

Transitions

Items of interest to professionals in end-of-life,
hospice, palliative care and public policy

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NHPCO: Make COVID-19 Reg Changes Permanent

Edo Banach, President and CEO of National Hospice and Palliative Care Organization, penned a letter to HHS Secretary Alex Azar and CMS Administrator Seema Verma. The letter responds to Executive Order 13924, which established regulatory rules for economic relief after the COVID-19 pandemic.

In his letter, Banach voices appreciation for the administration's efforts to "to reduce red tape and promote pro-growth policies." He praises these changes and their support of small businesses, including small hospice and palliative care providers. "NHPCO appreciates the President's direction to agencies to avoid over-enforcement of regulations for organizations working in good faith to follow HHS and CMS direction during this national emergency," Banach says. In that spirit, he voices support of Executive Order 13924 Regulatory Relief to Support the Economic Recovery and submits further recommendations.

First, he makes a number of recommendations for "regulatory flexibilities that encourage economic recovery." He suggests that hospice face-to-face visits being allowed through telehealth should continue permanently after the coronavirus crisis. "The additional flexibility to conduct this administrative task by telehealth has already made a direct impact on improving workforce shortage issues by allowing physicians and nurse practitioners to provide needed medical care to patients in addition to the face-to-face requirement," he says. He further suggests continued flexibility on palliative telehealth services and suggests that audio-only advance care planning visits continue to be allowed permanently after the pandemic. He additionally suggests telehealth visits be added to hospice claim forms and that pseudo patients continue to be used for hospice aide competency testing.

To encourage innovative care and economic recovery, Banach suggests a community-based palliative care model. "NHPCO along with the National Coalition for Hospice and Palliative Care urges CMS to implement a community-based palliative care demonstration under the authority of the CMS Innovation Center (CMMI) to provide essential person-centered interdisciplinary care, in their homes, for people at increased risk for poor outcomes from COVID-19 due to social isolation and other factors," he says.

Finally, several recommendations are made along the lines of enforcing laws and regulations. Because hospice providers are using all their resources to respond to COVID-19, Banach suggests a continued suspension of Targeted Probe and Educate (TPE) and other audits for at least a year after the health crisis resolves. He also addresses issues that hospice providers have been facing in caring for their patients in nursing homes. To improve this situation, he suggests that hospice workers be deemed essential workers in nursing home facilities. (NHPCO, 6/5, www.nhpc.org/wp-content/uploads/NHPCO-Comments-on-Regulatory-Flexibility_060520.pdf)

Study: Video Can Change Perception of Hospice Care

A study that examines the effectiveness of a hospice informational video shows no change in viewers' hospice care preferences, but an improvement in viewers' perception of hospice care. *Healio* explains that the six-minute educational video is more effective in changing viewers' perception of hospice than a verbal intervention. After receiving either a verbal explanation of hospice or viewing the video, study participants were asked if hospice care is only about death. Of those who were given a verbal explanation, 21.6% responded that hospice is only about dying, while only 6.7% of those who had viewed the video responded in the same manner. Additionally, an analysis of participants who later died showed that those who saw the video were more likely to have used hospice and have a longer length of stay.

The study revealed other findings. The video did not, however, have significant effects on participants preferences toward hospice care. Between those who watched the video and the control group, 86.7% vs. 82.7% indicated a change in preference. The video was effective for caregivers who participated in the study. They reported greater knowledge of hospice care after video intervention and also seemed to be more likely to prefer hospice services for their loved ones.

Researchers say that misperceptions of hospice care contribute largely to its underuse. This includes misunderstandings of financial coverage, eligibility, appropriate timing of enrollment and the scope of care. “We have always envisioned the use of these videos as part of clinical care, as part of a larger conversation that patients should have with their oncologists about their overall goals,” says assistant professor of medicine at Massachusetts General Cancer Center, instructor of medicine at Harvard Medical School, and study author, Areej El-Jawahri, M.D. “Therefore, I think integrating these into the context of clinical care at the institution level is the best and most promising strategy for implementation.”

The researchers hope to expand the study further. “We need to replicate these findings in a large multisite trial to ensure their generalizability across care settings,” El-Jawahri says. “It is hard to change the standard of care based on an intervention that is done in one relatively small study at one institution. I would advocate for future multisite studies to include a focus on implementation and dissemination so that we think of innovative strategies to integrate this into patient care.” (*Healio*, 6/9, www.healio.com/news/hematology-oncology/20200609/video-alters-hospice-perceptions-but-not-preferences-among-patients-with-advanced-cancer)

Hospices’ Kids’ Grief Camps Seek Pandemic-Safe Options

Summer grief camps for children are finding pandemic-safe alternatives this year. With children’s grief support being especially important in the midst of the coronavirus pandemic, day camps are moving online or to drive-through formats.

Camp Good Grief, hosted by Mountain Hospice in Belington, W.V., is continuing as a drive-through camp this year due to COVID-19 concerns. The camp has taken place annually for 15 years and usually hosts between 25 and 75 children in a day camp format. “We do this camp every year, but with everything going on we still wanted to make sure we got the resources to the families so we had to make some changes and it turned out pretty well,” says Mountain Hospice director of quality and compliance Jessica McHenry. Visitors to the camp were able to pick up backpacks and t-shirts from volunteers as they drove by. The backpacks contain crafts and activities along with family resources for grief and COVID-19. Mountain Hospice hopes to hold a second drive-through camp in nearby Randolph County. They are also offering services for the terminally ill and bereaved. Grief support services and support groups are open to anyone, including those who have not used Mountain Hospice’s services.

Similarly, Camp Encourage, hosted by State of the Heart Care in Ohio, is offering its 20th annual grief camp in a virtual format this year. The camp will take place July 10–12 and is open to kids aged six through 15 who have suffered the loss of a loved one. Attendees will receive a box of activities, swag and treats that normally would be distributed throughout the weekend camp. Camp Encourage at Home will feature planned virtual meetings, group video support chats, an expert panel discussion and music therapy sessions. All events are led and staffed by trained volunteers, physicians, counselors and chaplains. “We understand the sensitivity of grief and that children do not always have the means to express themselves,” says State of the Heart Care. “That is why throughout the remainder of the weekend, campers will be able to connect and ask questions to our hospice staff and volunteers so that they have the support that they need during a vulnerable time for them.” (*The Inter-Mountain*, 6/13, www.theintermountain.com/news/local-news/2020/06/camp%E2%80%88good%E2%80%88grief/; *Times Bulletin*, 6/13, <https://timesbulletin.com/Content/News/Community-News/Article/State-of-the-Heart-Care-to-Host-20th-Annual-Grief-Camp/2/1170/224508>)

HOSPICE NOTES

- Hospice and Palliative Nurses Association (HPNA) and the Social Work Hospice and Palliative Care Network (SWHPN), are hosting a free webinar on June 23 from 3:00 – 4:00 p.m. The webinar will feature a panel discussion focusing on guilt, trauma and coping with changes during the COVID-19 crisis. Topics to be covered include clinician guilt and survivor guilt, the problems with using “hero” language, the feeling of loss of immedi-

ate and long-term future, feeling excluded from COVID-19 treatment teams, dealing with high demand of counseling service and dealing with personal loss while attending to patients' losses. Registration is required for the free webinar, through the link below. (*Hospice and Palliative Nurses Association (HPNA)* and *Social Work Hospice and Palliative Care Network (SWHPN)*, 6/23, https://advancingexpertcare.org/Shared_Content/Events/Event_Display.aspx?EventKey=SWHPNHPNA&WebsiteKey=b1bae5a7-e24a-4d4c-a697-2303ec0b2a8d)

- The Centers for Medicaid & Medicare Services released a COVID-19 FAQ targeting “Non Long-Term Care Facilities and Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IIDs).” The document seeks to provide clarification on existing guidance provided by CMS. The FAQ includes revised answers to a previously published document. FAQ entries cover coronavirus questions pertaining to ambulatory surgical centers, hospitals and critical access hospitals, hospice, intermediate care facilities for individuals with intellectual disabilities, rural health clinics/federally qualified health centers, and general questions. Hospice questions include topics such as how hospices should monitor or restrict staff and volunteers, when it’s safe to discontinue transmission-based precautions for inpatient or home-based patients with COVID-19, what PPE hospice workers should wear for home visits and many other pertinent questions. The 18-page document can be accessed at the provided link. (CMS, 6/2020, www.cms.gov/files/document/covid-faqs-non-long-term-care-facilities-and-intermediate-care-facilities-individuals-intellectual.pdf)

- The CARES Act has sent funds to many hospice providers that did not apply for the coronavirus relief. With unclear guidance from HHS on the rules and restrictions for using the funds, many recipients are left wondering if they should spend the money or return it. As an example, “Home health and hospice provider The Pennant Group (NASDAQ: PNTG) received nearly \$9.9 million in CARES Act relief funds for which the company did not apply,” says *Hospice News*. “The company remains uncertain as to whether they will keep or return the funds, holding the money in a segregated account while they assess the amount of revenues lost due to the pandemic, CFO Jennifer Freeman indicated in the company’s first quarter earnings call.” A recent *JD Supra* podcast episode tackles some of the confusion surrounding the CARES Act funds, with hospice and palliative care attorneys and accounting professionals as guests. The group shares legal and accounting perspectives as well as practical considerations to help hospices as they operationalize their use of relief payments. (*Hospice News*, 6/9, <https://hospicenews.com/2020/06/09/hospices-contend-with-covid-relief-funding-questions/>; *JD Supra*, 6/3, www.jdsupra.com/legalnews/covid-19-hospice-how-to-series-legal-an-85153/)

PALLIATIVE CARE NOTES

- *The Kansas City Star* writes of a group of musical palliative care nurses at Vanderbilt University Medical Center who are writing songs together about the COVID-19 pandemic. House of Songs, a songwriters’ collaborative nonprofit, partnered with the medical staff in their off hours. One of the musicians, nurse and singer-songwriter Megan Palmer, says the musical staff often use their talents to comfort patients and family members. Since the co-workers were essentially already quarantining together, “It seemed like a safe and good idea to get creative and process some of what we do in the time of this pandemic,” Palmer says. Songs they have worked on together include “Stop For a Minute,” which begins by relating the experience of rushing to check on a patient’s call light. Musician and palliative care unit nurse manager Paul Raymond co-wrote with Palmer a song called “Take Good Care.” Raymond hopes that other health care workers will find some comfort in their songs during these demanding times. “If we can shed some light into the world of nurses and working with people in a really vulnerable time in their lives, then all the better,” he says. (*The Kansas City Star*, 6/11, www.kansascity.com/entertainment/article243455901.html)

- *Palliative Medicine Reports (PMR)* is a new open-access companion journal to *Journal of Palliative Medicine (JPM)*. As palliative care has grown to be more widely integrated across every area of medical care, palliative care journalism has been slower to expand, *PMR* says. *JPM* receives more submissions than it can print and *PMR* aims to be an effective outlet for publishing quality, peer-reviewed articles. “For those without access, especially true in resource-limited countries, accessing articles published in traditional journals can be impossible,” *PMR* says. For this reason, they have adopted the “open access” model. “Articles will be freely available because the cost of publishing is paid by authors on a sliding scale depending on the socio-economic status of the authors’ country of origin.” They see this as an important part of future academic publishing worldwide. “*Palliative Medicine Reports* is proud to be at the vanguard of this movement,” they say. “We at *PMR* are excited to support authors with clinical research, cases, position papers, reflections, and opinions to share as we make quality information in palliative care and related fields accessible to the world.” (*Palliative Medicine Reports*, 4/30, www.liebertpub.com/doi/10.1089/pmr.2020.28999.editorial)

OTHER NOTES

- Episode number 250 of the End of Life University podcast is titled “Anti-Racism: The Inner and Outer Work.” The special episode approaches the collective grief Americans are experiencing after the death of George Floyd and the current reckoning with racism in our country. Host Dr. Karen Wyatt shares several quotes that are guiding her during this time, resources for exploring anti-racism, and her commitments against anti-racism. Those commitments include recognizing that “racism is everywhere, including within me, no matter how liberal or educated or conscious or caring I am”; being “‘un-fragile’ and holding myself accountable for my unconscious bias and racism”; listening and learning from those who are different from herself; and being explicitly “anti-racist” instead of just “not a racist.” Wyatt additionally shares links to several informative podcasts, articles, and books. (*End of Life University*, 6/8, <https://eolupodcast.com/2020/06/08/ep-250-anti-racism-the-inner-and-outer-work/>)
- In a piece for *AARP* magazine, author and psychologist Barry J. Jacobs shares advice for caregivers who are experiencing guilt and relief when their loved one dies. “Few miss the anguish of seeing a loved one suffering and being unable to provide a remedy,” Jacobs says. “With the care recipient's death comes greater freedom and the leisure time to enjoy grandchildren, old friends and hours absorbed in a book or lingering over coffee.” However, many often feel guilty about the relief they experience and that can complicate the grieving process. It’s important to remember that “relief is earned,” Jacobs says. A caregiver often must give up normal parts of their lives and experience constant stress. Further, “relief is normal,” Jacobs says, and it may exist alongside other competing feelings. Relief should not be confused with “forgetting” or “regretting.” The bereaved are not moving on in a way that is dishonoring the memory of the deceased if they feel relief after the death of their loved one. Likewise, feeling relief does not mean that the caregiver regrets the help and support they provided. (*AARP*, 6/8, www.aarp.org/caregiving/life-balance/info-2017/relief-guilt-caregiving-ends.html)
- Clergy members from different faiths and cultures discuss grief and mourning rituals during the COVID-19 crisis in an article with *The Conversation*. Rabbi David A. Schuck explains Jewish mourning rituals, which include ritual washing of the body, sitting vigil with the body and the seven days of community-supported mourning when families observe shiva at home. “With these communal rituals inaccessible during the coronavirus pandemic, the trauma of losing loved ones is profound,” he says. Prof. Gina Hens-Piazza shares the perspective of the Catholic church. She cites Pope Francis’s words expressing that this time should be “for inventing, for creativity” in expressing the Catholic faith. Hens-Piazza says she is finding “examples of this creativity in how U.S. Catholic communities are using technology to accommodate gatherings of friends and family for consoling prayer, recitation of the rosary, online memorials and notes of remembrance,” mentioning also the volunteer support systems created by individual parishes. Finally, The Rev. Dr. Rodney Sadler Jr. illustrates the African American Baptist experience, describing death as “a communal experience.” He describes various traditions of “homegoing services,” including family coming in from out of town, parades or processions to the cemetery, and the community meal that follows the services. He gives the following advice: “In the coming months, stay in close contact with those who also mourn,” he says. “Call someone whenever you feel longing for the departed – share a sorrow, a song, a funny anecdote or a recollection of their quirks.” (*The Conversation*, 6/1, <https://theconversation.com/different-faiths-same-pain-how-to-grieve-a-death-in-the-coronavirus-pandemic-138185>)
- The Coalition to Transform Advance Care (C-TAC) National Policy Forum will be held on June 24. Registration is available for the free, virtual event which will take place from 1 to 4 p.m. Eastern Time. The forum features panel discussions such as “The Moment We Are In: Identifying the Healthcare Gaps Exposed by COVID-19 and Where We Go From Here,” a “Spotlight” on current C-TAC policy initiatives, “Facing New Policy Barriers to Advance Care Planning During COVID-19,” “Caring for those with Serious Illness by Supporting Our Workforce During COVID-19 and Beyond,” “Health Care Equity Issues Amid the COVID-19 Pandemic,” and others. The event agenda and registration is available at the provided link. (*Coalition to Transform Advance Care (C-TAC)*, 6/24, www.thectac.org/policyforumagenda)
- Minister, activist and Ph.D. candidate at Princeton Nyle Fort relates the experiences of his mother Terry Whigham and her partner Carolyn Whigham, both black undertakers. *The Boston Globe* article tells about Fort, who grew up involved in his mother’s funeral business. He is currently working on his dissertation on African American mourning, and says the coronavirus pandemic has been particularly tough on black communities. “Burial traditions have long animated African American culture, politics, and resistance,” he says, citing rebellions staged at slave funerals by insurrectionists like Gabriel Prosser and Nat Turner, or the open casket funeral of Emmett Till. With grief rituals holding such an important place in black culture, the COVID-19-related funeral bans represent an enormously difficult loss for black communities. Further, it’s not just the pandemic that is

affecting black America. “We’re still dying from pre-existing conditions of racial injustice. There is no ban on police brutality during this pandemic,” Fort says. In the middle of great loss due to COVID-19, black Americans are grieving and fighting against the unjust and violent losses of those such as Ahmaud Arbery, Breonna Taylor, Dreasjon Reed, McHale Rose and George Floyd. “Today, I marvel at the bravery of people across the country protesting George’s killing and resisting patterns of police violence amidst the deadliest pandemic in over a century,” Fort says. He sees the role of Carolyn and his mother at the center of it all. “My family’s funeral home embodies the incredibly essential work before us all today: burying our dead while refusing to let death have the last word.” (*Boston Globe*, 6/4, www.bostonglobe.com/2020/06/04/opinion/refusing-give-death-last-word/)

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HELP WANTED / POSITION WANTED

View job opportunities at “Career Center” at www.homecarenj.org. To list “help wanted” and “position wanted” ads, view the rate sheet at “Career Center,” www.homecarenj.org and contact susan@homecarenj.org

Homeside Hospice, a nurse owned and operated hospice, is looking for a highly motivated, compassionate and energetic candidate for a On Call RN, willing to travel throughout NJ. Must have a current and valid license to practice professional nursing in the state of NJ. Demonstrates professional competency, ability to assess and respond to the needs of patients and families in varied settings, and good organizational skills. Must be willing to travel to Ocean and Monmouth counties, will be compensated for paid tolls. Competitive pay, referral bonus programs, in-house continuing education, flexible shifts & schedules, supportive and caring management team. Responsible for but not limited to: after hours triage, admissions, pronouncements and emergency visits. Maintenance and restoration of health; prevents infection, accident and injury; performs an initial assessment and identifies problems for each patient upon admission to hospice; reassesses the patient’s nursing care needs on an ongoing, patient-specific basis and provides care which is consistent with the Plan of Care; and monitors the patient’s response to nursing care. Also responsible for teaching, supervising and counseling the patient, family members, and staff regarding nursing care and the patient’s needs, including other related problems of the patient at home. Competitive pay. Email resume to jkaminsky@homesidehospice.com and Bridget@homesidehospice.com. [071020]

HOSPICE & HOMECARE NATIONAL WEBINAR SERIES

Register for the webinars below at <https://hospice.eewebinarnetwork.com/a/njhpc/category/live>.

Whenever **Volunteer Appreciation Package** (two 45-minute recorded webinars, plus planning guide)
The Importance of Boundaries: Special Challenges & Solutions for Volunteers
Beyond Active Listening: Raising the Bar for Volunteer Communication

6/20/20 How Emotional Intelligence Can Help Us through a Crisis
6/25/20 Hospice Billing FAQs: Clarifying the Confusion
7/7/20 Conducting Mock Surveys to Ensure Readiness & Compliance
7/9/20 How HIPAA Impacts Email & Text Messaging: Communication Compliance for Healthcare Providers
7/16/20 **Recorded Only:** From Referral to Admission: The Secret Ingredient to Compliant Growth
7/23/20 The Denial Myth: Skillfully Working with Real or Perceived Denial

NHPCO PODCASTS

The National Hospice and Palliative Care Organization offers podcasts on regulatory issues; new ones come online all the time. Recent podcasts include: “Serious Illness Population,” FY2020 Hospice Wage Index Final Rule,” “Palliative Care Opportunities and Education,” “Top Issues for Providers,” “CAHPS Hospice Survey,” “Hospice Compare Update,” “MA and Hospice,” “Hospice Compliance Certificate Program & Standards of Practice,” “Valuable Resources: STAR and Your People,” “Trends in Hospice Audits,” “Legal and Regulatory Issues in Community-Based Palliative Care,” “Dialogue with CMS,” “Serious Illness Care,” “Medical Director” and “Deficiency List Repeat Offender.” For all the offerings, go to <https://www.nhpc.org/podcast/>

UPCOMING OBSERVANCES

June

Alzheimer's and Brain Awareness Month
Cataract Awareness Month
Hernia Awareness Month
Men's Health Month
Myasthenia Gravis Awareness Month
National Aphasia Awareness Month
National Congenital Cytomegalovirus Awareness Month
National Safety Month
National Scleroderma Awareness Month
Scoliosis Awareness Month
World Sickle Cell Day (June 19)
PTSD Awareness Day (June 27)
Helen Keller Deaf-Blind Awareness Week (June 28–July 4)

July

Cord Blood Awareness Month
International Group B Strep Awareness Month
Juvenile Arthritis Awareness Month
National Cleft & Craniofacial Awareness & Prevention Month
Sarcoma Awareness Month
UV Safety Month
July 28 - World Hepatitis Day

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