



IHO Update

Bi-weekly News for Hospice Professionals in Iowa

January 14, 2005

Family Evaluation of Care Survey Participation for Non-members

The Iowa Hospice Organization board is dedicated to increasing the number of Iowa hospices involved in the NHPCO Family Evaluation of Care (FEC) Survey. Recognizing that not all hospices are members of NHPCO, IHO urged the national organization to develop a way for non-NHPCO members to participate in this invaluable survey. NHPCO has responded with a non-NHPCO member option.

Non-NHPCO member hospices interested in only participating in the FEC survey can contact the NHPCO membership department at 800-646-6460 and request to become an FEC member. This membership is \$4 per patient served as opposed to \$7 per patient served for full NHPCO membership.

If you have any questions regarding this, please contact Jennifer Lucas at Iowa Hospice Organization at 515-243-1046 or lucasj@ihaonline.org

Wellmark Makes End-of-Life Care Priority: Grant Deadline February 7

Wellmark Foundation has made it easy for your hospice to apply for a grant—they've compiled a list of resources, information and potential project ideas at www.wellmark.com. Click on "The Wellmark Foundation" for more information on the grant program that seeks to advance comfort, choice and control in care at the end of life for Iowans. Wellmark's grant funding is a starting point for initiatives that will potentially contribute substantively to improvement of end-of-life care. **February 7 is the final deadline to submit proposals.**

IHO Members Return Data Collection Survey

Last month directors of IHO member hospices were sent a survey seeking feedback on individual hospice data collection efforts and roadblocks. The list of hospices that submitted their surveys as of January 13 is provided as an enclosure with this week's *IHO Update*. Survey results are being tabulated and will provide direction to the IHO Board data work group relative to future IHO efforts and initiatives.

IHO thanks each hospice for taking the time to complete the survey. Contact Becky Anthony at IHO or IHO Board Members Marvin Fagerlind or Bruce Kawahara with any questions.

Web Based Data Entry Now Available for FEC

NHPCO has developed a web-based system for submission of Family Evaluation of Hospice Care (FEHC) data. The web-based system has been developed in an effort to make submission of FEHC data more straightforward and less challenging.

For details, view the *NHPCO Web-based Data Entry System Tips and Instructions* document on the FEHC page of the NHPCO website. Questions regarding the FEHC web-based data entry system, or any aspect of the FEHC survey process, should be sent to FEHC@nhpco.org. Be sure to include the

Member ID your agency is using to upload data and a telephone number where staff entering the data can be reached.

CMS to Measure Provider Satisfaction with Contractors

Beginning in January 2005, the Centers for Medicare & Medicaid Services (CMS) will initiate the Medicare Contractor Provider Satisfaction Survey (MCPSS), a pilot project to measure provider satisfaction with and perceptions about the services provided by 12 Medicare fee-for-service (FFS) Contractors, including Noridian Mutual/Blue Cross Blue Shield, the Medicare Part B contractor for Iowa. Contractors were selected based on a broad range of criteria, such as claims workload, geographic location, and provider type. Westat, a statistical survey research firm has been awarded the contract to administer the pilot survey.

The MCPSS is intended to satisfy a requirement in the Medicare Modernization Act to measure provider satisfaction, to support and assist Contractors in using provider feedback to identify and implement best practices, and to establish provider satisfaction as a standard measurement in performance-based contracting or incentive contracting.

The survey instrument will assess seven administrative functions of each Contractor, including:

- Provider communications
- Provider inquiries
- Claims processing
- Appeals
- Provider enrollment
- Medical review
- Provider reimbursement

A sample of approximately 7,400 Medicare FFS providers will be chosen to participate in the project. All information will be kept confidential and individual providers will not be identified. Sampled providers will receive a pre-notification letter one week prior to receiving a letter containing a URL, username, and password information. Providers will have the opportunity to respond via mail, fax, or Internet. A key contact person or “survey coordinator” at each provider organization will be responsible for distributing the information to the appropriate staff, collecting the responses, and compiling them into a single submission.

Each Contractor will receive Contractor-specific reports, including comparisons and recommendations with those who participated in the pilot. CMS does not intend to use this information to evaluate Contractor performance nor does it intend to share this information with the public.

Final reports are expected in June 2005, with national administration of the MCPSS, which will include all Medicare Contractors, scheduled for 2006.

More information regarding this initiative can be found on the CMS Web site at www.cms.hhs.gov/providers/mcpss/default.asp

Questions regarding this initiative can be directed to Heather Olson (olsonh@ihaonline.org) at IHA.

Help Iowans Recover from Crises: An Opportunity for Continued Education

Staff Public Policy Group (SPPG) is offering crisis training for individuals seeking continuing education credits, while helping Iowans recover from crises at the same time.

This six-session series will use the Iowa Communications Network (ICN) and DVD technology to provide ten hours of content to natural helpers in Iowa communities (e.g. Mental Health Providers, Public Safety, Case Managers, Social Workers, etc.) Visit www.iowacrisistraining.com 2005 to learn more and to sign up.

AARP Study Evaluates EOL Care in Nursing Homes

An AARP study found end-of-life care in nursing homes often results in unnecessary suffering due mainly to a lack of staff time, training and communication. Approximately 25% of American adults die in nursing homes, so why aren't basic needs—treatment for pain, hospice and emotional support—being met? Many nursing homes simply don't have money to provide the level of care and support that the dying need. Even at the best facilities, aides earn wages comparable to staff at McDonald's.

Researchers noted the difficulty of identifying symptoms of terminal illness. Simply stated, appropriate end-of-life care is sometimes not provided because staffers do not realize a patient is dying. The study also cited family members concerned by task-focused versus person-centered care, stating physicians were often times “missing in action”.

AARP's study offered a number of recommendations for improving nursing home end-of-life care, such as:

- Improved training for healthcare staff and administrators
- Improved training for physicians, including medical residents
- Increased reimbursements
- Providing incentives and removing disincentives for nursing homes to contract with hospices. (AARP News, 12/14; UPI, 12/16)

ACHE Revises Ethical Policy Statement on EOL Decisions

The American College of Healthcare Executives (ACHE) revised its ethical policy statement to state: health care executives should address the ethical dilemmas and problems surrounding death and promote public dialog that will lead to awareness and resolution of death with dignity concerns.

According to ACHE, executives are urged to:

- Raise moral and ethical questions to aid in public understanding of the growing correlation between death and dying
- Become advocates for preparedness through advance directives, living wills and durable healthcare powers of attorney
- Provide support for patients and their families as treatment decisions are reached
- Develop clear guidelines to assist in resolving disputes regarding treatments as well as provide support for physicians and families responsible treatment decisions
- Encourage ethical decision making and sensitivity to ethical dilemmas
- Ensure information is disclosed about organizational policies that limit end-of-life options
- Support the development of resources and programs that promote pain control as a crucial modality in the management of patients at the end of life

The full statement can be found at: www.ache.org/policy/endoflif.cfm

Patients Prefer Painkiller Risk to Chronic Pain

A number of patients prefer the unknown degree of heart risk from drugs such as Vioxx, Bextra and Celebrex to the chronic pain suffered without them. These drugs, all COX-2 inhibitors, were thought to be preferable to older drugs because they were less likely to cause GI bleeding. Newer studies have failed to confirm that advantage or to demonstrate that they provide better pain relief than drugs that have been on the market longer. The new studies have also raised questions about the increased risk of heart attacks.

Dr. Robert Bucholz, president of the American Academy of Orthopedic Surgeons, says patients should put the cardiac risks into perspective. "All life is a series of risks, and you've got to measure the risks versus the benefits. And that's true of any drug," he says. Bucholz himself takes Vioxx, has a supply on hand and doesn't plan to get rid of it.

Further clouding the issue is the fact that some of the studies contradict each other, leaving both patients and physicians confused. New studies of both Celebrex and Aleve contradict earlier studies that found no heart risk. Rheumatologist John Conte, of Providence, Rhode Island, says that he and other doctors are getting incomplete information through the press, because the Aleve study has not yet been published in medical journals. Gerard Valotta, director of sports rehabilitation at New York Medical Center's Rusk Institute, blames the media for "blowing things out of proportion and creating alarm in people that don't necessarily need to be alarmed." Valotta says that the risks of not taking the medications may be greater than the risk of taking them. (USA Today, 1/5; US News & World Report, 1/10)

Pain and Drug Notes

- Ziconotide, a new kind of pain killer that blocks the transmission of pain signals, was developed from the venom of the cone sea snail and is 1,000 times more potent than morphine. Pain specialists see the drug as "a major breakthrough." Ziconotide, which is marketed as Elan Corporation's Prialt, is administered through an infusion pump and will be available in the US this month. (AP, 12/19; London Daily Mail, 1/4)
- Pfizer has received FDA approval for Lyrica™ for the treatment of the neuropathic pain of diabetic peripheral neuropathy and post herpetic neuralgia. The press release says that Lyrica has a "newly defined mechanism of action" and will be available in the near future. (PR Newswire, 12/31)
- The FDA has given administrative approval for testing the street drug "ecstasy" in patients with advanced cancer who have severe anxiety. This will be the first test of a psychedelic at Harvard since Timothy Leary's 1960's experiments with LSD. An NHPCO NewsBrief says that the NHPCO supports "methodologically sound studies to improve care at the end of life..." (The Washington Post, 12/27; NHPCO NewsBriefs, 12/30; Houston Chronicle, 12/19)

Resources for Better Serving Spanish Speaking Patients and Families

If your hospice is looking for some Spanish language resources to use in providing services, you may find the following resources helpful.

- *Hope through Healing: The Grief Mail Series* offers a series of publications in English and Spanish. Headquartered in Mesa, AZ, their contact number is: (480) 777-5828.
- www.alfinlibros.com offers a wealth of excellent books that we are all familiar with in English, but the Spanish version--books by Niemeyer, Wolfelt, Centering Corporation, Barbara

Karnes, Bob Deits, Medic Publishing, Heegaard, all excellent resources for adults as well as children.

- www.compassionbooks.com has over 400 resources in Spanish
- *Bereavement Magazine* has articles in Spanish and allows you to copy their articles as long as you give them credit
- AARP offers a variety of pamphlets on aspects of grief, all in Spanish

Research and Resource Notes

- *Consumer Reports* has launched *Best Buy Drugs Web Site*, www.crbestbuydrugs.org, to help consumers save money on prescription drugs by comparing price, effectiveness and safety of drugs. The site will eventually compare 20 different categories of drugs, but for now, the first category compares cholesterol-lowering medications, treatments for heartburn, acid reflux and anti-inflammatory used for arthritis.
- The *US News and World Report* now offers a “Roadmap for Alzheimer’s”, including the official online mental exam physicians use to screen for the disease. Visit www.usnews.com/usnews/health/hehome.htmoff for more information about the prevention and treatment of Alzheimer’s. (*US News and World Report Website*, 12/20)
- *The Quality of Life: Living Well, Dying Well*, by Janet Lembke, is reviewed at [www.augustafreepress.com/stories/storyReader\\$29768](http://www.augustafreepress.com/stories/storyReader$29768). Lembke, who cared for her mother during a long illness, says: “One of the aims is to help people, like me, learn to care for someone who is old and frail and not always rational.” (*Augusta Free Press*, 12/16)
- The winter issue of Population-Based Palliative Care Research Network (PoPCRN) newsletter focuses on the use of information technology in hospice and palliative care, with articles on the current use of technology (mostly for administrative purposes), telehealth and the hospice information system created by the Hospice and Palliative Care Association of New York State. Visit www.uchsc.edu/popcrn/ for the entire newsletter. (*PoPCRN*, Winter/2004)
- A review of *Ethical Foundations of Palliative Care for Alzheimer’s disease*, edited by Purtilo and Have, says, “Death with dementia challenges a society not only to rethink but also revalue its health care system.” The review notes several limitations of the book but says editors and authors should be congratulated for creating a space that allows us to retell our individual and social stories of dying with dementia. (*NEJM*, 2004; 351: 2885)

District Meeting Rescheduled

The next District 5 Meeting is scheduled for March 11, at 10 a.m. in Williamsburg. Contact Kristin Paris from Hospice of Monroe County (Albia) with questions at 641.932.1701 or e-mail her at kparis@mchalbia.com

The District 4 meeting has been rescheduled for Wednesday, January 19, from 1:30 to 3:30 p.m. in Atlantic. Please contact mgowdy@mcmh.org with questions.

Upcoming IHO Meetings

January 25 – IHO Education Committee, IHO Offices

February 1 – EOL Statewide Partnership Meeting, IHO Offices

February 3 – IHO Board Meeting via conference call

March 1 – IHO Legislative Day

Enclosure

Survey on IHO Member Data Collection List