

NEW HAMPSHIRE HOSPICE and PALLIATIVE CARE ORGANIZATION

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Letter from the Executive Director:

After another successful conference we are looking to meet the educational needs of our members by offering programs through out the year as well.

The educational committee met in November and has formed two committees, a clinical committee chaired by Carol Tubman that will focus on the educational needs of all interdisciplinary members of hospice and palliative care, and a volunteer/community committee chaired by Sue Fortier. In order to plan the programs we need your input. Enclosed with this newsletter is a survey and we ask that you complete it and mail, fax or e-mail it back to us by **Dec 23rd**.

All programs we offer will be open to all members.

Thank you for your support over the last year. Have a wonderful Holiday Season and all good wishes for the New Year.

Ann

Registered Nurse Certification Exam

The next testing date will be **Saturday, March 15, 2003**

Note: NHHPCO will be offering a course in February 2003 to help those taking the test in March. Details will be sent later.

Pittsburgh, PA The National Board for Certification of Hospice and Palliative Nurses seeks to promote the highest standards of excellence for hospice and palliative care. To this end, they initiated the certification process in 1994. As a result of this most recent exam, there are now 6,868 currently certified nurses. Certification indicates the individual, through testing, has demonstrated the certifying knowledge and competency in hospice and palliative nursing. The individual who successfully passes this examination, therefore, earns the right to be called a Certified Hospice and Palliative Nurse (CHPN). Information related to the eligibility requirements, examination application deadline, examination fees and other policies are included in the Certification Examination Candidate Handbook. This Candidate Handbook and the Certification Examination Application are available online at www.hpna.org/nbchpn/ or by telephone from the testing service, Applied Measurement Professionals at 1-888-519-9901.

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NHHPCO Newsletter via E-Mail

If you would like to receive this newsletter by e-mail, notify Ann Blair at hosp@nhho.org. Please specify what word processing program you use. For those with adobe acrobat reader, the newsletter is available as an adobe file.

Help Save NHHPCO some money.

Notes

CMS Holds Monthly Home Health, Hospice, and DME Open Door Meeting. On November 5, 2002, CMS held its monthly Home Health, Hospice and DME Open Door meeting in downtown Washington, DC. One hospice-specific question was answered regarding verbal agreement to the hospice election form, signed by the patient or the patient's representative. CMS central staff stated that verbal agreement with the patient or the patient's representative for the election of the Medicare Hospice Benefit is NOT allowed. The form electing the Medicare Hospice Benefit must be signed. The effective date of care can be no earlier than the date on the election form. If the patient's durable (or health care) power of attorney is not in the area, the election form may be signed by the power of attorney and faxed to the hospice. This should not be confused with a verbal order from a physician for certification of terminal illness. A verbal order is appropriate and allowed, as long as there is a signed physician certification prior to the first billing.

A recent study of patients with recurrent ovarian cancer found that their choice between palliation and further treatment is determined more by the quantity of life left to them than by its quality. The group with recurrent cancer also said they would switch from treatment to palliation when their survival time was about five months. Healthy volunteers in the same study estimated that they'd make the switch at eight months. (*Healthfacts*, 9/1)

Frailty, and even life-ending events, can open new meanings that deepen the quality of life, according to an article in Wisconsin's *Capital Times*. One 90-year-old woman in the study described her strong sense of well being, distinguishing it from being well. Philosopher and teacher Ram Dass calls his stroke of several years ago "heavy grace." He says he believes in the "domain of immobility, where the commotion of the world finally ceases, we are brought closer to the sacred, a realm that thrives through silence and relinquishment." (*Capital Times*, 10/22)

GlaxoSmithKline and Bristol-Myers Squibb will resume the **pharmacy discounts available to low-income Medicare beneficiaries** under their Together Rx program. The discounts had been decreased because of uncertainty over the meaning of a CMS ruling about whether the same discounts had to be offered to Medicaid beneficiaries. CMS clarified the ruling on October 23, and the two companies immediately said they would restore the larger Medicare discounts and reimburse program participants for any additional costs incurred while the smaller discounts were in effect. (*Kaisernetwork.org Daily Reports*, 10/24)

This week, **CMS released a program memorandum, "Medicare Certified Hospices – Clarification of Acceptable Parameters for Some Contractual Arrangements."** The memo clarifies under what conditions a hospice may contract with another entity for non-hospice, but desirable, services. See www.cms.gov/manuals/memos for more information. (*CMS*, 10/25)

The producers of "And Thou Shalt Honor," the PBS special on caregiving aired last month, have created the Thou Shalt Honor Foundation that will continue to offer advocacy and public education to support family caregivers. The Foundation has just issued the first issue of *Caregiver USA News*, a weekly publication for family caregivers and organizations that support

them. Subscriptions are available online at www.thoushalt-honor.org/newsltr/. (*Caregiver USA News*, 11/4)

Social Workers Needed for Social Work Study. The Social Work Section of the National Council of Hospice and Palliative Professionals (NCHPP) is beginning the Model Social Work Performance Improvement Project using the Social Work Assessment Tool (SWAT). The SWAT is a useful one-page checklist that is used to guide psychosocial assessment and measure client outcomes in areas demonstrated by research to be important in end-of-life care. The social worker completes the SWAT after every client contact. When the case is closed, scores for the first and last contact can be compared to demonstrate client progress.

For the study, we will ask one social worker from a hospice or palliative care program to complete the SWAT for one case at a time for a six month period, and ask two patients and their primary caregivers to complete a special version of the SWAT. The SWAT is the first measure of social work outcomes, and our hope is that it will be used nationally for routine social work performance improvement efforts. If you are interested in participating in this important study, contact Dona Reese, Social Worker Section Leader, at reese@uark.edu or 479/575-3782

Medical personnel who work with patients who have **end-stage renal disease (ESRD)** can access the ESRD Peer Workgroup recommendations on palliative care online. The report, which can be downloaded from www.promotingexcellence.org/esrd, has a quality of life assessment instrument, a model policy for DNR order in dialysis units, and a comprehensive bibliography on end-of-life and palliative care in nephrology. (*Promoting Excellence In End-of-Life Care*)

The Center to Advance Palliative Care (CAPC) is offering a free resource on billing for palliative care professional services of physicians. A conference call, featuring Charles von Gunten, MD, will be held on December 4 at 1:00 PM EST. Call Margaret Schutz at 212-201-2671. (*Last Acts E-Newsletter*, 11/21)

"When is Refusal of Lifesaving Treatment a Refusal?" explores the ethical considerations of physicians and medical personnel dealing patients who wish to refuse treatment for treatable conditions. The article, which can be downloaded from <http://www.mmhc.com/nhm/articles/NHM0210/Gordon.pdf>, explores the patient's autonomy versus the physician's commitment to providing life-saving care, or beneficence. (*Annals of Long Term Care*, 2002;10(10);21-24)

The November-December issue of *Innovations in End-of-Life Care* examines ways of enhancing meaning, hope and dignity near the end of life. The online journal is available at www2.edc.org/lastacts. (*Center for Applied Ethics and Professional Practice*)

NH Cancer Pain Initiative-Strategic Planning Meeting

Mary Bennett from the **Alliance of American Cancer Pain Initiatives** will be facilitating a strategic planning meeting at the office on January 24, 2003 1:00 - 3:00 pm.

All members interested in pain management are encouraged to attend.

End-of-Life Planning & Discussions Vary by Culture

The North American culture advocates individual autonomy, truthful disclosure of terminal diagnoses and advance planning for the end-of-life. But this advocacy is not universally accepted or appreciated, even by significant sub-cultures within North America. So says Lucy M. Candib, MD, author of "Truth Telling and Advance Planning at the End of Life," which was published in a recent issue of *Families, Systems & Health*. Candib, a professor at the University of Massachusetts Medical School, provides an extensive review of practices and needs in sharing terminal diagnoses and determining patient wishes in end-of-life care. Theoretical issues in underlying discussions about end-of-life care; and considers cultural differences that impact patient preferences.

Candib points out that differences in cultures cannot be used to predict the response of a single individual within a culture. She says, "The diversity of responses within cultural groups means that generalizations about any given ethnic group will not be useful in the care of individual patients. Nevertheless, the centrality of family for decision-making emerges in multiple studies.

In the lengthy article, Candib provides an overview of the history of providing medical disclosure to patients; offers four case studies that demonstrate some of the difficulties; reviews a number of empirical studies; identifies and discusses several expressing a desire to understand the patient's culture and own beliefs, three areas of discussion should be explored.

She cites Blackhall, et al, who studied 800 independent elders in the Los Angeles area – 200 each of Korean, European, Mexican and African Americans.

- ◆ Forty-seven percent of the Korean Americans, 65% of the Mexican Americans, 87% of the European Americans, and 89% of the African Americans agreed that a patient should be told when s/he has cancer.
- ◆ Regarding who should decide about the use of life-support, 28%, 41%, 60% and 65%, respectively, think the patient should be the one to decide. Fifty-seven percent of the Korean Americans and 45% of the Mexican Americans felt the family should decide.
- ◆ Mexican and European Americans know more about advance directives than the other groups, but Mexican Americans join Korean Americans in being more likely to have a negative attitude about advance decision-making.
- ◆ A higher degree of education, more acculturation, and personal experience with illness increased the likelihood of having advance directives for all groups except Korean Americans.

Candib explores other cultural factors that impact end-of-life care. The Navajo belief system, she says, holds that thought and language "have the power to shape reality and control events. Bringing up in conversation the possibility of death is tantamount to wishing death upon the person." Navajo culture is thus in direct conflict with the Patient Self-Determination Act which mandates advance directives. Research is underway to find a culturally acceptable way to conduct end-of-life discussions with the Navajo.

Candib supports the practice of primary healthcare providers working with patients to address end-of-life issues while the patient is healthy. After the doctor introduces the topic by expressing a desire to understand the patient's culture and own beliefs, three areas of discussion should be explored.

- ◆ Individual or family decision-making. Using the hypothetical "if you were to be gravely ill," explore who should make final decisions, and whether they should know now what the patient wants to be done, or wait until the time comes.
- ◆ Intensity of intervention. If the patient were seriously ill, would s/he want to be allowed to die comfortably and quietly, or should heroic measures to maintain life be used?
- ◆ Disclosure of information. In case of serious illness would the patient want to know the diagnosis? If not, who should know?

At the same time, Candib knows that these discussions often do not happen until an emergency situation arises. Then, Candib says, patients and families should be questioned about their own preferences in how they want to discuss a serious illness. Until such discussions can take place, Candib proposes relying on hospital policies of CPR unless told specifically by patients and/or families that they do not want aggressive care.

Candib concludes by saying, "We need to recognize that we, too, are culture-bound in our approach, and that our assumptions about truth-telling and the end of life are not universally applicable or appropriate. Recognizing this first step is essential to addressing the needs of all the families who seek our help for care at the end of life."

Additional commentary on Dr. Candib's article also appears in the same issue of the magazine. (*Families, Systems & Health*, 20(3), 213-228)

CMS Addresses Impact of Nursing Shortage on Hospice

On September 12, 2002, the Centers for Medicare and Medicaid Services (CMS) issued a memo to the Regional Offices and state survey agencies designating the current nursing shortage as an "extraordinary circumstance" under the hospice Conditions of Participation 418.80 to allow hospices affected by the shortage to utilize contracted nursing staff. This memo goes into effect October 1, 2002, and expires September 30, 2004. In order to qualify for "extraordinary circumstance" exemption, the hospice must provide written notification to the state Department of Health and Human Services documenting the following:

- ◆ An estimate of the number of patients it has not been able to admit during the past three months due to the nursing shortage and provide the current desired patient/nurse ratio for the hospice.
- ◆ Evidence that the hospice has made a good faith effort to hire and retain nurses, and continues to try and recruit nurses on an ongoing basis.
- ◆ Demonstrate that it has a training program in place to assure that contracted staff is trained in the hospice philosophy and the provision of palliative care prior to patient contact.
- ◆ Assure that contracted staff providing care do so in a manner consistent with the hospice philosophy and the patient's plan of care.
- ◆ Contracted nurses are used to supplement the hospice nurses employed directly. Contracted nurses should not be used solely to provide continuous nursing care or on-call services.

Pain Information

Fear of Addiction Major Barrier to Pain Treatment

Dr. Kathy Foley, neurologist at Memorial Sloan Kettering Cancer Center and professor at Cornell University Medical College, author of the lead piece in the current “Ideas” paper of the Open Society Institute, says that many of the 50 million chronic pain sufferers in the US do not take prescription pain medication because of fear of addiction. That fear, she adds, is fueled by sensational media reports of OxyContin and other opioid abuses.

“By highlighting OxyContin's illegal use, we fail to educate the public about the role such analgesic drugs play in providing relief for millions of patients suffering from severe pain,” Foley said. She also says that misconceptions about these drugs influence not only patients, but also pharmacists and physicians. Additionally, pain's economic impact on society is over \$100 billion per year, which Foley thinks could largely be avoided.

Current and past issues of “Ideas” can be obtained at www.soros.org by searching for publications from the upper left-hand search tool and then linking to “Pain Management in America.” (*PR Newswire*, 10/22)

A solicitous spouse can make your chronic backache worse.

So say researchers at the University of Heidelberg. Patients whose partners downplayed their pain by leaving the room or distracting the patient with activities had far less brain activity when their spouse was in the room than patients whose partners treated them with massage, medicine, and other comforts. The overly-supportive spouse may, says the article, serve as a stimulating cue for pain. The study was reported at the annual meeting of the Society for Neuroscience. (*The Deseret News*, 11/5)

Findings presented at the annual meeting of the **Society for Neuroscience** show that baby mice who were given morphine after abdominal surgery on their first day of life showed the same responses to pain later in life as mice who had not had surgery. Mice undergoing surgery but getting no pain medication had decreased responses to painful stimuli. University of San Francisco researchers identified a special sensory molecule in nerve endings, called the capsaicin receptor, that may be a promising target for drug therapy in cases of chronic cancer pain. (*San Francisco Chronicle*, 11/4)

In November 2003, *JAMA* and several archives journals will publish theme issues on various aspects of the **management of pain**. To that end, they invite authors to submit manuscripts involving original research including randomized clinical trials and high-quality observational research; systematic reviews; scholarly commentaries; and special communications addressing pain management. Basic science and translational research studies that provide insight to underlying mechanisms of pain and its management are also wanted. (*JAMA*, 2002;288:2174)

University of Florida experts warn that efforts to stop **oxycodone (OxyContin) abuse** by prescribing methadone instead may have backfired. Florida had a 71% increase in methadone-related deaths from 2000 to 2001, and methadone is now implicated in more deaths in Florida than heroin. (*Pain & Central Nervous System Week*, 11/4)

Last Acts State-By-State Report Gets Wide Coverage

The November 18 Last Acts state-by-state report, “Means to a Better End,” received extensive international coverage. A Google search on the terms “end-of-life care” and “Last Acts” found references to 86 newspapers and television stations that covered the report, from the tiny Henderson, Kentucky, *Gleaner*, to the *Honolulu Advertiser*, *Times of India*, *Newsday*, *ABC News*, *PBS* and *NPR*. Many media gave their own slant to the story, focusing on such issues as underutilization of hospice, the plight of long-term care patients, or pain management. All reports say, as does the report, that states need to do better at end-of-life care.

The data from the Last Acts survey of public opinion on end-of-life care, conducted in the summer of 2001, found that Americans are critical of the care received by the dying in this county, and think it most important to improve the system.

- ◆ Fifty-nine percent rate the current state of end-of-life care as only fair, or poor, with 11% saying it is good or excellent. The percentages were similar both for those who had lost loved ones in the last five years, and those who had not.
- ◆ Seven percent could not rate end-of-life care, which the designers of the survey say suggest that it is an issue to which they have not given much thought.
- ◆ Seventy-three percent rate the current system as only fair or poor at making sure families' savings are not wiped out by end-of-life care. Those who have lost loved ones recently are more critical than those who have not. Forty-six percent say the system is only fair or poor at providing emotional support to dying people, and those suffering losses rate the system more harshly than those who have not.
- ◆ Forty-six percent say the system is only fair or poor at providing emotional support to dying people, and those suffering losses rate the system more harshly than those who have not.
- ◆ Forty-six percent rate the system as good or better on assuring that dying patients' wishes are followed.
- ◆ About half of respondents think the system is at least good or better on involving family members, and on making sure patients are comfortable and pain-free at the end of life.
- ◆ Fifty four percent say the system does well on respecting the spiritual and religious beliefs of the dying.
- ◆ Ninety-three percent rated it very or somewhat important to improve how our system cares for dying people.

The polling data can be found at www.lastacts.org/files/publications/pollingdata.pdf, with more information and links at www.rwjf.org/newsEvents/means.jhtml. (*Last Acts*; *Google*)

Hospice National Dataset 2001

The 2001 NHPCO National Data Set results are available at www.perforum.net. Detailed data from over 900 agencies, representing 250,000 admissions and 15 million patient days, covers more than one-third of the US hospice activity. Summary reports show national and state trend comparisons. Custom reports can be produced for an additional fee. (*E-mail from Martha Tecca at Perforum*, 10/31)

NHHPCO Meetings - 2002/2003	
NHCPI Committee	January 24, 2003, 1:00 pm - 3:00 pm. Call Ann Blair for more details.
NHHPCO Full Board	January 2003, 2:00 - 4:00 pm at the NHHPCO office
NHHPCO Executive Board	January 2003, 1:00 – 2:00 pm on full board meeting days, 2:00 – 4:00 pm other months,
Volunteer Coordinators	December 12, 11:00 - 1:00 pm. Contact Lorraine Bishop at Home Healthcare, Hospice & Community Services, (603) 352-2253
Social Workers – Homecare/Hospice	January 14, 8:30 am - 10:00 am at the NHHPCO office 125 Airport Rd., Concord. Contact Charlene Thayer, (603) 622-3781
Chaplains Supervision Group	At VNA Manchester. Contact Chan Newton, (603) 695-4005.
Physicians	Contact person is Pat Clary MD, (603) 692-4018 ext.303.
Patient Care Coordinators/Managers	January 14, 2:00 - 4:00 pm. at NHHPCO office. Contact Susan DiBona, (603) 524-8444
Bereavement Coordinators	January 14, 12:00 noon - 2:00 pm at NHHPCO office. Contact Jeanne Emerson, (603) 332-1133
Seacoast Regional Meeting	January 2, 2003, Thursday, 8:00 am - 9:30 am Contact Wayne VanGundy, Rockingham VNA and Hospice, (603) 772-2981.
Southern Region	Contact Lee Page, NHHPCO, (603) 225-0900 ext.221
Northern Region	Contact Elaine Vieira, Pemi-Baker Hospice, Plymouth, (603) 536-2232.

Conferences

2003 NHPCO/HPNA Joint Clinical Conference. Save the date! The 4th Joint Clinical Conference, Scaling the Peaks of Excellence on Hospice and Palliative Care, will be held April 10 - 12, 2003 at the Adams Mark Hotel in Denver, CO. In addition to HPNA, the following organizations are partnering with NHPCO on the conference: Partnership for Caring, Colorado Hospice Organization, and the Center to Advance Palliative Care (CAPC). Great room rates are available, \$135 single/double, to make hotel reservations call (303) 893-3333. To view the agenda at a glance or to register online, go to www.nhpc.org/JCC2003. Register before the end of the year and save!

Volunteer/Volunteer Manager Conference—August 3 - 4, 2003, Hyatt Regency, Columbus, OH, sponsored by NHPCO and Ohio Hospice and Palliative Care Organization (OHPCO).

Management and Leadership Conference—September 7 - 9, 2003, Sheraton Wild Horse Pass, Phoenix, AZ.

Free Train-the-Trainer Program Available From Hospice of the Florida Suncoast. The Hospice Institute of the Florida Suncoast is offering a free train-the-trainer program to help hospices reach out to and train caregivers. Applications now are being accepted for this unique train-the-trainer opportunity! The goal of the *Caregiving at Life's End* program, which is based on a national needs assessment of hospice family caregivers, is to help family caregivers find growth and meaning in the end-of-life caregiving. This training program will prepare hospices and community leaders to promote and provide the *Caregiving at Life's End* program in their communities.

The Hospice Institute of the Florida Suncoast is offering five free national caregiver education and outreach training sessions. The first free training will be held in Florida the week of March 3-7, 2003. Other trainings are scheduled for April, June, July, and August 2003.

Hospice, aging/elder care, caregiving, long-term care and palliative care professionals nationwide are invited to apply to attend the ***Caregiving at Life's End Training Program***. For more information, go to www.thehospice.org/inst.htm or e-mail andreaoettel@thehospice.org or kathybrandt@thehospice.org

Education Information

The End-of-Life Nursing Education Consortium (ELNEC) is having a significant impact on nursing education in the US, according to a recent survey that evaluated the project's preliminary outcomes. The first two cohorts of trainers shared their expertise with 16,000 nursing students and clinicians. Ten additional courses have since been offered, with more than 1000 nurse educators participating. ELNEC also announced the winners of its first annual Awards of Excellence. (*US Newswire*, 11/6)

Advance Practice Nursing: Pioneering Practices in Palliative Care, a monograph published by Promoting Excellence in End-of-Life Care, can be downloaded from www.promoting-excellence.org. The monograph highlights several models of palliative care in nursing practice and also looks at training of advance care nurses. (*Promoting Excellence in End-of-Life Care*)

December Audio Conference - Self Care and Effective Bound-aries: A Combination that Works! December 12, 2002,, 2:30 - 4:00 pm. EST [Note audio conference begin a half hour later than usual.] Presenter: Marcia Lattanzi-Licht, MA, RN, LPC. 1.5 Nursing CEUs available. To register online for these audio conferences, visit the Professional Education section of www.nhpc.org.