
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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MEDPAC RECOMMENDS THAT MEDICARE ADVANTAGE INCLUDE HOSPICE

In its March 2014 report to Congress, MedPAC recommended regulatory changes that would limit the choices of dying individuals to enroll in the hospice program of their choice. Since its creation in 1983, the Medicare hospice benefit has been “carved-out” of Medicare Advantage. This means that when patients choose hospice, “payments for both hospice and other services unrelated to the individual’s terminal condition revert to fee-for-service Medicare, and health plans remain liable for only the Part D or supplemental benefits they provide.”

This policy, in place for the past three decades, is now being challenged by MedPAC’s recommendation that suggest the termination of the hospice carve-out. If implemented, this change could have a major impact across the entire hospice community - patients, providers, and hospice organizations. The complete March 2014 “*Report to the Congress: Medicare Payment Policy*” is available online at the link below.

Some within the hospice industry are highly skeptical of this recommended change. Others, such as the authors of a recently published piece in *The Journal of the American Medical Association*, see both potential positives and negatives to the proposed changes.

The NHPCO is sounding the alarm that the proposed changes would lead to diminished patient options for end-of-life care. “Should the [Medicare Hospice Benefit] be changed to a ‘carved-in’ benefit, patients, families, caregivers, the hospice community and Medicare will be significantly and negatively impacted,” says J. Donald Schumacher, president and CEO of NHPCO. **Patients, who could see their scope of choice reduced, might feel the greatest impact.** Currently, Medicare Advantage (MA) patients are eligible to enroll in any hospice program that is certified by Medicare. However, if the recommended changes were made, new “carve-in” criteria would direct patients to specifically MA-contracted hospices.

Schumacher urges policymakers to think twice about the MedPAC recommendation, warning that the quality of life of many dying Americans and their families could be impacted. “End-of-life care is a deeply personal experience. **It is both unreasonable and insensitive to require families to conform their needs and preferences to those of a MA plan.**”

In addition to the reduction of choice, NHPCO warns that the MedPAC recommendations could ultimately result in higher costs for those enrolling in end-of-life care. The proposed

changes present the possibility that MA plans might require additional co-payments or other fees. Under the current system, hospice patients pay very little in additional expenses. “By their very design MA plans are concerned about risks and the bottom line. By advancing this recommendation, MedPAC seems to find it an acceptable risk for financial incentives to shape or even limit hospice choice and quality,” says Schumacher.

NHPCO goes on to warn of other possible negative impacts, including a potential added cost to Medicare of \$1.3 billion over a ten-year period. NHPCO also sounds the alarm that the proposed regulatory changes would almost certainly have a negative impact on hospice organizations themselves. **“At a time when MA plans are under immense financial pressure, the carve-in would surely leave hospices vulnerable to further reimbursement cuts.”** NHPCO’s Hospice Advocacy Network has posted resources related to this issue and they are online at the link below.

Writing for *The Journal of the American Medical Association*, Dr. David G. Stevenson and Dr. Haiden A. Huskamp view the proposed changes with somewhat less skepticism. “Integrating hospice into the Medicare Advantage program has a number of potential advantages and tradeoffs,” they write. At the same time, there are risks involved with this change, which should be prepared for. “Should such a change move forward, important safeguards must be in place to ensure optimal end-of-life care for Medicare beneficiaries.”

Stevenson and Huskamp observe that the current system provides a strong incentive for insurance providers to encourage their customers to enroll in hospice care, since this will mean the end of most expenses for the private insurer. Effectively, the financial burden is shifted from private insurers onto the taxpayer. **“Removing the hospice carve-out would require plans to coordinate care for all enrollees at the end of life, whether or not they elect hospice, and ideally would encourage plans to integrate hospice and other palliative services with the care they deliver to patients with advanced illness.”**

“Perhaps more important,” they continue, “by giving plans greater flexibility in their targeting and delivery of services, **eliminating the hospice carve-out could reduce the difficult and arbitrary distinctions that Medicare hospice eligibility criteria force clinicians, patients, and families to make about having an expected prognosis of 6 months or less and about forgoing potentially life-prolonging therapies.** ... An integrated hospice benefit could also diminish concerns about longer hospice stays in the context of per diem hospice payments and shift attention to ensuring high-quality end-of-life care.”

The biggest potential advantage of these changes, says the article, might be removing the sharp distinction that currently exists between the hospice care path and the curative path. This would be consistent with “Medicare’s current emphasis on eliminating payment silos, decreasing fragmentation across settings, and providing patient-centered care.”

On the other hand, Stevenson and Huskamp recognize that, in addition to the potential strengths provided by the proposed changes, there are good reasons to proceed with caution. The move to integrate the hospice Medicare benefit into Medicare Advantage would directly tie hospice care into the broader financial considerations of the Medicare system. Enrollment in hospice care would likely be shaped in part by these considerations. Importantly, they note, “a hallmark of successful hospice programs is the comprehensive and interdisciplinary

nature of the teams that provide care, something that could be undercut if hospice services are offered individually and not as an integrated package.”

As underscored by NHPCO, Stevenson and Huskamp acknowledge that the changes could lead to reduced patient choice of which program to enroll in. “Plans might include only a subset of local hospice agencies in their contracted networks (perhaps negotiating lower rates for higher patient volume), which could limit choice...” The Medicare Advantage plan would become the primary driver in the planning process for and oversight of end-of-life care for hospice enrollees. **This change “could lessen the role of clinicians who have the most relevant, specialized experience.”**

In order to avoid this outcome, the authors insist that Medicare Advantage plans be held accountable for the quality of end-of-life care. To this end, they foresee that “a combination of monitoring, public reporting, and performance incentives must be in place.” In many cases, such quality reporting is not yet in place, as “several key components of federal payment and oversight do not include quality measures with relevance to end-of-life care.”

In addition, the authors suggest giving patients the option to re-assert their freedom of choice if important needs are not being met, allowing patients to “disenroll from their Medicare Advantage plans into the traditional Medicare hospice benefit if they determine their end-of-life care needs are not being met.” While this could potential disincentivize health insurance companies from providing high-quality end-of-life coverage, “stop-gap mechanisms that penalize plans with relatively high disenrollment rates or require plans to reimburse a portion of the beneficiaries’ out-of-network care could be devised.” (*Report to Congress: Medicare Payment Policy*, 3/14, www.medpac.gov/documents/Mar14_EntireReport.pdf; jama.jamanetwork.com/article.aspx?articleID=1849362; *NHPCO*, 3/14, <http://www.nhpc.org/press-room/press-releases/response-medpac-medicare-advantage-proposal>; *Hospice Advocacy Network*, 3/2014, <http://hospiceactionnetwork.org/get-informed/issues/medicare-advantage-and-hospice/>)

HOW DO WE CARE FOR CAREGIVERS?

Being the primary caregiver for a loved one can be a rich, rewarding experience. It can also be hugely challenging and draining. While providing 24-hour care to individuals who cannot care for their own basic needs - eating, drinking, using the bathroom and bathing - is more than a full-time job, it is one that more and more Americans are being called upon to take on. **Articles recently published in *The Journal of the American Medical Association* explore the challenges of caregiving.** In “Caregiver Burden,” Ronald Adelman, MD, and others note that **there are times that caregivers themselves can become an “invisible patient,” lost in the shuffle of care for the chronically ill person being cared for.**

Being on call for another person all day and night often leaves little space in the caregiver’s life to provide for his or her own basic needs. “Over time, this can have negative effects on the caregiver: socially, psychologically, and physically.” **Though caregivers are frequently overlooked in the care process, momentum has been building in recent years in the**

community of doctors, social workers, and others, to practice greater awareness of and care for those who are the primary caregivers for their loved ones.

One challenge to this process is the fact that caregiver stress can be a difficult subject to talk about. Precisely because they are caring for a seriously ill loved one, many will prefer not to talk about their own needs. **In order to break through this barrier, clinicians and others can help by asking simple questions, such as “How would you describe your quality of life?” or Who gives you help when you need it?”**

If the answers to these questions give cause for concern, JAMA provides recommendations for resources that can be useful in caring for caregivers who are struggling under the stress. Resources include links to the CDC, AARP, Caregiver Action Network, and Family Caregiver Alliance. Joanne Lynn, MD, writes about “Strategies to Ease the Burden of Family Caregivers.” Lynn says, “Federal policy has been inattentive to family caregiving,” and she backs up her assertion with clear examples. She notes the work of the VA and the progress it has made in supporting family caregivers.

JAMA also published a piece by Marjorie S. Rosenthal, MD, MPH, who writes about her own personal experience as a caregiver, and issues a call for physicians to practice caregiver-centered care. In her role as a pediatrician, she reflects on the fact that she has often failed to take caregiver needs into consideration when prescribing medication, for example. “When I was a pediatric resident, I barely paid attention to someone’s life outside the office. I prescribed a medication four times a day for a toddler without checking if there was one that could be given twice a day. I gave what I thought was the most highly effective medicine without regard for how difficult it might be to take.”

Over time, Rosenthal has learned to be more aware of the practical needs of her patients and their caregivers, not simply the cut-and-dried medical situation. “I am better now at considering the whole family,” she reflects. Yet, even now, she acknowledges that she struggles to take the full implications of care into account when making medical determinations. **She issues an appeal to her fellow physicians, to join her in this work of considering the needs of family and caregivers in all of their clinical decisions.** “As we, as a society, dedicate resources to solving [medical mysteries]... I hope we are dedicating resources to assessing how best to help caregivers get the support they need - both social support and within a medical system that considers their high-risk occupation.”(JAMA, 3/12, <http://jama.jamanetwork.com/article.aspx?articleid=1840211>; JAMA, 3/12, <http://jama.jamanetwork.com/article.aspx?articleid=1840238>; JAMA, 3/12, <http://jama.jamanetwork.com/article.aspx?articleid=1840219>; JAMA, 3/12 <http://jama.jamanetwork.com/article.aspx?articleid=1840240>)

HOSPICE NOTES

*** NHPCO has released a study on how to assist family caregivers in managing medications for home hospice patients.** The study found that “one third of hospice providers encounter home-caregivers who experience difficulties in properly administering medical management.” It suggests that quality of care by home hospice caregivers can be increased through greater

involvement by hospice organizations. (*eHospice*, 3/11, www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/9446/language/en-GB/View.aspx#.UySByvldWbN)

* **PBS features a video documentary of the story of one man facing the end of life in hospice care.** The film tells the story of Norman Briggs, his life, and his special connection to High Peaks Hospice. **The film is available online:** mountainlake.org/high-peaks-hospice (*Press Republican*, 3/11, www.pressrepublican.com/0800_special_sections/x1387856762/Local-man-shares-hospice-experiences-in-video)

END-OF-LIFE, PALLIATIVE CARE AND OTHER NOTES

* **The West Virginia Center for End-of-Life Care established its e-Directive registry in 2012.** The registry “allows users to file online for advance directives related to end-of-life care.” The registry saw a 35% increase in 2013 with 10,836 submissions. The online database is available to caregivers and helps to insure that citizens’ wishes in care are honored. Chris Zinn, director of The Hospice Council of West Virginia, says, ““We want to protect them from interventions that they don't want, which is why we find it so important to participate in the e-registry.” (*Gazette Mail*, 3/15, <http://www.wvgazette.com/News/201403150088>)

* **Emergency responders and disability advocates in Connecticut are backing an end-of-life proposal that would create a pilot program for medical orders for life sustaining treatment (MOLST).** Many now believe that a MOLST bill in the Connecticut legislature has a good chance of becoming law. (*The CT Mirror*, 3/14, ctmirror.org/emergency-responders-disability-advocates-backing-end-of-life-care-proposal/)

* **Dancers in Vermont have made end-of-life issues the center of their performance.** “‘To You, Around You, About You’ explores the themes of aging, memory, loss and the transition to death.” (*Vermont Public Radio*, 3/13, digital.vpr.net/post/dance-performance-focuses-end-life-issues)

* **New Mexico’s Attorney General Gary King is appealing the decision of a lower court that found that the New Mexico state constitution provides for a right to assisted suicide.** Judge Nan Nash, who made the original decision, wrote in his opinion, “This court cannot envision a right more fundamental, more private or more integral to the liberty, safety and happiness of a New Mexican than the right of a competent, terminally ill patient to choose aid in dying.” (*National Right to Life News*, 3/12, www.nationalrighttolifenews.org/news/2014/03/new-mexico-attorney-general-appeals-assisted-suicide-lower-court-decision/#.UySBBvldWbN)

* **One dying man’s last wish? To see assisted suicide become legal.** Charles Selsberg spent his last days on earth advocating for the “right to die.” Selsberg wrote an op-ed for *The Denver Post*, urging state lawmakers “to pass legislation that allows for physician-assisted suicide.” (*The Denver Post*, 3/10, www.denverpost.com/news/ci_25315690/denver-mans-dying-wish-seeks-assisted-death-legislation?source=rss)

Correction: In the last edition of HNN, in an article about the Barbara Mancini case, we incorrectly reported that, “Following Yourshaw’s death, a hospice nurse contacted her supervisors and police.” In fact, the hospice nurse called police after she arrived at the home, where the father was still alive. Police insisted that the father be transported to a hospital, where he died about four days later. We apologize for any confusion resulting from this error.

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