top priority in hospice care. Hospice care shares in this opinion, but problems with some organizations, such as those covered by recent reports by the U.S. Department of Health and Human Services Office of Inspector General, may prevent patients from receiving the best care toward those goals.

Mancini therefore suggests doing research and asking for recommendations when seeking hospice care. She offers an extensive list of questions and considerations to that end. Among them: “Who will direct the hospice patient’s care?” “Is the hospice concerned about opiate addiction in its patients? (‘If the answer is yes, run, don’t walk, away from that hospice,’ Ms. Mancini counsels.)” “How many patients and caregivers have terminated services? What are the reasons?” and, importantly, “Will you ever override a patient’s advance directive? Under what circumstances?”.

Finally, Mancini emphasizes how important advance directives are for ensuring a patient receives the care they wish for. “She also believes in the importance of individuals being well-informed about the rights of the patient and the responsibilities of hospice providers,” *ElderLawAnswers* says.

More of Mancini’s advice can be found in her interview with *ElderLawAnswers* available on their website. (*ElderLawAnswers*, 10/24, www.elderlawanswers.com/how-to-get-good-hospice-care-hard-won-advice-from-the-pennsylvania-nurse-prosecuted-for-aiding-her-fathers-death-17423)

INTEGRATING PALLIATIVE CARE INTO CRITICAL CARE

Deborah (Debi) A. Boyle MSN, RN, AOCNS, FAAN, writer, editor, and oncology clinical nurse specialist, makes the argument for incorporating palliative care into critical care. Boyle admits that, in 2002 when she returned to work in a hospital after some time away, she thought it “seemed like an oxymoron” that a palliative care nurse practitioner was now working in the ICU. However, she came to realize why this made so much sense after all.

The death rate in intensive care is high at 20%-35%, Boyle says. Additionally, many patients end up in intensive care in the last months of their lives. This number has risen in recent years to nearly 30%. Further, many patients admitted to intensive care – up to one-third – have cancer. Boyle also notes, “The use of aggressive cancer therapies heightens the prevalence of emergent scenarios.”

Decision-making, distress and discomfort from symptoms, and poor communication between family members and the care team are other prevalent issues in intensive care. “Palliative care-related symptoms (i.e., thirst, anxiety, sleep disturbance, dyspnea) also require management,”

Boyle says. To better consider such issues, Boyle has several suggestions. First, “Establish a routine schedule for rounding with the palliative care team in both the oncology unit and intensive care settings,” she says. “This includes developing a proactive approach to identifying patients who could benefit from palliative care interventions with the delineation of triggers for palliative care consults.” Secondly, for the ICU setting, she suggests setting a plan for regular meetings with family. Family members should also be informed of common symptoms and complications that may arise. Protocols should also be developed for managing such symptoms. Finally, training for communication focused on critical care scenarios should be mandated.

“The inevitability of oncology patients being cared for, and possibly dying, in the critical care setting is a real one in today’s acute care environment,” Boyle concludes. “Because of the prominence of cancer today, all nurses need to ensure they have the expertise and confidence to care for oncology patients at varied points along the cancer continuum.” (*Oncology Nursing News*, 10/18, www.oncnursingnews.com/contributor/debi-boyle/2019/10/incorporating-palliative-practice-into-critical-care)

HOSPICE NOTES

* **The US House passed the Palliative Care and Hospice Education and Training Act (PCHETA), HR 647.** PCHETA now advances to the Senate and advocates are hopeful for swift advancement. (*C-TAC*, 10/28, <https://www.thectac.org/2019/10/palliative-care-and-hospice-education-and-training-act-passed-by-u-s-house/>)

* **The first homeless hospice center on the west coast is set to open in downtown Sacramento in early spring of 2020.** The hospice center, Joshua’s House, was started as a project three years ago by founder and CEO Marlene Von Friedrichs-Fitzwater. Von Friedrichs-Fitzwater saw the need for Joshua’s House when her grandson, Joshua, died of cancer while he was experiencing homelessness. The hospice will open with the capacity for caring for 20 patients. **“Each individual will be loved, respected, and provided with high quality hospice care in a home-like setting with meals, clothing, companionship and art & music therapy,”** says an invitation to a Joshua House Hospice fundraiser, shared by *News Radio KFBK*. (*News Radio KFBK*, 10/23, <https://kfbk.iheart.com/featured/the-afternoon-news-with-kitty-o-neal/content/2019-10-23-joshuas-house-will-be-first-homeless-hospice-center-for-the-terminally-ill/>)

* **Veterans in hospice care at Hospice of St. Francis in Brevard County, Florida, will be able to experience a Space Coast Honor Flight through virtual reality.** The hospice began offering virtual reality to patients in early 2019. The hospice is collaborating with Space Coast Honor Flight, and their production partner Design Interactive, Inc, to expand with this new offering for veterans. “When it comes to our Veteran patients, we are especially focused on making sure they feel the respect and appreciation they deserve and have earned through their service,” says Joe Killian, President and CEO of Hospice of St. Francis. **“When we got the idea to produce this VRE video we felt it would be one more way that our care could uplift the lives and service of our Veterans and demonstrate our gratitude for that service.”** Killian says the next step is to expand the offering, made possible with funding from Hospice of St. Francis and its foundation, to other vets in hospice care across the country. (*Space Coast Daily*,

10/24, <https://spacecoastdaily.com/2019/10/virtual-reality-trip-of-a-lifetime-captures-highlights-of-actual-space-coast-honor-flight-experience/>)

END-OF-LIFE NOTES

* **A recent study published with *DocWire* looks at agitation in patients with dementia, particularly those near end-of-life. The study examines how a care team interprets agitation in patients, and how this may affect quality of care.** Through observation, two main staff response categories were established. “In the first, staff attribute agitated behaviors to the person’s ‘moral judgement,’ making them prone to rejecting or punitive responses,” study authors explain. A more “needs-based approach” is seen in the second category, in which “agitation behaviors are regarded as meaningful and managed with proactive and investigative approaches.” The study notes correlation between the two different responses and resources and values within the care team organization. Staff disengagement from those with dementia “may be associated with low-resource institutions with minimal staff training where the personhood of staff may be neglected,” the study concludes. **“Care worker knowledge about agitation is not enough, and staff need organizational support to care better for people living with dementia towards end of life.”** (*DocWire*, 10/24, www.docwirenews.com/abstracts/agitation-near-the-end-of-life-with-dementia-an-ethnographic-study-of-care/)

* **A recent study published with *JAMA Oncology* examines whether population-based quality indicators (QIs) are appropriate when applied to cancer patients with advanced disease or who are near end-of-life.** The study explains that QIs are important to improving the quality of cancer care. However, these measures are primarily used to evaluate care in its earliest stages. Often, these are still curative treatments. **The study shows that most of these QIs are not transferrable to evaluating care at more advanced stages.** “The findings suggest that only a small proportion of QIs developed for the care of patients with cancer who have advanced disease and/or are at the end of life have received adequate testing and/or are appropriate for use,” the study concludes. More testing may be necessary, as well as more research “to establish benchmarking data and to expand QIs relevant to psychosocial, cultural, and spiritual care domains.” (*JAMA Oncology*, 10/24, <https://jamanetwork.com/journals/jamaoncology/article-abstract/2753176>)

* ***Connecticut Magazine* profiles several local death doulas and community efforts toward approaching death.** Along with her company, A Gentler Parting, Nathalie Bonafé, a molecular biologist turned death doula, provides numerous services such as helping a client write a will, downsize an estate, receive legal counseling, offer grief management, and receive other services dealing with both the logistic and emotional aspects of the end-of-life. They also “conduct free workshops, seminars and discussions known as “Death Cafes” to get people talking about death more often.” Ingrid Harrison, likewise an end-of-life doula and formerly a veterinary technician, brings a pet-focused specialization to her work. She strives to keep patients together with their animal companions. Dawn Whelan provides similar services through her company, My Last Gift. The article concludes with some lessons Bonafé has gathered from her work in the death positive movement: “Everyone has a story;” “Everyone wants validation;” “People tend to die the same way they chose to live;” “Listening is more powerful than speaking;” and “It’s worth

living to learn.” (*Connecticut Magazine*, 10/24, www.connecticutmag.com/health-and-science/end-of-life-doulas-and-death-cafes-are-changing-the/article_31418a18-f514-11e9-bd75-0f09b7357ff0.html)

* **Amy Florian, author, speaker, CEO, and grief expert, writes for *Thrive Global* about a troubling issue she commonly sees in grief support groups. Community support is plentiful at diagnosis and early stages of serious illness, but falls off as the disease progresses – particularly when curative treatment has ceased.** Florian says this isn’t out of lack of caring, but, rather, misconceptions and lack of knowledge about dying. “We’ve simply never been taught how to accompany dying people or what they need,” Florian says. Citing palliative care physician and psychologist Dr. Ira Byock, Florian says we can begin to improve this by not waiting to say “thank you” to loved ones who are dying. Because dying individuals are likely to go through a process of “life review,” wondering if they made a difference, it brings them peace when we let them know. **“It is incredibly meaningful when people tell dying people what lessons they learned from them, what memories stick with them from their shared lives, and how important they have been in various ways,”** Florian says in summary of Byock’s research. With this in mind, Florian advises on how best to visit the dying and tell them “thank you.” These could be the most meaningful conversations you’ll ever have,” Florian says. “You help a dying person find peace, offer genuine comfort, and often come away with greater gifts than you could have imagined.” (*Thrive Global*, 10/24, <https://thriveglobal.com/stories/say-thank-you-to-someone-who-is-dying/>)

PALLIATIVE CARE NOTES

* **The latest episode of the *GeriPal* podcast discusses the Care Ecosystem project with guests Kate Possin, PhD and Sarah Dulaney, RN CNS of UCSF.** This project, a study published in *JAMA Internal Medicine*, says, **“Lay health workers helped caregivers of persons with dementia navigate the health care system by providing support, education, and care coordination with dementia specialists,” *GeriPal* explains. The intervention showed impressive results in improving quality of life for patients with dementia. Emergency room visits and caregiver depression were shown to be reduced as well.** Lay Health Navigators were “the words on everyone’s lips” at the National Palliative Care Research Center’s recent annual Foley retreat, according to *GeriPal*. The podcast further explores how these professionals could be revolutionary to palliative care as they help patients navigate the complexities of the medical system. (*GeriPal*, 10/24, www.geripal.org/2019/10/health-navigators-improve-dementia-care.html)

* **The Coalition to Transform Advanced Care (C-TAC) writes that the Stupski Foundation has announced an investment of more than \$14 million toward end-of-life care.** The investment will go to seven health care systems across San Francisco and Alameda counties in California. This is part of a \$40 million investment announced in 2018 that will benefit serious illness care across the Bay Area and Hawaii over the course of the next 10 years. “The investments announced by the Stupski Foundation are designed to expand specialty palliative care services by over one-third, double the number of patients receiving home-based palliative care and train hundreds of primary care doctors and support staff on palliative care and how to guide and document conversations on care preferences,” C-TAC says. An update on these efforts

was given by the Stupski Foundation during the 2019 C-TAC summit. More information on these updates is linked to from the C-TAC article. (*Coalition to Transform Advanced Care*, 10/25, www.thectac.org/2019/10/stupski-foundation-announces-investment-of-more-than-14-million-to-transform-end-of-life-experience-across-bay-area)

OTHER NOTES

* **CMS recently announced their Primary Care First Model Options. The Primary Care First Model is** “a set of voluntary five-year payment options that reward value and quality by offering an innovative payment structure to support delivery of advanced primary care.” The new, alternative payment model targets practices who are “ready to accept financial risk in exchange for greater flexibility, increased transparency, and performance-based payments that reward participants for outcomes,” NHPCO reports. Practices can choose to participate in one of three different levels by opting to participate in both the Seriously Ill Population (SIP) and PCF-General components, or just one or the other. CMS says that **“The objective of the SIP component is to identify seriously ill beneficiaries who are experiencing fragmented, uncoordinated care under Medicare FFS,”** then **“stabilize” their treatment and improve the long-term patient-care team relationship. Offerings were announced by CMS as beginning in 26 regions starting in 2020. However, the Trump administration said it would delay the start date to 2021. “CMS said that the reason for the delay was to give stakeholders more time to consider participation,”** says *Fierce Healthcare*. “The delay also helps practices prepare by giving them additional time to move away from fee-for-service, the agency added.” (*NHPCO*, 10/24, www.nhpco.org/nhpco-statement-on-primary-care-first-sip-model/; *CMS*, 10/25, <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>; *Fierce Healthcare*, 10/24, www.fiercehealthcare.com/practices/cmml-delays-start-new-primary-care-payment-model-to-2021)

* ***The Conversation* examines advance care planning in a comprehensive article on their website. Opening with a patient narrative, they illustrate how a traumatic lonely death rife with stressful medical tests can be the result of a lack of planning and conversation about one’s end-of-life wishes.** *The Conversation* offers solutions. Pamphlets can help initiate conversations. “In our study, 84 per cent of residents and families who received a pamphlet felt encouraged to think about their future care and 70 per cent felt clearer about what to talk about,” *The Conversation* says. **Further, discussing death can be a great source of relief for patients, despite family members’ and physician’s tendency to feel they are protecting a patient by not bringing the topic up.** Finally, care home staff need further training in matters surrounding advance care planning. *The Conversation* says, “We need to clarify roles and provide the necessary training to support long-term care home staff, especially those who develop strong relationships with residents.” (*The Conversation*, 10/24, <http://theconversation.com/to-die-well-we-must-talk-about-death-before-the-end-of-life-124256>)

* **Earlier this year, Dr. Barbara Morris, a Colorado geriatrician, was fired from Centura Health for trying to assist a patient in taking advantage of Colorado’s medical aid-in-dying laws. Now, *The Denver Post* reports, she has accepted a new job with Stride Community Health Center.** Morris was fired in August after filing a lawsuit alleging that Centura had violated the law by interfering with a patient’s rights to medical aid-in-dying on religious

grounds. Centura argued in turn that their actions were protected by the First Amendment. *The Denver Post* says that Colorado’s medical aid-in-dying law “allows hospitals and health systems to opt out of allowing patients to end their lives on hospital property, but forbids limiting a physician’s medical judgment on the issue.” Vice president of development at Stride, Laura Larson, says that Stride has no comment on medical aid-in-dying. They are focused on Morris’s “experience and passion” for geriatric care instead. (*The Denver Post*, 10/25, www.denverpost.com/2019/10/25/colorado-doctor-fired-aid-dying-new-job/)

*** A recent study in the *Journal of Palliative Medicine* sought to better understand the extent to which cancer patients may be using cannabis to alleviate symptoms.** Because of rising cannabis use by cancer patients, and the increasing accessibility of medical marijuana, “unsanctioned cannabis use is likely to increase,” the study authors say. However, an understanding of cannabis use outside of formalized palliative cannabis has not yet been established. The results show that nearly one-fifth of participants tested positive for cannabis use. Some demographic trends were established. Users were more likely to be male, younger, recently diagnosed, and had received radiotherapy. Further, “Certain moderate-to-severe symptoms, such as lack of appetite, shortness of breath, tiredness, difficulty sleeping, anxiety, and depression, were associated with use after accounting for sociodemographic and clinical differences between cannabis users and nonusers.” The study concludes, “Patients seeking specialized symptom management are self-treating with cannabis, despite the lack of high-quality evidence for its use in palliative care,” and “unsanctioned use is likely to increase in cancer patients.” More information is “urgently needed” to help guide patients in its use. (*Journal of Palliative Medicine*, 9/30, www.liebertpub.com/doi/10.1089/jpm.2018.0533)

*** Amazon has just made its second major healthcare acquisition, according to *Healthcare Dive*. The tech giant has bought Health Navigator, a tech startup in the healthcare industry.** This comes after Amazon bought PillPack last year. Health Navigator “provides online symptom checking, clinical documentation support and triage tools to route patients to the correct site of care.” The services that come along with Health Navigator will be integrated into Amazon’s “virtual medical clinic,” Amazon Care. Launched as a telehealth benefits pilot for its Seattle-area employees last month, Amazon Care includes many of the standard benefits of telehealth along with prescription delivery. “The Health Navigator acquisition is likely to add fuel to speculation that telemedicine is the next healthcare sector Amazon could disrupt, though a potential commercial launch of Amazon Care to the general public is likely a ways away,” *Healthcare Dive* says. (*Healthcare Dive*, 10/24, www.healthcarediver.com/news/amazon-acquires-digital-health-startup-1-year-post-pillpack/565744/)

Hospice Analytics is the national sponsor of Hospice News Network for 2019. Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of-life care. For additional information, please call Dr. Cordt Kassner, CEO, at 719-209- 1237 or see www.HospiceAnalytics.com.

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