

# NEW HAMPSHIRE HOSPICE and PALLIATIVE CARE ORGANIZATION

Vol.4 June/July 2003 issue

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## From The President

Dear Friends:

We have moved the physical location of the office. Thank you to everyone who was involved. Our physical location is at Seacoast Hospice, 642 Central Avenue, Dover, NH 03820.

Our mailing address will continue to be 125 Airport Road, Concord, NH 03301 for the time being

Please note our new toll-free number - 1-877-646-7742

During the transition, please contact your discipline chair for the dates and locations of the regular meetings. We will continue to print them in this newsletter as we receive the information.

We thank you for your patience and continued support during these changes.

Enjoy the Summer.

*Sue*

## SAVE THE DATE

**NHHPCO/NHCPI Annual Conference**

**Pain & Beyond:2003**

**October 2, 2003**

**Geneva Point Center, Center Harbor, NH**

**Nessa Coyle, PhD, NP, FAAN** "Use of Sedation at the End of Life"  
Director of the Pain and Palliative Care Services, Sloan-Kettering Cancer Center, NY.

Co-editor: Textbook of Palliative Nursing.

**Brad Stuart, MD** "Care Beyond Cure: Palliation in Non-Cancer Disease"  
Medical Director, Sutter VNA & Hospice, Emeryville, CA

**Kenneth J. Doka, PhD, M.Div.** "Disenfranchised Grief"  
Professor of Gerontology, College of New Rochelle

**SEE FLYER INSIDE FOR MORE DETAILS**

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## New Hampshire Hospice and Palliative Care Organization (NHHPCO)

125 Airport Road  
Concord, NH 03301

### Officers

President – Susan DiBona  
Vice President - Patrick Clary, MD  
Treasurer – William Bushnell  
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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](mailto: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

Researchers at Harvard Medical School and Dana Farber Cancer Institute have released a study showing that **oncologists are treating more dying and terminally ill patients with chemotherapy** even though patients are not likely to benefit from the treatment. The study does not address the causes of the increase, but the scientists said that economic incentives to oncologists, as well as pressures placed on patients and families, could be responsible. According to the article, oncologists earn much of their income from selling chemotherapy to patients, and Medicare payments to oncologists for chemotherapy are among Medicare's top expenditures. (USA Today, 6/4); (HNN)

Rosemary Gibson has written Wall of Silence: **The Untold Story of the Medical Mistakes That Kill and Injure Millions of Americans**. Gibson says that reasons for the number of errors that occur are the huge volume (4 billion) of different doses of medicine given in hospitals each year; non-computerized prescription systems, including handwriting; the nursing shortage; and lack of communication among healthcare providers taking care of the same patient. Gibson also reports that a common theme among the patients she interviewed was that they and their caregivers were not believed when they reported pain. An interview with Gibson is online at [www.painfoundation.org/news0603/gibson.htm](http://www.painfoundation.org/news0603/gibson.htm). (APF Pain Monitor, 6/2003); (HNN)

Patricia Moore writes in The Washington Post of her experience as a volunteer at a hospice on Maryland's Eastern Shore. Her initial idea of offering foot rubs to patients, supported by hospice staff and graciously accepted by patients, turned very quickly into full massages. Moore says, "Touching and holding are the most meaningful human connections, conducive to airing out the heavy blankets of defense against the loneliness of dying." Her article is online at [www.washingtonpost.com/wp-dyn/articles/A60906-2003May31.html](http://www.washingtonpost.com/wp-dyn/articles/A60906-2003May31.html). (The Washington Post, 6/2); (HNN)

**Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED)** is a new tool that assesses caregiver exposure to patient distress. Caregivers reported exposure to SCARED experiences such as mistakenly thinking that a patient had died, or witnessing patients in severe pain. Researchers evaluating the tool found that high SCARED scores correlated with social and role impairment, negative health perceptions, and less energy. The study concludes that the tool may be useful in identifying care-givers who are at risk for major depressive disorders, and may also target potential aspects of caregiving for treatment. (American Journal of Geriatric Psychiatry, 11:309-319, June 2003); (HNN)

Cancer Weekly reports that **short course radiation is commonly used as a palliative measure for elderly cancer patients**, but "the lack of prospective trials tailored for these patients makes [it] even more difficult to tailor the choice of treatment on standardized treatment guidelines." More widespread use of radiation for these patients is controversial. The researchers concluded that, for some tumor types, radiation therapy "can be scheduled conveniently and effectively in order to achieve local disease control and/or symptom relief with the least discomfort and treatment-related morbidity for elderly patients." (Critical Reviews in Oncology Hematology, 2003;45(3):305-311); (HNN)

The National Board for the Certification of Hospice and Palliative Nurses (NBCHPN) is developing a new certification examination for **LPNs and LVNs**. Target date for the examination is September 2004. LPNs and LVNs interested in the exam may write [nbchpn@hpna.org](mailto:nbchpn@hpna.org) or call 412-787-1057 to be added to the mailing list. (NBCHPN News Release, 5/20); (HNN)

The current issue of Innovations in End-of-Life Care is the second of a two-part series focused on **advance planning**. The online issue is at [www2.edc.org/lastacts/crntissue.asp](http://www2.edc.org/lastacts/crntissue.asp). (Innovations in End-of-Life Care, May-June/2003); (HNN)

JAMA published an article on **patterns of functional decline at the end of life**. Four illness trajectories were studied - sudden death, cancer death, death from organ failure, and frailty. Frail elders were eight times more likely to be dependent in activities of daily living than those who died suddenly. The study found much variation in trajectories of functional decline, and concluded that "differentiating among expected trajectories and related needs would help shape tailored strategies and better programs of care prior to death." (JAMA, 2003;289:2387-2392); (HNN)

**A sense of spiritual well-being may lessen despair and hopelessness for dying patients**. This is one of the findings of a study by Barry Rosenfeld, professor of psychology at Fordham University. The role of spirituality in coping with terminal illness is becoming increasingly recognized, says Rosenfeld. His study focused on 160 cancer patients in a New York hospice. (WebMD Medical News, 5/8); (HNN)

A team from Yale University has developed a new assessment tool, the **Stressful Caregiving Adult Reactions to Experiences of Dying**, for evaluating persons caring for terminally ill family members or friends. Dr. Holly Prigerson says, "What we're saying is that simply watching a loved one suffering has its own, discrete negative psychological consequences that can affect the caregiver's well-being. What we need to do is take a step back and think about how we can help them deal with the mental health aspect of their experience." (Health Newswire Professional, 5/13)

David E. Weissman, MD, director of palliative care at the Medical College Wisconsin and co-director of EPERC, is coordinating a program to encourage **national residency programs to incorporate palliative care and end-of-life training into their curricula**. Eighty programs are being recruited for the 2003-2004 calendar year. For more information, contact Rose Hackbarth at [rhackbar@mcw.edu](mailto:rhackbar@mcw.edu), or call 414-805-4607. (Last Acts E-Newsletter, 4/15); (HNN)

"A Family Undertaking," a new documentary film by Elizabeth Westrate, examines the complex issues surrounding the growing popularity of **home funerals**. The film also goes behind the scenes of the American funeral industry. It will air on public television in the near future. For more information, see [www.fivespotfilms.com](http://www.fivespotfilms.com). (Five Spot Films Website); (HNN 6/17)

Families of **Alzheimer's patients** are going online to order memantine, a drug that blocks a brain chemical, glutamate, which has been implicated in nerve cell death. Forest Laboratories has licensed it in this country, and has applied for FDA approval. Meanwhile, several companies in Europe supply the American market. German physicians consider memantine safe, and it has been in use in Germany for years. A recent NEJM article detailed

a study that indicated that memantine might slow the decline of Alzheimer's patients. (The Houston Chronicle, 6/15); (HNN 6/17)

### **Pain Information**

The JCAHO website has made available **two monographs on pain**, "Pain: Current Understanding of Assessment, Management and Treatments," and "Improving the Quality of Pain Management Through Measurement and Action Both are available to read online or download from [www.jcaho.org](http://www.jcaho.org). Click on "News Room," then on "Health Care Issues" and scroll down to "Pain Management." (JCAHO Website); (HNN)

The June issue of **Pain Medicine is online**. Abstracts are free, full articles require a paid subscription. Articles include opioid use in terminal cancer patients and evaluation of a screening tool for treating addicted and non-addicted patients with opioids. See the abstracts at [www.blackwell-synergy.com/links/toc/pme/4/2](http://www.blackwell-synergy.com/links/toc/pme/4/2). (Pain Medicine, 6/2003); (HNN)

Research into sunburns has found a **new pain control mechanism** in the body and believe it may someday lead to treatment for pain from such diseases as arthritis and shingles. Scientists investigating why inflammation makes nerve cells more sensitive to heat found a molecule called PIP2, which inhibits the movement of pain signals by blocking the movement of sodium and calcium. Inflammation destroys PIP2, making it easier for pain signals to reach the brain. A Johns Hopkins researcher says that drugs could conceivably be developed which would treat pain by regulating that control point. (Houston Chronicle, 6/5); (HNN)

Earlier studies suggested that **pain relievers** such as NSAIDs might slow or prevent **Alzheimer's disease**, but a recent study at Georgetown University found that a year of treatment with Vioxx or Aleve left patients no better off than those who took placebos. Neil Buckholtz, chief of the National Institute on Aging's division of dementias in aging, says that NSAIDs might still prevent the development of the disease in the first place. The study was conducted, in part, because some people who use a lot of NSAIDs, like those with arthritis, seem to be less prone to developing Alzheimer's. (The Houston Chronicle, 6/3); (HNN)

Past teleconferences of **Cancer Care**, available for online listening, include "Strategies to Improve Assessment and Management of Breakthrough Pain." Go to [www.cancercare.org](http://www.cancercare.org), click on Educational Programs under "For Professionals." Scroll down to Professional Education Teleconference Listings and click on it, then scroll to and click on Listen to Previously Recorded Professional Teleconferences. (Cancer Care Website, 4/15); (HNN)

Tylenol is sponsoring the Active Pain Council and a new website, [www.activepain.com](http://www.activepain.com), to educate Americans about dealing with active pain. The term is a new description for the aches and pains suffered after physical activity or exertion. The campaign coincides with the release of Tylenol's new pain medication, Tylenol(r) 8 Hour, an extended release medication that provides eight hours of relief with just one dose. (Active Pain Council); (HNN)

A study of chronic pain sufferers among patients in methadone maintenance treatment programs found that chronic severe pain is "prevalent" among persons in substance abuse treatment programs. One problem is that substance users enrolled in free drug-

treatment programs tend to self-medicate for pain with psychoactive drugs. The study calls for the development of comprehensive and structured pain management programs in substance abuse programs. (JAMA, 2003;289:2370-2378); (HNN)

Washington University School of Medicine researchers have found that terminally ill **children with neuropathic pain** in the last days of life require more opioids than those without neuropathic pain. Additionally, a cocktail of several narcotics was more effective than simply increasing the dosage of morphine and benzodiazepine, two commonly used opioids. (Cancer Weekly, 5/13; Journal of Pediatrics, 2003 Apr;142(4):373-6); (HNN)

### **Education**

**June 25-29, 2003**

**Principles and Practice of Pain Medicine**

Location: Boston, MA

Sponsor: Harvard Medical School; Dept. of Continuing Education, Dept. of Anesthesia and Critical Care & Beth Israel Deaconess Medical Center. Email: [hms-cme@hms.harvard.edu](mailto:hms-cme@hms.harvard.edu)  
Web: [www.med.harvard.edu/conted](http://www.med.harvard.edu/conted)

**August 8-9, 2003**

**Clinical Review for the Generalist Hospice and Palliative Nurse**

Ramada Inn, Auburn, MA

Sponsor: Hospice & Palliative Care Federation of MA.  
(781) 255-7077 or e-mail [hospicefed@aol.com](mailto:hospicefed@aol.com)

**September 12-14, 2003**

**Second annual Dementia Congress** will be held in Washington, DC. The conference, which has no registration fee, is hosted by the Academy for Healthcare Education, the UCLA Center on Aging and the Alzheimer's Association. See [www.dementiacongress.com](http://www.dementiacongress.com) for more information. (Dementia Congress website)

**October 2, 2003**

**NHHPCO/NHCPI Annual Conference**

**Pain and Beyond: 2003**

Geneva Point, Center Harbor, NH

1-877-646-7742

[www.nhho.org](http://www.nhho.org)

### **Public Policy Notes**

A debate at a meeting of the American Pain Society in Chicago on whether opioids should be used for treating non-cancer chronic pain drew a full house. Steven Passik, PhD, is director of the symptom management and palliative care program at the Markey Cancer Center at the University of Kentucky. Passik asserts that opioids are safe for non-cancer chronic pain if they're given to the right patients in the right treatment setting. R. Norman Harden, MD, director for the center for pain studies at the Rehabilitation Institute of Chicago, opposes it, saying that the risks of adverse events and addiction are too high, and there are many alternatives. Both arguments are online at [www.medicalpost.com](http://www.medicalpost.com). Click on "Back Issues" and choose the April 22, 2003 issue. (Medical Post, 4/22); (HNN)

## Cancer Centers Demonstrate Palliative Care Models

Promoting Excellence in End-of-Life Care, a RWJF program, in partnership with the National Coalition for Cancer Survivorship, has issued *Living and Dying Well With Cancer: Successfully Integrating Palliative Care and Cancer Treatment*. The booklet summarizes the philosophies and programs of four centers. These centers, the authors believe, have built new delivery models that are proven "feasible, well accepted and clinically effective." Dr. Kathleen M. Foley says that the "results demonstrate that concurrent palliative care and treatment are possible, are desirable, are implementable, and they work." The authors note that the projects were finished in 2002 and that the data are still being studied. Findings in the monograph should be considered preliminary. But, while sample sizes were often too small to generalize to larger settings, the "results are intriguing in a hopeful way that demands broader study."

The Ireland Cancer Center in Cleveland and the Hospice of Western Reserve collaborated on Project Safe Conduct to provide palliative care for lung cancer patients who are being actively treated for cancer. The hospice team was fully integrated into the cancer center, wearing badges that identified them as ICC staff. The interdisciplinary team had to overcome a number of barriers such as helping ICC staff learn to embrace the role of the family; finding hospice workers who could function in an acute care setting; and learning to function as an interdisciplinary team rather than a multidisciplinary one.

The results were impressive, with hospice referrals increasing from 13% to 80%, and the average length of hospice stay from 10 days to 43 days. The number of hospital admissions per patient per year dropped from 3.20 to 1.05. Unplanned hospitalizations and ER visits went from 6.3 per patient to 3.1. Average per day pharmaceutical costs dropped from \$60.90 per patient to \$18.45. Preliminary data from the Missoula-VITAS Quality of Life Index suggests that patient perceptions of the Safe Conduct program may be as good as or better than those for hospice.

The University of California at Davis focused on palliative care for patients in clinical trials. One result of the study is that it determined that patients in clinical trials are interested in end-of-life issues. Receiving palliative care did not change compliance with treatment routines.

Surveys measuring quality of life issues found quality increases for patients receiving palliative care and decreases for those who did not, though the differences were small. Ninety-two percent of those receiving palliative care were referred to hospice, versus 53% of those who did not. The authors say "the study suggests that clinical trial patients would likely choose hospice services during far-advanced stages of illness if health care professionals supported and introduced the palliative care to them."

The Comprehensive Cancer Center at the University of Michigan and Hospice of Michigan jointly worked on a clinical trial to compare the outcomes of patients with standard cancer care with those who had standard care and additional palliative services. Preliminary data found, unexpectedly, that patients who receive palliative care may actually live longer. Additional benefits are improved quality of care, reduced caregiver burden, and a reduction in the cost of care.

One lesson the staff learned early on was that patients and families want ongoing treatments despite the odds. Two-thirds of eligible patients chose not to enroll in the study. Those that did wanted to be identified as palliative care patients, not hospice patients.

The project found many of the same benefits as the one at UC Davis but documented more carefully the cost savings. The average cost of care for patients receiving palliative care was \$12,682, with an average length of life of 266 days, compared to \$19,970 and 227 days for those receiving standard care. However, when the project ended, so did the access to concurrent palliative care because of uncompensated costs of care to Hospice of Michigan (HOM), which was more than \$1.5 million over budget. The savings went to Medicare and other payers. A HOM spokesman says, "even though providing these services is the right thing to do, we have stopped, because we can't afford it. There is no reimbursement stream for what we are doing."

Dartmouth's Norris Cotton Cancer Center (NCCC) and the Hospice of Vermont and New Hampshire sponsored Project ENABLE (Educate, Nurture, Advise, Before Life Ends) to bring palliative care to advanced cancer patients living with poor prognoses. The project ran at three sites - NCCC, a physician practice, and a rural hospital. The project was so successful at the practice and NCCC that those sites continue to provide concurrent care after the end of the study. The rural hospital encountered a number of difficulties unrelated to the project, so no definitive conclusions can be drawn about whether ENABLE would work in a setting with relatively few cancer patients.

Patients participated in "Charting Your Course" workshops, modeled after childbirth classes. The workshops gave participants information and tools for dealing with the healthcare system and taught them strategies for communicating with healthcare providers. The participants were enthusiastic about the workshops, rating them at a 1.5 on a 5-point scale where 1 was the highest grade. One participant said, "Keep those workshops going. They made us talk about things we never would have touched. They really helped."

In summary, the authors say that clinicians in the projects discovered that "cancer treatment and palliative care do go together." "They became enthusiastic supporters of the concurrent models because they saw it improve the quality of care for their patients, thereby enhancing their own professional satisfaction as well." The differences between palliation and treatment were found not to be insurmountable, and dealing with end-of-life issues didn't detract from compliance with ongoing treatments. Ellen Stovall, president and CEO NCSS, says, "The simplicity of these lessons poses a question about providing care any differently."

See [www.promotingexcellence.org/content/cancer.html](http://www.promotingexcellence.org/content/cancer.html) to read the monograph online, or to download it. (Promoting Excellence in End-of-Life Care website); (HNN)

<b>NHHPCO Meetings - 2003</b>	
NHHPCO Full Board	Contact Sue DiBona at 1-877-646-7742-
NHHPCO Executive Board	Contact Sue DiBona at 1-877-646-7742
NHCPI Committee	Contact Sue DiBona at 1-877-646-7742
Volunteer Coordinators	Contact Lorraine Bishop at Home Healthcare, Hospice & Community Services, (603) 352-2253
Social Workers – Homecare/Hospice	Contact Charlene Thayer, (603) 622-3781
Chaplains Supervision Group	At VNA Manchester. Contact Chan Newton, (603) 695-4005.
Physicians	Contact Pat Clary MD, (603) 692-4018 ext.303.
Patient Care Coordinators/Managers	Contact Susan Herrmann HCS, Keene 1-800-541-4145 ext 192
Bereavement Coordinators	Contact Jeanne Emerson, (603) 332-1133
Seacoast Regional Meeting	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.

### **Websites**

Making the Link," a new program developed by the **National Association of Area Agencies on Aging** (n4a), is designed to help physicians identify caregivers and refer them to services offered by Area Agencies on Aging (AAAs). More information is available at [www.n4a.org](http://www.n4a.org). (E-Mail from Les Plooster, National Alliance for Caregiving, 5/28); (HNN)

Growth House Radio provides **music and educational features on end-of-life care** over the Internet. Links on the site take the reader to music thanatology, hospice and palliative care, and information on pain, grief, and death with dignity. Windows Media Player is required. See [www.growthhouse.org/radio.html](http://www.growthhouse.org/radio.html) for more information. (Growth House Radio); (HNN)

Last Acts and NHHPCO Place **New Web Content Online**. NHHPCO's redesigned website is now online at [www.nhhpco.org](http://www.nhhpco.org). The Global Leadership section tells of NHHPCO's recent participation in the first ever meeting of national and international hospice and palliative care associations in The Hague. The attendees, including representatives from 25 countries, several funding organizations and governmental groups, discussed needs and opportunities for worldwide development of hospice and palliative care. (HNN)

Last Acts recently added a **Palliative Care Resource Center** to its website at [www.lastacts.org/palliativecare/](http://www.lastacts.org/palliativecare/). It offers resources for administrators, advocates and clinicians in hospitals, nursing homes, hospices and long-term care facilities. One of its features is the Promising Practice of the Day, which lists innovative ways to deliver end-of-life care. Another is a section with documents on principles of palliative care. Last Acts' report, "On the Road From Theory to Practice," may be downloaded and links to other palliative care resources are available. (Last Acts) (HNN)

A webcast and a written transcript of "**Hidden Costs, Value Lost Uninsurance in America**" is online at [Kaisernetwork.org](http://Kaisernetwork.org). This is the fifth in a series of six reports on the consequences of uninsurance in the US Click on Healthcast at [www.kaisernetwork.org](http://www.kaisernetwork.org) and scroll down to the report. (Kaisernetwork.org, 6/17) (HNN)

Dignity Resources has a new website designed to help people understand the **resources and financial options** available to them during serious illnesses, and to assist them in making informed decisions appropriate to their circumstances. A number of links explain insurance provisions, such as accelerated death benefits, adjusting insurance coverage, avoiding policy lapses, and loans. See [www.dignityresources.com](http://www.dignityresources.com) for more information.(Dignity Resources) (HNN)

**Doctors following pain guidelines shouldn't fear boards.** The American Medical News recently reported on three studies that each send the same message to doctors: "Don't fear discipline from medical boards or criminal prosecution if you follow pain guidelines and appropriately prescribe medications."

- One survey of 38 medical boards found that "boards were abandoning drug quantity as a marker of questionable practice and assessing instead whether a doctor properly evaluated a patient and followed the board's pain-treatment guidelines."
- A study of county prosecutors in three states reported that the likelihood of investigation or prosecution was "extremely low."
- The third study found an increased number of boards that had adopted pain-management guidelines, recommended better training on pain standards for investigators, and worked toward better circulation of guidelines to physicians.

The studies are reported in the current issue of the Journal of Law, Medicine and Ethics (see HNN, 5/13). The article is online at [www.amednews.com/content/pick\\_03/prsc0616.htm](http://www.amednews.com/content/pick_03/prsc0616.htm). (American Medical News, 6/16) (HNN)