
HOSPICE NEWS NETWORK

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

A Service of State Hospice Organizations

OFFERING QUALITY LGBTQ END-OF-LIFE CARE

“Getting to know a patient enough to be able to be ‘holistic’ can be difficult,” writes Vivian Lam for *Pallimed*. “And in the case of LGBTQ individuals, getting to know the patient as a whole is not only all the more important—it’s integral.” She explains that a basic cultural competency exists for working with the community, with its own historical and ongoing experiences with healthcare. Over 4% of U.S. adults openly identify as LGBTQ (about 10 million adults), according to a recent Gallup survey, and this means that medical providers, social service professionals, and mental health providers should be attuned to these particular needs. Lam says, “Small steps can quickly translate into big steps.”

Both historical trauma and ongoing discrimination often prevent those in the LGBTQ community from seeking or obtaining needed healthcare, Lam points out. **Even with hospice and palliative care, many prospective patients anticipate receiving treatment that may be less than that received by their straight and gender-conforming peers.** “Some feel that they must go ‘back into the closet’ in order to protect themselves from the hostility of hospital or assisted living staff and patients,” Lam says, “and transgender individuals’ wishes to be recognized and die as their preferred gender are often disrespected.”

To combat a barrier to access, Lam suggests following some best practices for creating a welcoming environment. These measures include hanging signs that signal the office is LGBTQ-friendly and providing brochures relevant to the relevant health issues. Care providers can add transgender options alongside “male/female” intake options and be mindful not to presume a patient’s sexuality or gender identity. It’s also appropriate to introduce oneself with preferred pronouns and ask the patient about theirs. “Do not assume that a trans patient desires or has undergone surgical or hormonal transition,” Lam points out. It’s important to “make it clear that you are comfortable with their identity, and are willing to learn how to support them through identity-specific issues.” **Most simply, Lam proposes having a conversation about fears and needs with an attention to the use of pronouns.**

Lam offers up open-ended questions such as: “Who are the most important people in your life? Do you have a significant other? Are you in a relationship? Do you live with anyone? Tell me more about yourself?” Due to many factors, LGBTQ individuals are more likely to be single or be estranged from their birth families. They’re also less likely to have children. This makes it important to consider that many will have “families of choice” that serve as an important support network.

Legal issues may be a concern because LGBTQ individuals may fear their partner will not be recognized as a durable power of attorney. If individuals are estranged from their families, the idea of not having a medical and legal advocate can be frightening. This extends to the

treatment of the bereaved, because non-registered surviving partners are denied family leave, benefits, automatic inheritance, property, and other rights. In short, says Lam, “For LGBTQ individuals, having a power of attorney in place is top priority.” For providers, it’s important to address these issues clearly and be aware of who they feel is an important part of their decision-making process. (*Pallimed*, 11/13, www.pallimed.org/2017/11/lgbtq-at-end-of-life-needs-and.html; *Rainbow Welcome*, 11/2017, www.rainbowwelcome.org/uploads/pdfs/Creating%20a%20Welcome%20Clinical%20Environment%20for%20LGBT%20Patients.pdf)

SHARE YOUR WISHES IN A VIDEO ADVANCE DIRECTIVE

Many patients have turned to creating videos to express their wishes for end-of-life care in order to add a human touch to their written advance directives. Dr. Angelo Volandes, an internal medicine doctor at Massachusetts General Hospital, is considered a pioneer in facilitating such videos. Volandes says patients are more comfortable with the process than many imagine. “They were very comfortable and far more articulate than we give them credit for,” Volandes says of a group of heart failure patients he consulted.

In a recent article, *Kaiser Health News* tells the story of Wendy Forman, a 70-year-old Philadelphia therapist who assembled orders for her medical wishes, which refused cardiopulmonary resuscitation. “I was terrified of losing control,” she said. After learning of “video advance directives,” she remembered thinking, “Oh my God, it’s like someone was reading my diary — this is exactly what I want.”

In fact, companies including HealthCare Directives, MyDirectives, Life Message Media, and In My Own Words now provide video advance directive services. The services walk patients through care scenarios, with answers ranging from 15 seconds to a minute long. Patients may also create their own tapes, which serve to supplement written documents and reassure patients and families that their wishes are clear and followed with care.

Dr. Monica Williams-Murphy, medical director of advance-care planning and end-of-life education for Huntsville Hospital System in Alabama, says that videos can help ease the emotional burden in end-of-life care. **“A family gets to hear Mom saying, in her own words, what she wants,” she says, “which can be profoundly reassuring.”**

Doctors can also be guided in their work by such videos, as evidenced in a 2017 article in the *Journal of Patient Safety*. The authors found that physicians were more likely to agree on end-of-life interventions when a video accompanied written advance directives. **“When you can see a patient expressing what their true intended wishes are, in their own voice, looking into a camera, that’s a very powerful tool,” says Ferdinando Mirarchi, DO, founder of the Institute on Healthcare Directives.**

The logistics of accessing these videos in a timely manner is a complication. As of now, it’s clearly essential, but not always practical, writes *Kaiser Health News*. “The institute houses videos on a server; they can be called up on digital devices via QR codes, or hyperlinked bar codes, that are printed on cards given to clients.” Still, videos are taken into account when there’s a dispute over care, and overall physicians are receptive to consulting them.

Moving forward, those like Dr. Angelo Volandes see Medicare-funded advance-care planning adapting with the technology. He imagines a primary care doctor using a simple cellphone or desktop camera to document wishes and, ideally, family members could participate either in person or over services like Skype. In this way, videos would serve as an oral and visual document that confirms the written orders. It would add a sense of humanity to everyone involved in what can be very grim moments and decisions. (*Becker’s Healthcare*, 11/30, www.beckershospitalreview.com/quality/more-patients-using-videos-to-inform-end-of-life-care-4-things-to-know.html; *KHN*, 11/30, <https://khn.org/news/straight-from-the-patients-mouth-videos-can->

clearly-state-your-end-of-life-wishes; *Dayton Daily News*, 11/30, www.mydaytondailynews.com/news/have-you-had-end-life-conversations-with-family-now-time/Fmt17KCOpiIMv1KH0dNLfl)

NAVIGATING AGING IN AMERICA'S HEALTHCARE SYSTEM

When patients are hospitalized, it's common that a physician they've never met treats them. These encounters rarely allow for an understanding of daily concerns like dizziness, sleep troubles, or more minor symptoms. The broad stroke approach of this kind of care can lead to “questionable tests and treatments that might end up compromising your health,” according to *Kaiser Health News*.

KHN's recent article “How Older Patients Can Dodge Pitfalls Entrenched In Health Care System,” focused on the prospects of aging within the American medical system. The piece features an interview with Dr. Muriel Gillick, author of *Old & Sick in America: The Journey Through the Health Care System*. Gillick, professor of population medicine at Harvard Medical School, talked about the concerns of aging within America's medical system.

Gillick says, “In general, physicians tend to focus on different organ systems.” So while they may treat the heart, lungs, or kidneys, it doesn't necessarily mean a physician spots conditions that go across organ systems, “so-called geriatric syndromes. Things like falling, becoming confused or dealing with incontinence.” For patients, this means speaking up, but also finding those who are providing care being attuned to your needs.

Another option is to offer a geriatric assessment, which “looks at the whole person.” This consultation can address issues that directly impact quality of life, such as mobility, ability to cook meals, or maintain finances. “When someone starts being frail — having consistent difficulty doing things,” Dr. Gillick says, “an assessment of this kind is often a good idea.”

In the hospital, Gillick cautions that the pursuit for a diagnosis, though helpful to some, may not improve quality of life. Seemingly non-invasive tests like a CT scan can include complications, like kidney failure caused by the dye. In other cases, medication side effects or infection can make matters worse. Generally, says the article, “Doctors want to do whatever it takes to diagnose a problem,” but it's important to balance this with the goals of the patient. **To make a determination about what care to offer, Dr. Gillick proposes that patients ask their doctor directly: “How important is it to pursue this diagnosis?” Or, “How will the results change what you do?”**

Skilled nursing facilities are another setting that people find themselves in after the hospital, and direct talks with doctors become less frequent. This transition can vary widely based on the facility and condition of the patient. “When you arrive at a SNF, it's a new cast of characters,” says Gillick. **For caregivers, it's important to have face time with staffers, and SNFs are required to provide a care-planning meeting with the team within the first week of care.** “This is a good place to say something along the lines of ‘My mother has been through a lot, and now that we've met you and seen what you can do, we'd like you to do your best to treat her here and not send her back to the hospital.’”

In the hospital or SNF, the quality of treatment depends largely on communication and trust. **If doctors and staffers understand who patients are, what things are typical for their bodies and routines, and their broader wishes for care, it reduces confusion and “has the potential**

to allow everyone to figure out what's important and what the plan will be going forward.” (*KHN*, 11/16, www.khn.org/news/how-older-patients-can-dodge-pitfalls-entrenched-in-health-care-system)

CONGRESSIONAL MEMBERS SERVE AS CAREGIVERS TOO

Caring for a member of your family in old age is a stressful endeavor, even for members of Congress. In a recent article in *Forbes*, Rita Rubin examines the engagement and conversations on Capitol Hill about the support provided to caregivers around the country, and the proposals put forward to elevate their burdens.

Michelle Lujan Grisham is the co-founder of the bipartisan Assisting Caregivers Today (ACT) Caucus. Grisham is also a congresswoman (D-NM). She says she has difficulty navigating care for her own mother. **This experience in part led her to introduce the National Care Corps Act of 2017, which she says could, like Peace Corps, allow young adults with an interest in caregiving to receive health insurance and education costs in exchange for service to older adults and adults with disabilities in communities with need.** However, since the legislation's introduction to congress in July, it has seen no movement.

In her own experience as a lawyer and a congresswoman, Grisham says, “I have to be on it every single minute of every single day, and I need help.” She shared her experiences at a Capitol Hill briefing sponsored by the Gerontological Society of America (GSA) and the John A. Hartford Foundation, in partnership with AARP, the Alzheimer's Association, and the National Alliance for Caregiving. The event aimed to direct attention during National Family Caregivers Month on the recommendations offered in the “Families Caring for an Aging America” report.

Grisham is not alone in her experience. Even within congress, she finds similar stories of caregiving challenges. **Congresswoman Jacky Rosen (D-NV) quit her job as a computer programmer to care for her parents and in-laws.** Rosen co-sponsored a bipartisan effort called the Credit For Caring Act of 2017 that would create a federal, nonrefundable tax credit of up to \$3,000 for family caregivers who both work and spend their own money to provide care to relatives and other loved ones.

Similarly, Chris Smith (R-NJ) tells the story of his own mother, who lived with his family for a year during the 90s after she was diagnosed with brain cancer and early Alzheimer's. Smith shared that they put a baby monitor in his mother's bedroom to make sure she was all right overnight. Smith said they'd tell her, “Mom, you are not a burden. We love you. And there is no other place on Earth we would want you to be than with us.”

Jan Schakowsky (D-IL) emphasized the importance of not just the financial aspects of care. Schakowsky took in her father during the last seven years of his life, and says, “It's the emotional support that's so important ... if the demands are heavy over time, we [caregivers] can become exhausted, stressed and sick ourselves.” As a co-chair of the Seniors Task Force, she introduced the Geriatrics Workforce and Caregiver Enhancement Act and, along with her colleagues, says that it's time to move for real change in the way we support caregivers. “It's time that we invest in the quality of care that our seniors deserve.” (*Forbes*, 11/10, www.forbes.com/sites/nextavenue/2017/11/10/members-of-congress-on-their-caregiving-challenges/#6dd5a2473a93; *National Academies Press*, 2016, www.nap.edu/read/23606/chapter/1#xiii)

ARTICLE EXPLORES BARRIERS TO EARLIER HOSPICE ADMISSIONS

An article in *Home Health Care News*, written by Amy Baxter, explores the issue of short stays in hospice due to late admissions. Baxter reports that nearly half of all hospice patients are enrolled in hospice during the last two weeks of their lives. Yet the Medicare Hospice Benefit was designed for much longer utilization.

Baxter sets out to understand why so many admissions to hospice occur so late in life. Among key reasons, she notes, are “a lack of knowledge or misunderstanding about what hospice care is, what it can provide and how it is paid for.” Further, a lack of overall understanding impacts why many enter hospice so late. Michael Mencias, MD, adds, “So many people, even some physicians, are surprised that the hospice benefit is free. There are no co-pay and no charges for medicine that are related to terminal illness.”

Now, with growth in palliative care and “other supportive care,” hospice may face more competition, according to Edo Banach, CEO of NHPCPO. **Banach says, “As you’ve had a lot more activity in care management and care coordination and palliative care, all the noise competes for folks’ attention. That sometimes prevents or delays folks from making a decision.”** Banach explains that, unlike hospice, palliative care allows patients to continue curative treatment and can also be implemented anytime during peoples’ illnesses. Banach adds, “A lot of folks delay hospice care; they are holding out hope or the family is. I don’t fault folks for that; that’s the reality.”

What can improve and encourage earlier admissions? Mencias says there aren’t resources to help, and there are “no published best-practice guidelines.” Mencias suggest that the slow work of outreach to physicians and provision of information may be the best route. But it may not be enough, because it really comes down to each patient and family. And backgrounds influence those decisions as well.

Adding reimbursement for physician discussions with patients is helpful, but is not the end all, notes Banach. **As health care continues to shift, it is important, Banach adds, “that hospices are engaged in and competing with the folks further upstream.”** All providers—hospitals, home health and long term care “need to work together around the concept that hospice isn’t radical, but that it is about what people want.” (*Home Health Care News*, 11/26, <https://homehealthcarenews.com/2017/11/hospices-aim-to-improve-transition-times/>)

HOSPICE SOCIAL WORKERS BRING RELIEF AND ESSENTIAL CARE

J. Scott Janssen, MSW, LCSW, discusses hospice in the nursing home setting in his article “Hospice Social Work in Nursing Homes,” published in *Social Work Today*. When most people think of hospice care, notes the article, they imagine it taking place at home or in a freestanding hospice facility. So it’s sometimes a surprise, says Janssen, to find that the Medicare Hospice Benefit allows for hospice care in assisted living facilities and skilled nursing facilities, which are so often site of rehabilitation and the stabilization of individuals.

Janssen cites John Cagle, PhD, MWS, an associate professor in the School of Social Work at the University of Maryland, who says that almost a quarter of all deaths in the United States occur in nursing homes. Clearly, this makes the nursing home an essential location to focus end-of-life care. But no matter the location of hospice care, the core principles remain the same: hospice provides interdisciplinary care for those near the end of life, and focuses on symptom management, comfort, and emotional or spiritual support.

In a recent article in the *Journal of Pain and Symptom Management*, Cagle and colleagues interviewed nursing home employees and found them “generally positive about involving hospice in the care of dying patients.” Cagle says that nursing home staff “reported, for example, that hospice provides a welcomed layer of extra support, needed expertise in pain and symptom management, and helpful bereavement care for families.” And at the center of this care, says the article, are hospice social workers.

For most nursing home facility workers, says Cagle, “Caseloads are high, regulations require time-consuming documentation, and many nursing home social workers have additional responsibilities related to tasks such as admissions, marketing, discharge planning, and participating in regular meetings.” Cagle also notes, “Few have substantial training in end-of-life intervention, and most do not have the experience or credentials for providing the kind of psychological counseling available from a hospice social worker.”

Caitlin Connolly, MSW, LICSW, is a social worker with Hospice of the Northwest. Connolly says, **“The awareness we hold of resources available to patients and families in the community, both while on service and after a patient dies, relieves feelings of abandonment or isolation that families may carry after a loved one dies.”**

According to the article, “Residents and families are often forced to conform to set routines and adapt to limited space with little room for keepsakes and other personal belongings. Given multiple demands on staff and often high staff-to-resident ratios, residents often must wait longer than they or their families would like for assistance, which can become a source of stress and friction.”

Nursing homes also see a high percentage of cognitive impairments like dementia in patients. This can lead to behavioral issues, make communication more difficult, and undercut the process of sharing information about a patient’s life and wishes. **The hospice social workers often become important figures for families, Smith says, by “relaying information, giving updates, understanding the situation the family is in, and reassuring them that their loved one is comfortable and cared for.”**

Nursing homes must also navigate regulatory challenges. Cagle says, “The metrics used by skilled nursing facilities that assess the quality of care may not be congruent with end-of-life care.” For example, a patient whose reduced fluid intake is an expected part of the dying process could be viewed negatively by facility staff who may push IV fluids in response. In this case, “The tensions will be high.” Judi Lund Person, MPH, CHC, vice president of regulatory and compliance for the National Hospice and Palliative Care Organization says that hospice staff should be sensitive to the pressures of such a context.

Today there are 1.5 million individuals living in nursing homes. The integration of hospice social

workers into the team of caregivers is key, and Smith reiterates the importance of fostering relationships and trust. **“Understanding the dynamics in a facility, appreciating their struggles in providing care in that system, having a knowledge of a facility's culture, and becoming an integral part in the facility shows that we care about them,”** she says. (*Social Work Today*, 11/2017, www.socialworktoday.com/archive/ND17p20.shtml)

COMPASSION FATIGUE IMPACTS NURSE AND PATIENT HEALTH

The emotional stress and continuous demands that come with providing quality care are leading to “compassion fatigue,” says Jennifer Flynn, CPHRM, and Mary M. Gullatte, PhD, RN. This is not only applicable to nurses, but to any caregivers, and can lead to errors in care or even lead to skilled nurses leaving the profession. The co-authors outline the effects of this continual emotional exercise in “When Compassionate Care Takes a Turn Toward Fatigue,” an article appearing in *Medpage Today*.

The authors share that 13% of newly licensed RNs left nursing for a different career within one year of gaining their license, according to the American Association of Colleges of Nursing, and 37% said they were ready to change jobs. While some of these cases could be attributed to management, wages, or other professional issues, they suggest that ongoing emotional stress is an often-ignored factor.

Compassion fatigue is not just a small slump. It is a “state of psychic exhaustion where caregivers face a severe sense of malaise.” The notable mindset has been discussed by others like Charles Figley, PhD, a trauma therapist, who refers to the phenomenon as the “cost of caring” for others in emotional pain. Nurses are particularly vulnerable because they’re so intimately connected to the lives of patients at a critical time in their life. They are not just observers. Indeed, they are participants in the moments of “life, death, sadness, and loss.”

Psychotherapist Dennis Portnoy, a specialist in professional burnout, created a self-assessment tool for caregivers. He says that those who experience compassion fatigue tend to identify strongly with statements like: “People rely on me for support,” “When I make a mistake, I have difficulty forgiving myself,” or “I take work home frequently.” By the depth of their giving themselves to their patients and, caring about the quality of their work, they begin to feel as if they’re “running on empty.”

Some might see this as an “occupational hazard,” but it has an impact on caregivers, patients, and the industry at large. The fatigue can lead to real consequences -- like an inability to react sympathetically during a crisis. It can lead to trauma for the caregiver due to extreme states of tension or preoccupation with suffering. It can also manifest as “cynicism, emotional exhaustion, or self-centeredness” in otherwise caring individuals.

How can we address compassion fatigue? The authors outline long-term solutions that begin with the seemingly simple act of “acknowledging the severe emotional impact of a nurse’s obligation to routinely meet a patients immediate and comprehensive needs.” The industry can also promote self-care and encourage activities that are beneficial to physical, emotional, and spiritual health. The authors also point to Employee Assistance Programs,

which can provide forms of counseling and emotional support.

The authors urge both management and nurses “to foster the environment and demand the resources necessary to overcome the issue.” (*Medpage Today*, 11/17, www.medpagetoday.com/nursing/nursing/69366)

HOSPICE NOTES

* **The community-based nonprofit Hospice and Palliative Care of Greensboro will no longer provide its Kids Path program at the end of the month.** The services have been provided for 15 years, but the program is no longer financially viable and the hospice says a plan is in effect to transition 21 children with serious or terminal illnesses to alternative providers. “It’s just such a loss. They’re like family,” says Dania Erementrout, whose terminally ill daughter Moira is under their care. “They helped our family cope with everything and guide us through really, really difficult times.” Other parents are alarmed at the speed of the transition, as *Fox 8* reports. (*Fox 8*, 11/14, <http://myfox8.com/2017/11/14/21-guilford-county-children-losing-home-health-care-services>)

* **The National Partnership for Hospice Innovation (NPHI) hosted its first annual Igniting Innovation Summit in Dallas, Texas.** The three-day meeting provided a forum for discussions on critical healthcare topics and innovations in approaches to end-of-life care. “The NPHI movement will truly impact the way advanced illness care and end-of-life care will be delivered, setting a new course for NPHI hospices that will be sustainable in the future,” says Mary Ann Boccolini, President & CEO of Samaritan Healthcare & Hospice. An overview of presenters is online. (*Markets Insider*, 11/14, <http://markets.businessinsider.com/news/stocks/NPHI-Summit-Ignites-Hospice-Innovation-to-Benefit-Communities-1008004107>; *Crimson PR Newswire*, 11/14, www.prnewswire.com/news-releases/nphi-summit-ignites-hospice-innovation-to-benefit-communities-300555480.html)

* **In San Diego, a three-year-old black Labrador named Stevie is bringing joy to patients.** In a local TV news segment, her “TLC” interactions were captured. For Carrie Greenstein, who recently lost her mother-in-law, she says Stevie “brought me a smile to my face and she brought a sense of ‘everything is gonna be OK’.” Stevie was originally taught by inmate trainers at Donovan Correction Facility and now, along with her handler Danielle Nowicki, they serve as the first certified dog team at a hospice in San Diego County. (*CBS8*, 11/15, www.cbs8.com/story/36853409/one-of-a-kind-hospice-dog-heals-hearts)

* **NHPCO has released a new video highlighting the benefits of palliative care.** The video features Michael Sampair and his wife Liz, and relates their experiences with treatment while he was a patient at The Elizabeth Hospice in San Diego. It also features thoughts and explanations of palliative medicine from George Delgado, MD, FAAFP, HMDC. “When patients don’t have pain under control, it’s hard for them to really enjoy life and to live life to the fullest,” says Delgado. “[Michael] was really finding he had a lot of life still to live but he wasn’t able to enjoy it or to be fulfilled because of the pain.” In a press release from NHPCO, President and CEO Edo Banach says, “**The philosophy of palliative care is the same as with hospice –patient-centered care that addresses the medical, psycho-social and spiritual needs of the person**

and family caregivers.” (NHPCO, 11/15, www.nhpco.org/press-room/press-releases/palliative-care-providing-comfort-and-hope)

* **“Improving Individual and Family Outcomes through Continuity and Coordination of Care in Hospice” is a funding opportunity issued by NIH.** NIH issued this call under the PA-18-148, R01 Research Project Grant. **The effort seeks to support research that focuses on reducing negative outcomes that might be related to “unwanted transitions at the end of life and optimizing the individual and family outcomes related to high quality coordination of care of care of individuals who are enrolled in hospice.”** This can be in any hospice setting, including the home, inpatient facility, assisted living, or hospital. Details are online and proposals will be accepted beginning in January 2018. (NIH, 11/7, <https://grants.nih.gov/grants/guide/pa-files/PA-18-166.html>)

* **Thanksgiving and Christmas are good times to discuss end-of-life wishes, says Paul Malley, president of Aging with Dignity.** “We see a bit of a Thanksgiving rush and a bit of a Christmas rush in December,” he says, pointing out that as people come together for the holidays they increasingly take action on securing documents. “It’s a natural time to discuss which one of us boys do you want to be your health care agent?” Malley says. He’s one of three brothers and says, “My parents are teaching us about advance-care planning by doing this together as a family.” (News Medical, 11/22, www.news-medical.net/news/20171122/This-Thanksgiving-carve-out-time-for-lively-discourse-on-end-of-life-wishes.aspx)

* **A children’s hospice in Crescent Cove, in Minnesota, is only one of three similar facilities in the country, says an article in Star Tribune.** After years of planning and fundraising, it opens its doors in January as a respite and hospice for children with life-threatening illnesses. Founder Katie Lindenfelser describes the 6,7000 square foot facility as a “dream come true.” Parents share stories about how the group will “meet you where you’re at and support you.” Dr. Michele Peterson, a pediatrician on the nonprofit’s board, is optimistic about the demand for its services, saying, “I don’t think it’s going to be hard to fill this place at all.” (Star Tribune, 11/21, www.startribune.com/long-awaited-children-s-hospice-and-respite-home-a-dream-come-true/458385503)

* **An article in US News and World Report explores the utilization of Medicare-reimbursed discussions on patient preferences in end-of-life care.** Just over one percent of Medicare beneficiaries engaged in the advance care planning talks with their physicians in 2016. Donald Taylor, Duke University, examines the barriers and explains that increases in utilization are slow. Barriers include billing systems issues and physician discomfort with the process. Judi Lund Person, NHPCO, notes that utilizations, while low, are still impressive, with over ½ million people having these conversations during the first year of Medicare reimbursement for the talks. (US News and World Report, 11/22, <https://health.usnews.com/health-care/health-insurance/articles/2017-11-22/why-medicare-patients-are-more-likely-to-have-end-of-life-talks-with-their-doctors>)

END-OF-LIFE NOTES

* **“Greater wisdom” is necessary when it comes to end-of-life care says Pope Francis.** In

a statement to medical professionals, he urged caregivers not to “step back from the patient” as they face mortality. He called for avoiding the temptation to euthanize while, at the same time, still always pursuing treatments treatments that are best for the individual. **He cautioned that with advances in medicine, we see “treatments that have powerful effects on the body, yet at times do not serve the integral good of the person.”** (*EWTN*, 11/16, www.ewtnnews.com/catholic-news/Vatican.php?id=16586)

* **A new study published in *Aging & Mental Health* reviews articles that address end-of-life care for patients with neurodegenerative diseases.** The study describes four areas or themes among patients. First, they value autonomy and control. Second, they want the health knowledge needed to make informed choices. Third, they’re concerned with contextual factors including familial or social input, disease progression, and feelings of hope. Fourth, patients are concerned about the quality and accessibility of care. As one patient put it, “I get pats on the cheek or, worst of all, on the head, like a child. So I hate it. That patronizes compassion.” (*ALS News Today*, 11/16, <https://alsnewstoday.com/2017/11/16/end-of-life-care-important-in-als-neurodegenerative-diseases-but-can-be-lacking-study-says>)

* **Much literature on terminally ill youth focuses on the attitudes of children. But a new study looks at 62 nurses, physicians, physical therapists, social workers, and psychologists, focusing on their perspectives on the distinct needs of adolescent patients.** Their experiences constitute a slice of the support teams’ perspective. “The first theme was that the reality of the loss was unthinkable to the teens. Another theme was that the loss generates negative emotions, including aggression, loneliness, uncertainty, and depression.” Further, the study discusses “loss as a catalyst for change”—forcing a maturation process—and the theme of “authentic relationships” between bereaved children and adult support staff. (*Medscape*, 11/6, www.medscape.com/viewarticle/887856)

PALLIATIVE CARE & ADVANCED CARE PLANNING NOTES

* Turn-Key Health is “a national company that serves payers by providing specialized palliative care to patients who are struggling with advanced illness and living at home. **Turn-Key Health’s Palliative Illness Management (PIM) program found that 97% were “satisfied” or “very satisfied” with their symptom management and saw a one-third reduction in health care expenditures.** Turn-Key Health’s proprietary analytic model identified members at risk for over-medicalized care or inappropriate death. The individuals in the PIM program spent 37% fewer days in intensive care units than the control group. *Health Affairs* highlights the potential of the program by presenting the case of Dwight. Dwight’s first visit was from a PIM nurse from a hospice. His story “represents a promising approach for those nearing the end of life: a patient-centered palliative model that aligns care with personal wishes, reduces economic burdens, improves outcomes, and enhances quality of life for patients and their family caregivers.” (*Health Affairs*, 11/15, www.healthaffairs.org/doi/10.1377/hblog20171108.84627/full)

* **Knowing that voluntarily stopping eating and drinking (VSED) is an option can ease the minds of dying patients, according to Dr. Timothy E. Quill at the University of Rochester Medical Center.** For some people, this knowledge “allows them to live longer, because they

don't feel as trapped ... they can hang in there longer because they know they have an escape.” Though patients usually die about 10 days after VSED begins, it also comes with difficult to address symptoms, namely thirst. “You have to have significant willpower to carry through,” says Dr. Quill. And patients need “expert palliative care to manage the associated thirst, and substantial caregiver support to respond to progressive debility.” The article in *Medscape* concludes by noting that VSED is “ethically controversial.” (*Medscape*, 11/9, www.medscape.com/viewarticle/888187; *JAMA*, 11/6, <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2661706>)

*** In the *Journal of Palliative Medicine*, Miguel Julião, MD, MSc, PhD, presents data on dignity therapy (DT).** Dignity therapy is “a novel, brief, individualized intervention, which gives terminally ill patients the opportunity to convey memories and important disclosures and to prepare a legacy document that can be given to patients for them to share or bequeath to individuals of their choice.” Julião begins with a review of a previous study showing that many family members find that DT: Enhanced patient dignity (78%); heightened meaning of life for the patient (72%); and, provided comfort in a time of grief (78%). Further, family members would recommend DT for other patients and families (95%). In the new study of 45 terminally ill patients, the same results weren't found, but showed “no significant differences.” These findings were attributed to the small sample size and that “loved ones already had a moderate-to-high level of psychological well-being and it would be challenging for an intervention to show a further increase or effect.” (*Journal of Palliative Medicine*, November 2017, 20(11): 1182-1183)

*** Residents at the University of Colorado Medical School are expected to have advance care planning (ACP) conversations with patients. But, they often feel inadequately prepared, according to the authors of a study in the *Journal of Palliative Medicine*.** The authors report on an intervention used at the school. Groups of 3-11 patients come together to discuss ACP in two 2-hour sessions. Four themes emerged regarding resident perspectives. They heard diverse patient perspectives. They modeled clinical interaction. The ACP process was clarified. And they learned how to better maximize the use of clinician time. “Resident participation in ACP group visits is a promising method of educating and modeling person-centered ACP,” the authors conclude. “Additional efforts are warranted to expand effective ways to educate residents about ACP conversations, including participation in ACP group visits. Residents involved in innovative efforts to improve ACP may be well positioned to lead future ACP initiatives.” (*Journal of Palliative Medicine*, Palliative Medicine. November 2017, 20(11): 1187-1188)