SPECIAL NOTE: HNN newsletter, on October 29, 2019, shared a summary of updates from the October 25, 2019 Oregon POLST Program News. National POLST contacted HNN to correct inaccuracies in the Oregon POLST Newsletter covered in the recent HNN article. The National POLST response addresses “Oregon POLST’s separation from National POLST;” “Developing a uniform POLST form;” and, “Designation on the national POLST map.” Readers are encouraged to review the response from National POLST. It is online at the link below. (National POLST, 11/5, www.polst.org/hnn-oregon)

BIPARTISAN HOSPICE CARE IMPROVEMENT ACT INTRODUCED

Bipartisan legislation for improving hospice care was introduced November 7th by Rob Portman (R-OH) and Ben Cardin (D-MD). The Hospice Care Improvement Act of 2019 comes in response to reports released in July by the Office of the Inspector General (OIG) and the Department of Health and Human Services (HHS). The report found facility deficiencies and other hospice care inadequacies that led to patient harm. Safety protocols and transparency by hospices were found to be lacking, leading to the conditions outlined in the reports. A press release on Rob Portman’s website states that the bill will address concerns about hospice care by improving “oversight and accountability,” “improving patient awareness of hospice abuse,” and holding hospices responsible for a certain level of care.

“The findings from the HHS OIG report on hospice care abuse across our country are deeply upsetting and unacceptable,” says Senator Portman. “This legislation will provide the oversight needed for hospices and give patients and their families the transparency and accountability they deserve.”

Senator Cardin adds, “Families in need of hospice care should be able to concentrate on the comfort and care of their loved one without the worry of unacceptable safety and medical standards…” And, he continues, “The OIG and DOJ reports, coupled with HHS and stakeholder recommendations gave us a path forward that will increase transparency and patient safety, as well as increase the peace of mind and respect that should be ever present during hospice care.”

The proposed bill was developed around recommendations by the HHS, industry experts, and patients. Under the bill, hospice surveys would increase in frequency, and results of surveys would be published for patients. Education for hospices and surveyors would be
improved. Additionally, the bill would “establish penalties for bad actors in a manner commensurate with existing penalties for other providers, like nursing homes and home health agencies.” Portman’s website statement notes that, in the House, Congressmen Jimmy Panetta (D-CA), and Congressman Tom Reed (R-NY), are supporting similar legislation.

NHPCO voices support of the bill, saying they are “encouraged to see many of the hospice and palliative care community’s policy priorities reflected in this bill.” Edo Banach, NHPCO President and CEO says, “We will continue to work with Congress and the Administration on enhancing access to high quality, interdisciplinary, person-centered care for those facing serious illness, including those in underserved and rural areas.” Banach adds, “NHPCO supports regulations that promote accountability and safety and is eager to work with lawmakers to develop reasonable policies and enforcement mechanisms that promote program integrity. We must also update the hospice benefit and codify a palliative care benefit to allow people to get appropriate care when they need it.”

NHPCO explains the bill’s proposed improvements to the survey schedule, adding, “The legislation includes support for increased collaboration between hospice providers and accrediting organizations and state survey agencies.” This would require surveyors to provide educational measures to hospices to help them correct deficiencies. Consumer education will also be a focus, NHPCO explains, to allow better informed care decisions and transparency. Surveyors will also be required to report findings to the Center for Medicare and Medicaid Services’ Hospice Compare website.

“Congress has worked with key stakeholders to understand the intersection of high-quality care and program integrity,” NHPCO says. “NHPCO and the Hospice Action Network look forward to continuing to work with Senators Portman and Cardin as this legislation advances to achieve this important goal.” Senator Portman’s website provides a link to the bill. (Rob Portman US Senator for Ohio, 11/7, www.portman.senate.gov/newsroom/press-releases/portman-cardin-introduce-hospice-care-improvement-act-address-lack; NHPCO, 11/7, www.nhpco.org/bipartisan-legislation-to-enhance-smarter-oversight-of-hospice-care/)

HOSPICE OUTREACH TO SEATTLE’S HOMELESS

Seattle hospice and palliative care providers are trying to better serve a particular demographic: the homeless. Washington state has the fifth highest homeless population in the nation, and in King County, where Seattle is located, one-third of 2018 homeless deaths were due to natural causes, Crosscut reports. Homelessness comes with greater health risks, and the homeless who need hospice can find it difficult to access. One central Seattle hospital, Harborview, found that 90% of emergency department patients in 2017 were homeless.

Harborview now has a mobile homeless palliative care team. The three-person team “provides medical planning, symptom management and social support for those with chronic or serious illnesses,” and will follow patients through hospice care, if their illness worsens. Crosscut says that the team’s social worker, Michael Light, estimates that the team “actively serves about 25 people at a time, 15 others on an inactive list where they might need future
follow-up and upwards of 10 on a referral list. Of these, they have an average of five on hospice.”

Light says the team provides more than just care. They strive to humanize the patients to other medical care providers they may interact with, as well as organize other efforts to make their last months meaningful. Light shares the story of patient Alvin Taliaferro, who in addition to being homeless is a talented artist. While Taliaferro was in their care for metastatic prostate cancer, Light’s team helped him reunite with his daughter, establish a safe storage space for his art, and organize an art show.

Another hospice patient, Chuck King, is profiled throughout the Crosscut piece. While King was suffering with pneumonia, he was accepted into Plymouth Housing, a nonprofit supportive housing facility that considers applicants’ health in their admission process. After moving into Plymouth, King was diagnosed with heart failure and given a six-month prognosis. Harborview referred him to Providence Hospice of Seattle, and he began receiving visits from his hospice nurse, Laura Newcomb, who he’s become close to. King now has access to social workers and substance abuse treatment. “The people here are so open, caring. I couldn’t speak enough about this program. It saved my life,” he says.

Franciscan Hospice and Palliative Care is another hospice organization in Seattle that serves the homeless. Bonni Stratton, manager of business development, says the hospice serves about six to seven homeless patients every year. Hospice nurses make visits to patients living in shelters or even in vans. Stratton tells how they’ve supported patients by placing them in the 20-bed hospice facility, Hospice House, or even provided hotel rooms for patients who had no other options.

One patient wished to stay in his van until the very end. Stratton said this was very important for him to retain a sense of autonomy. “That was a real successful situation with the van because that’s really where he wanted to be,” she says. “We work with the patient from the very time that we start, if they have insecure housing, to really work with them: Where do you want to have this [care] as things change, as you decline?”

King speaks excitedly about the care he’s received from Newcomb and Plymouth Housing. He explains how he likes to go to the waterfront on days when he is more mobile because the water has allowed him to feel such healing throughout his life. From his words, the resources he’s found in Seattle seem to have provided healing as well. (Crosscut, 10/29, https://crosscut.com/2019/10/homeless-washingtonians-near-end-life-hospice-workers-offer-comfort-wherever-needed)

MEDICARE BENEFIT DOES NOT MEET DEMENTIA PATIENTS’ HOSPICE NEEDS

“Hospice care has a new face: Dementia now accounts for more Medicare spending on end-of-life services than any other disease.” And, according to an investigation done by Nashville’s Public Radio, WPLN, “Patients with the longest stays tend to get the least help.
Hospice care was not designed for dementia patients says a Nashville Public Radio presentation. According to the Medicare Payment Advisory Commission, the lengthening average hospice stay is due to the influence of dementia patients – particularly those who choose to begin care earlier. Pedro Gozalo of Brown University says that dementia and other terminal illnesses have shed light on holes in the hospice care formula.

Because the government hospice benefit was designed around the needs of cancer patients, hospice agencies had been equipped to largely deal in pain-management and not the kind of intensive care that dementia patients require. Gozalo says that hospices’ focus on managing pain was originally pitched as a Medicare money-saving intervention. With longer stays and more intensive care, however, the flat rate of the Medicare benefit doesn’t fit the bill for patients who are not suffering from terminal cancer. Many calls for reform of the Medicare benefit have been made recently, and NHPCO says the six-month prognosis is irrelevant to dementia patients whose life expectancy is very difficult to predict.

Nashville Public Radio shares the experience of the McCasland family to illustrate how this discrepancy can play out. Jean McCasland has been in hospice care receiving treatment for advanced dementia. Jean’s husband, John, noticed that the hospice company caring for Jean has been billing Medicare for $200 each day. However, Jean does not require much special care or equipment from hospice. In fact, the hospice care available to Jean has been ill-equipped to serve her needs to the point that John has been paying for a fulltime caregiver.

The provider of McCasland’s hospice is a small for-profit hospice agency. They explain that they’re restricted by the Medicare benefit in what services they can offer, Nashville Public Radio says. An administrator at the hospice agency says she is understanding of the difficult situation dementia patients are in, however. “I think everybody wishes we could provide the sitter service part of it,” she says. “But it’s not something that is covered by hospices.” When John reviewed the figures, he found that “His hospice agency has been making twice as much a week as what he’s paid his fulltime caregiver.” To keep Jean at home, John had to pay for even more help before Jean died in October.


HOSPICE NOTES

* The HHS Partnership Center is teaming up with NHPCO to offer a free two-part webinar series this month. The first, “National Webinar Part I: Demystifying Services for the Seriously Ill: Palliative Care and Hospice 101,” will take place on November 14th at 12:00 PM Eastern Time. It will give an overview of hospice and palliative care, outline differences between the two forms of care, and discuss how communities can be better connected to hospice and palliative care. The second part, “National Webinar Part II: Community Partnerships to Improve
Access to Hospice and Palliative Care,” will take place November 21st, 12:00 PM Eastern Time. This webinar will focus on educating communities and organizations about hospice and palliative care. It will address myths and barriers to care access, such as fears around end-of-life conversations. **Registration and more information such as a list of speakers are available at the links below.** *(HHS Partnership Center, 11/2019, https://zoom.us/webinar/register/WN__3ANcSPYQYq4tHqpYmy4yQ; https://zoom.us/webinar/register/WN_VcVR1V82RQyi2d0SpeFuOQ)*

* The Department of Justice reports that three individuals associated with hospice care companies across Texas were found guilty of health care fraud and money laundering by a federal jury. The owner, the CEO, and a medical director of a large health care company were engaged in a scheme which falsely enrolled patients in hospice care. To maximize revenue from Medicare claims, the company admitted patients who were told they had six months to live when they were, in fact, not terminally ill. Assistant Attorney General Brian A. Benczkowski of the Justice Department’s Criminal Division says the individuals “preyed on the most vulnerable population – those in need of hospice and home health care— to line their pockets with millions of dollars and engage in lavish spending… I thank our law enforcement partners for their hard work and dedication to bringing these health care fraudsters to justice. We look forward to continuing our partnership as we expand the [Medicare Fraud] Strike Force into the Rio Grande Valley.” *(The United States Department of Justice, 11/6, www.justice.gov/opa/pr/three-individuals-including-former-texas-mayor-ceo-and-owner-found-guilty-154-million-money)*

* Local *ABC News* affiliate WTVD in Raleigh shares the story of a surprise endowment to the Association for Home & Hospice Care of North Carolina (AHHC). AHHC CEO, Tim Rogers, found out by mail in 2016 that Mary Ellen Dryden, a cancer researcher and descendent of George Eastman of Eastman Kodak, had included the association in her will. Rogers learned that the Eastman family had a history of hospice involvement in North Carolina, having repurposed their Halifax County hunting lodge as the state’s first hospice center. Three years later, Rogers learned more details about the endowment: “It was a $750,000 endowment. The largest in the history of this association,” he says. The community’s emotional reception of the donation is shared on the *ABC11* website. *(ABC News WTVD, 11/7, https://abc11.com/community-events/$750000-donation-leaves-behind-to-help-dying-children/5676973/)*

* A recent *GeriPal* podcast interviews Vince Mor, Senior Health Research Scientist at the Providence VA Medical Center, and professor in the Department of Health Services, Policy and Practice at the Brown University School of Public Health. Mor shared about a study he published with *JAMA Oncology* in March. *Mor’s study found veterans in hospitals with high hospice use were more likely to receive concurrent care for advanced lung cancer. They were also less likely to receive aggressive care and incur large medical bills than if they were treated in hospitals who use hospice less frequently. GeriPal argues that this makes a strong case for the benefits of concurrent care.* The podcast is available for listening, and there is also a written transcript on the *GeriPal* website. *(GeriPal, 10/31, www.geripal.org/2019/10/Concurrent-care-allowing-for-chemotherapy-in-hospice.html; JAMA Oncology, 3/28, https://jamanetwork.com/journals/jamaoncology/article-abstract/2729064)*

* Four Seasons, a North Carolina hospice and palliative care provider, is the recipient of a two-year grant from the Agency of Healthcare Research and Quality (AHRQ). Focusing on
home-bound serious illness patients, the grant will fund a project that examines the impact of virtual pharmacists being integrated into the existing telehealth model. The grant will help build upon a pilot program Four Seasons participated in previously. A new platform is being developed as part of the project: ADAPT Health, offered by Delta Care Rx and powered by the TapCloud application. “Remote patient care and telehealth in general, are a part of the future of healthcare, especially in rural patient populations,” Michelle Mikus, VP of pharmacy services with Delta Care Rx, says. (mHealth Intelligence, 11/4, https://mhealthintelligence.com/news/telehealth-grant-to-support-pharmacy-services-in-palliative-care)

END-OF-LIFE NOTES

* Daniela Lamas, MD, doctor at Brigham and Women’s Hospital in Boston, and staff writer for TV medical drama “The Resident,” writes an essay for The New York Times about allowing loved ones to witness patients’ deaths in the ICU. Lamas writes that despite commonly held opinions, more and more research is suggesting that there could be benefits to allowing family members in the ICU during a “code.” The research shows that “relatives don’t distract the medical team or interfere with decision-making in a code. Doctors don’t feel pushed to continue CPR longer than we would otherwise or to stop sooner. Nor are there increases in legal ramifications,” Lamas says. Further, studies show incidence of PTSD, anxiety, and depression are not higher for those who witness CPR being administered to their loved ones. The evidence suggests the occurrence may even be lower. Lamas shares that, as part of the move to bring loved ones into critical care, they have even begun including family members in their morning rounds at her hospital. Throughout her argument for more inclusion of patients’ relatives, Lamas tells a touching personal account of including the wife of a patient with sudden heart failure. Though Lamas expressed doubt she had done the right thing in inviting her patient’s wife into the ICU, her story ends with a teary “thank you” from the wife, after she asks Lamas’s team to cease resuscitation efforts. (The New York Times, 10/25, www.nytimes.com/2019/10/25/well/live/should-family-members-see-patients-die-in-the-icu.html)

* Lizzy Miles, a hospice social worker and writer who brought the Death Café concept to the United States, writes an essay for Pallimed reframing elder care and the language we use around it. “No one should ever be ‘put’ in a nursing home,” Miles argues. “I would like to make the argument that no adult wants to be ‘put’ anywhere... When we are facing a situation in which the care needs exceed the family member’s ability, there are times where the best option is for the elder to move to a safer environment,” she says. Miles shares a few personal vignettes and anecdotes from her work in nursing homes to show that by focusing on giving the elderly the best, most supportive care, we can more positively frame this “community living” option. The elderly can thrive in nursing homes where more socialization and care are available to them. Family members can experience “respite” from demanding care schedules. They can focus on forming memories with their elderly loved ones and enjoying their time together. Miles says she saw this firsthand with her own mother, saying they became closer than ever before during her mother’s happiest years of life spent in a facility. “As it turned out, it was the best decision I could have made,” Miles says. (Pallimed, 11/1, www.pallimed.org/2019/11/community-living-for-hospice-patients.html)
**PALLIATIVE CARE NOTES**

* A new pain rating scale has been launched by the Department of Defense, reports *Pain Medicine News*. The Defense and Veterans Pain Rating Scale adds a new focus on functionality in addition to pain intensity. The new scale adds questions about how the pain is affecting patients’ ability to carry out daily activities including sleep and their mood. “This is a cultural change that we’re bringing, not only to our patients but also to ourselves as clinicians,” says Chester Buckenmaier III, MD, director of the Uniformed Services University Defense & Veterans Center for Integrative Pain Management at Walter Reed National Military Medical Center in Bethesda, Md. “The goal of pain management isn’t exactly getting pain down to zero, but optimizing both physical and emotional function.” Buckenmaier explained that when only pain levels are used to determine treatments, opioids are usually prescribed. Often, these prescriptions decrease functionality. Still, “It’s not to replace opioids; it would be a mistake to think so,” Buckenmaier says. Rather, the new scale can help find the most effective combination of opioids and non-pharmaceutical interventions to result in improved pain management. *(Pain Medicine News, 9/26, www.painmedicinenews.com/Online-First/Article/09-19/New-DoD-Pain-Scale-Focuses-on-Function-in-Addition-to-Intensity-/56040; Defense & Veterans Center for Integrative Pain Management, 2019, www.dvcipm.org/clinical-resources/defense-veterans-pain-rating-scale-dvprs/)*

* With the closing of the American Pain Society (APS), *Pain Medicine News* discusses the voids left in scholarship, advocacy, and research in the pain management field. Along with the end of the APS comes the end of their peer-reviewed publication *The Journal of Pain*, The APS Annual Scientific Meeting, and many other venues for academic work, pain management awareness, education, and lobbying. In the article, several professionals share how APS influenced their careers and the state of pain management in American health care. Gregory Terman, MD, PhD, anesthesiologist, director of the acute pain service at University of Washington Medical Center, and past APS president mentions a multidisciplinary pain management course developed by APS, which he says is unlikely to continue. He says of APS: “No organization exists that will advocate as aggressively as APS in support of multidisciplinary pain care and pain research. It’s ironic that if we were doing pain treatment the way APS wanted, there would not be an opioids crisis today.” *(Pain Medicine News, 10/2, www.painmedicinenews.com/Policy-and-Management/Article/10-19/American-Pain-Society-s-Closing-Leaves-Advocacy-Void/56147)*

* In a recent Q&A with MedPage Today, Alexander Wolf, DNP, RN, APRN, discusses his research on “moral distress” of critical care nurses. Wolf recently published a paper on this topic and how it applies to nursing and palliative care. “Critical care nurses tend to experience frequent and intense moral distress in situations pertaining to the end of life, such as providing treatment perceived as inappropriate or futile, prolongation of life or death and lying to or withholding information from patients or family members,” Wolf says in his study. Improved palliative care education is one solution Wolf sees for this issue. Further, he says that bedside nurses should be “empowered as leaders” in implementing palliative care into their teams’ practices. He says it would also be wise to include other health care professionals in palliative care continuing education because the nurses in his study “placed a high value on interprofessional collaboration.” He says “This could help foster increased recognition of
patients’ palliative care needs by all team members.” *(MedPage Today, 10/27, www.medpagetoday.com/nursing/nursing/82952)*

**PHYSICIAN ASSISTED SUICIDE NOTE**

* The Colorado medical aid-in-dying law includes a provision that allows individual health care providers the choice of whether or not to participate – regardless of their employer’s position. In response to a current court case against the law, Matthew Wynia, MD, of the Center for Bioethics and Humanities at the University of Colorado asks, “Will individual or corporate conscience prevail?” Wynia outlines the current court case in which Barbara Morris, MD, a geriatrician formerly employed by Centura Health, filed suit against Centura for not allowing her to prescribe medical aid-in-dying to one of her patients. Centura fired Morris, and has asked that the case be moved to federal court, arguing that Colorado’s law infringes on the corporation’s constitutional First Amendment rights. Additionally, Wynia dives into some of the history of the Colorado End-of-Life Options Act. He draws parallels to other high-profile corporate religious liberty cases in speculating how Morris’s case against Centura Health may play out. “If the courts rule that the Constitution allows hospitals to exert control over individual physicians’ claims of professional conscience, it will be a victory for corporate medicine,” Wynia says. “But if the state law is upheld, the case could establish that physicians’ professional conscience claims hold or take precedence over the ethical and religious directives of religiously affiliated hospitals.” *(JAMA, 10/29, https://jamanetwork.com/journals/jama/fullarticle/2753848)*

**OTHER NOTES**

* Last month, the annual meeting of the American Society for Bioethics and Humanities convened in Pittsburgh. Bioethicists gathered from around the world to examine the current state of bioethics. The Hastings Center shares a summary of the major themes that came out of this meeting. Economic disparities and technological influences informed many of the key themes. An important topic was that of America’s aging society. The Hastings Center notes that by 2030, the population over the age of 80 is expected to rise by 79%. “U.S. society is completely unprepared for the massive wave of older Americans who will need long-term assistance,” The Hastings Center says. “Most of them will not be able to pay for their basic needs.” *(The Hastings Center, 11/7, www.thehastingscenter.org/news/five-things-bioethicists-see-in-our-future/)*

* The National Institute on Aging, part of the National Institutes of Health (NIH) has given a five-year $3 million grant to Cornell’s Translational Research Institute on Pain in Later Life. More Americans are suffering from chronic pain than they are “heart disease, diabetes, and cancer combined,” says Cornell Chronicle. The NIH grant will help enable Cornell researchers to develop new pain interventions. “This grant will be the catalyst to bring together a diverse group of social and behavioral scientists and people working in clinical medicine, psychiatry, rehabilitation medicine and technology to create better solutions to the problem of chronic pain, which affects a huge number of older people and causes vast amounts of possibly preventable suffering,” says Karl Pillemer, the Hazel E. Reed Professor of Human
Development in the College of Human Ecology and co-director on the grant. *Cornell Chronicle explores their institution’s specific pain research efforts in their article covering the grant.* *(Cornell Chronicle, 10/31, http://news.cornell.edu/stories/2019/10/nih-grant-will-fund-non-pharmacological-pain-research)*

* In September, Johns Hopkins launched the US Center for Psychedelic and Consciousness Research. The research center, which Johns Hopkins believes to be the first focused on psychedelics in America, received a $17 million grant from four philanthropists and a private foundation. An article in *JAMA contains an interview with Roland Griffiths, PhD, center director and professor of behavioral biology.* Griffiths discusses the early research the center has done on psychedelics like psilocybin, lysergic acid diethylamide (LSD), and dimethyltryptamine (DMT). The initial studies, he says, show exciting promise in treating depression, anxiety, addiction, anorexia nervosa, and even early Alzheimer disease. “In studies that we ran in people with depression and anxiety secondary to a life-threatening cancer diagnosis, we saw very little relapse to those conditions 6 months afterward,” Griffiths says in the interview. “This intervention is quite different from any other in psychiatry… This kind of intervention occurs in a single session, and we’re seeing sustained and enduring effects.” *(JAMA, 10/31, https://jamanetwork.com/journals/jama/fullarticle/2754080)*

_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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