CALL TO ACTION TO ENGAGE CONSUMERS IN EOL ISSUES

*Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care* was recently published by Caring Connections, NHPCO’s initiative that provides information on “care, caregiving and community engagement.” An NHPCO Press Release says the booklet, a joint Robert Wood Johnson Foundation-NHPCO effort, “is a call to action that encourages – and provides a framework for – a national agenda for consumer engagement in end-of-life issues.”

The report discusses end-of-life care and its evolution in the United States. The authors relate the stories of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo, and how they have shaped the end-of-life discourse in this country. Other sections examine the RWJF initiatives to improve end-of-life care, including the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) in 1995, “The Quest to Die With Dignity: an Analysis of Americans’ Values, Opinions and Attitudes Concerning End-of-Life Care” in 1997, and Last Acts in 1999. Other organizations, including Partnership for Caring, Aging With Dignity, and Community State Partnerships to Improve End-of-Life Care also played significant roles in the national dialogue to improve dying in the US.

In the booklet, Caring Connections identifies ways that “individuals, communities and organizations can assume responsibility for meeting the concerns of those at the end of life.” The booklet calls for specific action from a number of stakeholders:

1) **Individuals** need to talk about, and document, their end-of-life wishes.
2) **Healthcare providers** need to “to initiate honest, timely and culturally relevant discussions about the burdens and benefits of treatment options in the last stages of an illness.”
3) **Communities** need to provide care and support so that no one dies alone or in pain.
4) **Healthcare payors** need to understand the continuum of care, beginning with palliative care at the beginning of a serious illness.
5) **Policy makers** “need to eliminate barriers that prevent timely access to hospice and palliative care.”
6) **Employers** need to support employees who are patients, or caregivers, or are grieving a loss.
7) **Researchers** need to continue their studies of end-of-life issues.
8) **The media** needs to find ways to “demystify” dying and conversations about end-of-life issues.

HOSPICE HOME CARE TEAM STAFFING GUIDELINES PUBLISHED BY NHPCO

In March, NHPCO published Staffing Guidelines for Hospice Home Care Teams, the first update of staffing guidelines since the Hospice Service Guidelines were published in 1994. Those staffing rations were developed “when hospice was still in its formative years and data on hospice operations were sparse, … hospice service models were more basic and uniform, and the patient population served was quite different from the population served today by hospice programs.” The new guidelines are “based on the recognition of the current diverse nature of hospice care and allows for individualization of staffing caseloads according to the organizational and environmental characteristics specific to each hospice, in much the same way hospices individualize patient care.”

The Guidelines document is divided into four sections:

* **Preparation**, which includes reviewing National Summary of Hospice Care data and comparing current caseloads to national statistics. There is information on care models and other factors. A key table, the “Hospice Homecare Staffing Guidelines Analysis, “delineates the factors you should use to compare your hospice’s characteristics (e.g., length of stay) with median hospice characteristics from NHPCO’s National Data Set.”

* **Analysis** of eleven factors, distilled from more than 90 identified by the taskforce that wrote the document, helps you decide whether your caseloads should be different than the national norms, how your hospice characteristics compare to the national norms, and how environmental and organizational factors affect your hospice. **Evaluation** includes “discussion of the Quality Assessment and Performance Improvement process (QAPI), the Family Evaluation of Hospice Care (FEHC), and other performance measurement tools that can be used in the evaluation process.” Action steps are also discussed.

* **Hospice Program Examples** provide “case scenarios” to illustrate different points.

* A **Glossary** and an **Appendix** conclude the sections.

The NewsLine article goes into detail about the development of the guidelines, and reminds readers that “this analysis only provides a starting point for determining estimated optimal staffing caseloads for your hospice. Ongoing evaluation must also be part of the process.”


FOCUS GIVEN TO PEDIATRIC ADVANCED CARE TEAM

*Kaiser Health News* and *The Boston Globe* recently featured pediatric palliative care and the Pediatric Advanced Care Team (PACT) at Children’s Hospital Boston and the Dana-Farber Cancer Institute. The main article, “Palliative Care Can Help Children and Families
Navigate Bewildering Medical Terrain,” has several vignettes of children living with life-threatening diseases and being supported by PACT.

The new federal health reform law allows terminally ill children covered by Medicaid or CHIPS (Children’s Health Insurance Program) to choose hospice or palliative care while continuing curative care. Massachusetts enacted the same provisions in 2006, when it overhauled its health insurance program. It also built a statewide palliative care network for pediatric patients.

Children’s Hospice International estimates that 1.3 million children and adolescents have serious or life-threatening diseases. NHPCO estimates say that 53,000 of them die each year.


PUBLIC POLICY NOTES

The Idaho Senate passed House Bill 187 which affirms the state’s “conscience law.” Passed last year, it allows “all health care professionals in the state to refuse to honor patients’ directives for legal end-of-life care and treatment.” The legislation has already passed the house, and is awaiting Governor C. L. Otter’s (R) signature. (Centre Daily Times, 3/29, www.centredaily.com/2011/03/29/2613916/idaho-senate-passes-bill-to-force.html)

CMS has posted the “Hospice Face-to-Face FAQ” at the link below. It discusses what happens if the face-to-face encounter is not conducted within the required timeframes, whether a hospice can bill using occurrence span code 77 for non-covered days if the face-to-face encounter is late, and whether the attestation can be completed later if the encounter is held in a timely fashion. (CMS, 3/25, www.cms.gov/Hospice/downloads/Hospice_Face2Face_FAQ_032511.pdf)

Specialists in kidney treatment say that the federal law which gives patients with end-stage renal disease free medical care “was meant to keep young and middle-aged people alive and productive.” But now, many of the patients are elderly and have other chronic problems. “Kidney specialists are pushing doctors to be more forthright with elderly people who have other serious medical conditions, to tell the patients that even though they are entitled to dialysis, they may want to decline such treatment and enter a hospice instead.” Some specialists are encouraging physicians to change their terminology – rather than saying that a patient has chosen not to have dialysis, or is stopping it, they say the patient “has chosen medical management without dialysis.” More than a third of dialysis patients are 65 or older, and account for 42% of dialysis costs. (The New York Times, 3/31, www.nytimes.com/2011/04/01/health/01dialysis.html)
A CMS requirement that took effect on April 1 mandates that Medicare home health patients see doctors 90 days before or 30 days after starting home health services, or the services cannot be reimbursed for the care. According to some in the industry, the visits will be difficult for home-bound frail seniors. The requirement is intended to prevent Medicare fraud, and some Medicare advisers to Congress say that it isn’t strict enough because patients can “start getting home health services before first seeing doctors to ensure that they need it.” (The Kansas City Star, 3/28, www.kansascity.com/2011/03/28/2757482/agencies-slam-new-medicare-rule.html)

RESEARCH & RESOURCE NOTES

On April 19, NHPCO will offer “The Experiences of Veterans from Different War Eras,” one of a series of webinars on care for veterans. Faculty for the webinar is Dr. Joshua Hauser, Director of Education in Palliative and End-of-Life Care (EPEC), and co-director of EPEC for veterans. See the NHPCO link below for registration information. (NHPCO, www.nhpco.org/i4a/pages/index.cfm?pageID=6400; EPEC, www.epec.net)

“Be Prepared: Reducing Nursing Home Transfers Near End of Life,” published by the California Healthcare Foundation, says, “Few nursing homes have developed a process for helping residents understand and document their end-of-life wishes nor established adequate procedures to care for residents when they are dying. As a result, nursing home residents too often are hospitalized during the last weeks and months of life, resulting in unnecessary suffering and the potential for increased health care costs.” The PREPARED project “addressed inappropriate nursing home-to-hospital transfers toward the end of life through improved advance care planning, including the use of Physician Orders for Life-Sustaining Treatment.” (California HealthCare Foundation, www.chcf.org/~/media/Files/PDF/B/PDF%20BePreparedReducingNursingHomeTransfers.pdf)

PALLIATIVE CARE NOTES

An article in The Washington Post says that the demand for palliative care is growing. “Hospitals like this type of care because it appears to be cost-effective and may improve health outcomes. Patients -- once they know about it -- like it because it may make them feel better.” The author says, “Despite its apparent cost-effectiveness, insurers typically don’t yet reimburse hospitals for palliative services beyond doctor visits and care related to hospice.” Michael Nisco, medical director of hospice and palliative services at St. Agnes Medical Center in Fresno, says, “Unless you have a health-care system or a large hospital funding the rest of the team, you really can’t provide [palliative] care.” (The Washington Post, 3/28, www.washingtonpost.com/national/hospitals-increasingly-offer-palliative-care/2011/03/24/AFuFAeqB_story.html; Kaiser Health News, 3/29, www.kaiserhealthnews.org/Features/Insuring-Your-Health/Michelle-Andrews-on-palliative-care.aspx)

Dr. Porter Storey, executive vice president of the Colorado Permanente Medical Group, contributes to a blog for the American Academy of Hospice and Palliative Medicine. He was recently invited to a MedPAC meeting on palliative care. He says, “It soon became clear that a new benefit for palliative care services is not on anyone’s drawing board, but the inclusion of palliative care services in new initiatives like Accountable Care Organizations, Community Health Teams to Support the Patient-Centered Medical Home, Hospital Value Based
Purchasing, or Center for Medicare and Medicaid Innovation at the Center for Medicare Services is a possibility. It was an energized discussion of wide-ranging aspects of our field, and we all hope the MedPAC staff can use what they learned from us to help Medicare beneficiaries with serious illnesses get the best possible care.” (American Academy of Hospice and Palliative Medicine Website, www.aahpm.org/apps/blog/?p=1093)

Thanks to Kathy McMahon and Maggy Murphy for contributions.

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