NO SHORTAGES OF RECOMMENDATIONS FOR NEW JERSEY END-OF-LIFE CARE

A new report on what New Jersey should be considering regarding end-of-life care has “no shortage of recommendations,” writes NJ Spotlight. “26 of them, in fact.” The report from the New Jersey Governor’s Advisory Council on End-of-Life Care, an independent organization under the state Department of Health, depicts a healthcare system that’s focused on saving lives, but often at the expense of hospice and palliative care treatments that can improve quality of life.

This imbalance can be seen in the fact that though most patients wish to die at home, just 30% do. Too few individuals discuss their wishes and prepare them in writing, the report finds. This leads to healthcare treatment that’s “misaligned with a patient’s preference and wishes.”

This lack of hospice and palliative care services is felt by patients and families across the state. NJTW News tells the story of the Gladden family, who received the news that all three of their teenage daughters were diagnosed with lupus. The parents spread their story of living within the healthcare system at forums like those held at Samaritan Healthcare & Hospice in Voorhees.

“They’ve been in the health care system for so long, that a comfortable day, was really, really, really important,” says Darryl Gladden. He and his wife Andrea had to talk to their children about their dying wishes.

“Danielle had no palliative care, no hospice care,” Andrea Gladden told those in attendance. “Life was difficult for us because we were her only help.” In fact, “A new report released by the Governor’s Advisory Council recommends increasing awareness and education around palliative, hospice care and end-of-life care directives.”

State health commissioner Dr. Shereef Elnahal says, “New Jersey patients experience more aggressive care at the end-of-life without evidence to suggest a corresponding medical benefit.” Looking forward to the services that will be required of an aging population, the report has a dire warning: “There is no clear vision of how the healthcare system will be able to meet the obvious growing needs for chronic, palliative, and end-of-life care. This increasing demand, as well as the need for improvements in accessing palliative and end-of-life care, are key challenges.”

The 47-page report urges big changes to get the state on track. The first recommendation is the creation of a statewide stakeholder coalition to oversee improvements in end-of-life care. However, NJ Spotlight notes that the DOH
“respectfully disagrees” with one of the group’s suggestions. The suggestion is, “Lawmakers should provide guidance to medical professionals on how to respond to family members’ requests for treatments that may be useless or even harmful to a patient at the end of life.”

Many of the report’s recommendations focus on improving education. For providers, new partnerships, fellowships, and standardized best-practice models would support a more robust and coherent response. For the public, culturally appropriate public awareness campaigns are recommended. The report underscores the importance of Practitioner Orders for Life-Sustaining-Treatment (POLST) and creating systems to document final wishes. Allowing intensive-care paramedics to treat chronically ill patients at home may also abide by patient wishes and avoid an unnecessary or unwanted trip to the hospital.

“A package of bills on palliative and advance care planning has languished in the Legislature,” writes NJTV News, but this new report urges bold action to provide patients with options and encourage them to document their wishes sooner.

“You want to have all the curative option exercise,’ says Cathleen Bennett, president & CEO of the New Jersey Hospital Association. ‘We’re not saying not to take the curative steps. We’re actually saying the opposite, we’re saying do all you can from a curative perspective. But when those options have been expired, make sure that you have the conversation about palliative, make sure you have the conversation about hospice care.’” The report refers repeatedly to hospice care. (NJ Spotlight, 11/26) Read more... (NJ Governor’s Advisory Council on EOL) Read more... (NJTV News, 11/27) Read more...

**DO PATIENTS WANT TO TALK ABOUT LIFE EXPECTANCY?**

“Do Older Patients Want to Talk About Life Expectancy?” asks Sheri Potter for AAFP News. She discusses the findings of a new study from the *Annals of Family Medicine* titled “Older Adults’ Preferences for Discussing Long-Term Life Expectancy: Results From a National Survey.” Clinical practice guidelines increasingly urge physicians to incorporate life expectancy into discussions about preventative care for older patients, and the study offers a window into patient sentiment in various scenarios.

Over 800 adults above the age of 65 were asked to imagine themselves in a scenario where they were not in imminent danger of dying, but they did have a limited life expectancy. In that situation, “Would they want to have a conversation with the doctor about how long they might live? Was it OK for the doctor to bring up this subject? Should the doctor talk to their family and friends about life expectancy? When should the doctor broach this topic?”

The researchers found that 59.4% of participants would not wish to discuss life expectancy. Of those respondents, 59.4% did not think it was appropriate for the physician to raise the topic. 88.7% would not want the doctor to discuss life expectancy with their family or friends.
The study also found that timing was important. “We found that the longer the hypothetical patient was expected to live, the smaller the proportion of participants who wanted to discuss life expectancy,” the authors write. “A sizable minority (16.5 percent) did not wish to have this discussion even when it was one month.” Still, 11% would discuss life expectancy even if it was 20 years.

“Although everyone can probably get behind the notion these are important conversations to have, it’s difficult to implement them in primary care, where there’s a lot of time pressure. We need a trigger to prompt these discussions,” Nancy Schoenborn, M.D., an assistant professor of medicine in the geriatric medicine and gerontology division at Johns Hopkins University School of Medicine in Baltimore, told AAFP News. “Sometimes these patients are sick but stable, and they’re just here for a follow-up. And all of a sudden, having this discussion about how long they might be expected to live blindsides them.”

Researches also found certain personal attributes associated with their responses. For instance, those with higher education have a belief that doctors can accurately predict life expectancy. And those with a past experiences with a life-threatening illness or having previously discussed life expectancy with a loved one are more likely to be open to life expectancy conversations. However, a patient’s belief that religion is important was negatively associated with a willingness to participate in such conversations.

Schoenborn urges physicians to take context into account and consider phrasing. “We have to find a way to present [life expectancy] to patients in a more acceptable way.” Not all patients want to hear this information, and physicians need to be aware of this variation in patient attitudes in order to provide the best care. (AAFP, 11/26) Read more... (Annals of Family Medicine, Volume 15, Number 6, November/December. 530-537) Read more...

**HOSPICE & END-OF-LIFE NOTES**

* Cordt Kassner, CEO of Hospice Analytics, posted a blog exploring the role that hospices can play in addressing issues of organ and tissue donation. Kassner acknowledges that hospices are quite limited, because of the patients we serve, in addressing organ donation. When it comes to tissue donations, he asserts, “Tissue donation is a different matter. Tissues (e.g., skin, bone, heart valves, eyes, etc.) can be donated up to 24 hours following death, and the demand for tissues is also great.”

Kassner provides resources, and encourages hospice leaders to ask patients about organ and tissue donations, and to include information about this in hospice admission packets. (National Hospice Analytics, 12/3) Read more...
* Circle in the Field Media presents *Circle in the Field: Hospice*, an 18-minute video sharing “stories of the lived experience of handling a terminal diagnosis, focusing on what hospice and/or palliative care can do to allow the final days of a life to be peaceful and comfortable for a dying person, and for family and friends.” The video consists of many interviews, and its ultimate goal is to increase hospice utilization. The video was made possible by the Elizabeth and William G. Heegaard Family Fund (Minneapolis Foundation), the Saint Paul Foundation, and Stratis Health “Building Healthier Communities.” (Circle in The Field, 11/17) Read more...

* The *Journal of Pain and Symptom Management* published “Hospice Underutilization in the U.S.: The Misalignment of Regulatory Policy and Clinical Reality.” The authors argue, ‘After three and a half decades of experience with the Medicare hospice benefit in the U.S., despite excellent quality outcomes in symptom management, patient and family satisfaction, and reduction in health care costs, only 12%-15% of beneficiaries’ days during the last year of life are spent being cared for within the highly cost-effective interdisciplinary coordinated advanced illness care model known as hospice.” With this in mind, the authors review “pertinent history and address the core problem of access to a health care benefit built on a policy that requires far greater prognostic certainty than any clinician can reasonably ascertain and fails to take into consideration the favorable impact hospice care has on terminally ill patients in improving prognosis.” (NCBI, 11/27) Read more...

* “Sen. Patty Murray (D-Wash.) is in the unique position to support increased education for hospice and palliative caregivers throughout Washington, by moving the Palliative Care and Hospice Education and Training Act (PCHETA) forward in the Senate,” writes Tri-City Herald opinion guest writer Gary Castillo. He makes a passionate case for the passage of PCHETA, ushered along by Sen. Murray, who is the ranking member of the Health, Education, Labor and Pensions Committee. Castillo argues for the ways it would benefit patients across the state. Further, PCHETA would include workforce training provisions to meet Washington’s growing need. The bill has passed the House and Castillo says “it’s time for the Senate to do the same.” (Tri-City Herald, 11/26) Read more...

* NHPCO President and CEO Edo Banach published an opinion piece in *The Hill* titled, “Hospice month celebrates success of nation’s first coordinated care model.” In a divided political landscape, Banach offers the Medicare Hospice Benefit as a program that stands “out as a reminder of how bipartisanship works at its best.” He provides a background of the program and its roots in the late 70s. It has been “invaluable,” and “never would have happened without lawmakers who were committed to the concept, and to working together.” Following the midterms, as “seasoned and novice legislators alike consider health policy reforms, they should look to the success of the hospice model as an example of preserving what works, and help expand access to comprehensive, coordinated care and person- and family- centered care to all patients with serious, advanced and life-limiting illness. We should also reinforce the foundation of hospice to ensure access, choice and quality care at the end of life.” (The Hill, 11/16) Read more...
* Next Avenue publishes “What Hospice Does and Doesn’t Do,” a starter to inform patients and families on their options ahead of time. The article begins with a hospice overview, eligibility, and a list of steps to enter hospice. However, hospice “doesn’t cover room and board fees at senior communities,” the article points out. “Unless a facility is approved to provide [hospice care], you may not receive [Medicare] reimbursement.” A list of additional resources is provided via NHPCO. The final section urges families to “Plan for Hospice When You’re Healthy.” (Next Avenue, 11/15) Read more...

* NHPCO has submitted a comment on CMS-3346-P, Medicare and Medicaid Programs; Regulatory Provisions to Promote Program Efficiency, Transparency, and Burden Reduction. “While we appreciate the proposed changes,” writes President and CEO Edo Banach, “NHPCO believes that they will not significantly reduce burden for providers or professionals.” The opening sections include: 1) Hospice Aides 2) Pharmacy Services 3) Nursing Facilities 4) Annual Emergency Preparedness Testing. The most extensive comments fall under the category of “Pharmacy Services.” The comment continues with a list of “other issues that hospice providers throughout the United States have suggested would help with the reduction of burden.” This includes sections devoted to reducing regulatory burden in Subpart B—Eligibility, Election and Duration of Benefits and Subpart C—Conditions of Participation—Patient Care, as well as hospice burden regarding continuous home care, audit education, and hospice face-to-face encounters. (NHPCO, 11/19) Read more...

* The Office of Inspector General reports the expected release of “Protecting Medicare Hospice Beneficiaries From Harm” in 2019. “The Medicare hospice program is an important benefit for beneficiaries and their families and caregivers at the end of a beneficiary’s life,” the office writes. “Surveys and complaint investigations are critical to oversight of the care hospices provide to beneficiaries. This study is a companion to Trends in Hospice Deficiencies and Complaints (OEI-02-17-00020), in which we determine the extent and nature of hospice deficiencies and complaints and identify trends. For this study, we will use the survey reports to provide more detail about poor-quality care that resulted in harm to beneficiaries. We will describe specific instances of harm to Medicare hospice beneficiaries and identify the vulnerabilities in Medicare's process for preventing and addressing harm.” (OIG, 11/2018) Read more...

* “What if psychedelics could revolutionize the way you die?” asks The Conversation contributor Bruce Tobin. His consideration began eight years ago when a client with debilitating depression and anxiety brought on by a breast cancer diagnosis requested that he supervise her in a therapeutic session with a psychedelic. No other therapy seemed to work, and her search for relief lead her to UCLA research on psilocybin to deal with “end-of-life distress.” Tobin describes the legal process of filing for an exemption and therapist risk involving criminal penalties in Canada. Ultimately, he’s guided by the professional code of ethics to serve the client’s “best interests” and “take care to maximize benefits and minimize potential harms.” He contends that such patients “are not in ordinary circumstances. They have terminal cancer. All other treatments have failed them; they have nothing left to lose. They have the right to die; surely they have the right to try!” (The Conversation, 11/25) Read more...
* California has become a “hotbed” for in-home palliative care after the state mandated the service for those in its Medicare program, Medi-Cal. “California is truly leading in this regard,” says Stacie Sinclair, senior policy manager for the Center to Advance Palliative Care, a national organization. *Forbes* highlights ResolutionCare, a provider serving clients in rural northern California. “We don’t take care of patients; we take care of people. We are person-centered,” says its founder, Dr. Michael Fratkin. “We’re damn good at managing symptoms — pain, breathlessness, anxiety — for a high quality of life. … We help them and their families to navigate what can be terribly complicated medical circumstances and a terribly dysfunctional health care delivery system.” Roughly two-thirds of ResolutionCare’s patients are on Medi-Cal, many in their 50s and 60s. *Forbes* takes a look back at the genesis of the Medi-Cal program and emphasize that it delivers “better care at a lower price.” *(Forbes, 11/27) Read more...*(Home Health Care News, 11/27) Read more...

* A new study in the *Journal of Palliative Medicine* approaches “Challenges Associated with Anticipatory Medications in Rural and Remote Settings.” Researchers conducted an online survey of 29 nurses across the South East of Victoria in Australia. They found that “provision of timely AM has the potential to improve the quality of life of patients and their caregivers. Key barriers to access AM can be overcome with community-level planning and nurses’ education. Advanced nurses’ roles have the opportunity to provide specialized care where access to specialist physicians is challenging.” Most of the responding nurses worked in a mixed practice providing community palliative and district nursing. A significant number worked in remote settings and the remainder were located in regional areas. Almost a third of respondents did not have specific guidance regarding the use of AM for their patients. *(Journal of Palliative Medicine, 11/14) Read more...*

* The *Journal of Palliative Medicine* published “Empower Seriously Ill Older Adults to Formulate Their Goals for Medical Care in the Emergency Department,” aimed at developing such an intervention. “In a single, urban, academic ED, we refined the prototype intervention with ED clinicians and patient advisors,” they write. “We tested the intervention for its acceptability in English-speaking patients 65 years old with serious illness or patients whose treating ED clinician answered ‘No’ to the ‘surprise question’ (‘Would not be surprised if died in the next 12 months?’). We excluded patients with advance directives or whose treating ED clinician determined the patient to be inappropriate.” After a process of refining the intervention with 16 mock clinical encounters of ED clinicians, they concluded, “An intervention to empower seriously ill older adults to understand the importance of future care planning in the ED was developed, and they found it acceptable.” *(Journal of Palliative Medicine, 11/12) Read more...*
OTHER NOTES

* A California appeals court has overturned a lower court ruling that declared The End of Life Options Act unconstitutional because it was adopted during a special legislative session. The three-judge appeals panel “did not rule on the merits of the case because it found doctors opposed to the law had no right to sue to block the law.” Further, “The doctors failed to show they were harmed because they could choose not to help terminally ill patients die.” AP writes, the “ruling is probably not the last word on the matter and could set the stage for future legal actions.” In fact, the court specifically addressed how future challenges might be able to show harm to plaintiffs. Attorney John Kappos, representing Compassion & Choices, commented, “The harsh reality is this case is likely to last several more years because the plaintiffs are hell-bent on depriving ... terminally ill Californians ... (of) a peaceful death, free of unbearable suffering.” (AP, 11/28) Read more...

* Delaware lawmakers are expected to consider legislation that would allow physician-assisted suicide again next year. A previous effort sponsored by State Rep. Paul Baumbach (D-Newark) did not make it to a floor vote. A quarter of the House membership will be new this year, and Baumbach says he hopes to convince some of those members to get the necessary votes. “The 25 percent turnover of new members in both chambers I think is a real positive for this,” he says. “This is also an issue which is shown to be roughly 70 percent supported by the public in every state that’s been looked at.” The previous version he sponsored required two doctors to make a diagnosis and that the patient self-administered the medication. Further, it required patients to ask for the medication twice and go through two waiting periods. (Delaware Public Media, 11/28) Read more...

* Medical Xpress offers “Key strategies when caring for a loved on with dementia.” Dr. Andrew Duxbury— a geriatrician in the Division of Gerontology, Geriatrics, and Palliative Care at University of Alabama at Birmingham— advises following “the safe and sane rule.” That is, choices should be made with making the patient safe and the family sane. Dr. Duxbury discusses practical considerations for caregivers regarding meal preparation, getting out of the house / transportation, personal finances, and medications. “Families need to remember that a person with dementia does not live in the same reality that we live in,” he concludes. “They live in a reality of their brain’s dementia. These individuals may have completely different perceptions of the world around them and what it means. … We have to accept their reality for what it is.” (Medical Xpress, 11/26) Read more...

Hospice Analytics is the national sponsor of Hospice News Network for 2018. 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.