

Quality of Life Matters®

End-of-life care news & clinical findings for physicians

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VA Expands Hospice Benefit for Dying Veterans

Goals Include Providing Hospice Care to Patients Earlier in Their Disease Progression

The federal Department of Veterans Affairs (VA), the largest integrated health care system in the nation, has released a report on advances achieved in its national efforts to provide expert, supportive end-of-life and palliative care for veterans on a system-wide basis.

Entitled “VA Transforms End-of-Life Care for Veterans,” the report was released as a joint project of the VA and the National Hospice and Palliative Care Organization (NHPCO) in February 2005.

“For the national VA system, recent advances in developing, refining, and expanding hospice and palliative care — an approach aimed at bringing hospice’s holistic, comfort-oriented care philosophy to seriously ill patients earlier in their disease progression — are not mere frills,” states the report.

AT A GLANCE:

- An estimated 1,600 veterans die each day in the United States; most served in World War II and are approaching the end of their natural life span
- Veterans now comprise about 28% of all national deaths each year
- Availability of quality, compassionate care through hospice is now mandated nationwide for dying veterans and their families
- Home hospice care is included in the VA budget for the first time, thanks to partnerships with local/regional/state hospice providers

That is because of the large number of veterans, most of whom served during World War II, now approaching the end of their natural life spans, the report notes.

Key statistics:

- An estimated 1,600 veterans die in the United States each day
- Veterans were projected to account for 28% of all national deaths in 2004

As part of its system-wide transformation aimed at providing quality, compassionate care for dying veterans and their families, the VA has not only issued directives mandating hospice and palliative care, but has also developed a national network of state and local hospice-veteran partnerships, according to Thomas Edes,

Continued on Page 2

Inside:

NewsLine 2-3

- ✓ DEA Plans Official Policy Statement on Prescription Pain Medications

Research Monitor 4-5

- ✓ Short Hospice Stay Increases Caregiver Risk of Post-Loss Depression
- ✓ Referring Patients for Spiritual Care: Practical Advice for Clinicians
- ✓ End-of-Life Care Content in National Clinical Guidelines Found Lacking

Physician Resources 6-7

- ✓ Tips for Preparing for End-of-Life Care Discussions with Patients
- ✓ PDA Downloads for Clinicians

Bereaved Families Wish They Had Known Extensive Benefits of Hospice Sooner

Physicians Urged to Refer Patients to Hospice Earlier

Once a patient enrolls in hospice, 99% of patients and their families discover features of hospice care that they consider valuable and that would have motivated their decision to enroll earlier, a team of Philadelphia researchers has found.

“By providing more information about hospice earlier in the illness course, clinicians may be able to facilitate more-informed and more-timely decisions about hospice enrollment,” write the authors of a report published in the November 2004

issue of the *Journal of the American Geriatrics Society*.

The researchers analyzed the interview responses of 100 family caregivers (female, 73%; white, 84%) of 100 patients (cancer as admitting diagnosis, 44%; median length of stay, 12 days) who had died in hospice two months earlier in one of three United States locations where the full range of hospice services is available.

The bereaved caregivers identified those

Continued on Page 3

UPDATE: DEA Plans Official Policy Statement on Prescription Pain Medications

State Attorneys General Call for Balanced Approach to 'Alleviate Suffering, Particularly at the End of Life'

The federal Drug Enforcement Administration (DEA) announced that it would take into consideration written input from physicians, pharmacists, and other interested parties as it prepared a document reiterating its role in administering the Controlled Substances Act with regard to the medical treatment of pain.

The notice was posted in the January 18, 2005, *Federal Register*, following the DEA's retraction of its support for a collaborative educational document developed to foster mutual understanding between medical professionals and law enforcement personnel, which was authored jointly by the DEA, the Pain & Policy Studies Group at the University of Wisconsin, and the Last Acts Partnership.

No revision of this joint document is currently planned. The DEA noted that its own upcoming document will recap existing legal concepts "to provide guidance and reassurance

to the overwhelming majority of physicians who engage in legitimate pain treatment while deterring unlawful prescribing and dispensing of pharmaceutical controlled substances."

A January 19, 2005, letter to the DEA administrator, signed by 30 members of the National Association of Attorneys General (NAAG), expressed concern that the DEA appeared to have shifted its policy in regard to balancing the provision of effective pain management with the prosecution of those who divert and abuse drugs.

"We believe this balance is very important to our citizens, who deserve the best pain relief available to alleviate suffering, particularly at the end of life," the letter stated.

The DEA notice "Solicitation of Comments on Dispensing of Controlled Substances for the Treatment of Pain" is available at www.deadiversion.usdoj.gov/fed_regs/rules/2005/fr0118.htm.

The NAAG letter to the DEA can be accessed at www.naag.org/news.

VA Expands Hospice Benefit for Dying Veterans

Continued from Page 1

MD, MS, the chief administrator overseeing the transformation.

"Hospice is now a covered benefit for all enrolled veterans, home hospice care is in the VA budget for the first time, and we have a national standard for purchasing hospice care from community providers," says Edes.

New national policy and standards for VA medical centers include:

- Provision of needed hospice services in all settings
- Inpatient hospice beds or access to them in the local community
- Referral assistance to area community hospices
- A designated hospice contact person responsible for local and national communications and for information distribution
- An interdisciplinary palliative care consult team
- Tracking of hospice services provided in all settings

The VA is also addressing the challenge of "changing the medical culture" at its facilities, notes the report, so that staff will have the information and training needed to feel comfortable discussing death and dying with patients as part of routine advance care planning and to refer patients to hospice and palliative care.

"I am concerned that in the past far too many veterans have suffered quietly, graciously accepting far less than the services they rightly deserve," comments Edes. "But we are raising expectations at the national and local levels, so that a terminally ill veteran can go to any VA facility and obtain hospice care. If needed hospice care is not forthcoming, we want them to contact us. And we now have champions working in every VA facility, so we are getting closer to our target."

A copy of the report is available at www.nhpco.org. For more information on VA end-of-life care initiatives, visit www.hospice.va.gov.

Bereaved Families Wish They Had Known Extensive Benefits of Hospice Sooner

Continued from Page 1

aspects of hospice care that they knew about beforehand and that were most influential when making the decision of whether to enroll.

These features of hospice care important to patients and family included:

- The availability of **terminal care at home** (30%)
- A team with **expertise in pain and symptom management** (26%)
- **Services for caregivers** (20%)

However, most of the family members (99%) reported that after the patient had been enrolled they and the patient discovered unanticipated benefits of hospice care that they wished they had known about earlier. Key findings include:

- **39%** of family members mentioned the value to themselves and the patient of hospice-provided **spiritual and emotional support services**, which they had not previously known about or realized they needed. These included handling the arrangements at the time of death, the availability of a chaplain, and bereavement counseling.
- **31%** were surprised and pleased to learn that **help 24 hours a day** by phone was available from the hospice team, giving them a sense of security in case of emergency or if questions arose.
- **27%** of family caregivers had not known there would be a **visiting nurse**, whose regular presence also contributed to their sense of security.
- **27%** had not realized that the hospice team would provide **education** on physical care of the patient and on what to expect during the dying process.
- **25%** had not expected that hospice would handle the **coordination of care and services**, freeing family members from many logistical burdens and allowing them to spend more time with the patient.
- **24%** of caregivers had not known that hospice would provide **pain and symptom management**.

Of those family members (69%) who identified an unexpected medical event as prompting hospice discussion, the most common reasons for consideration of hospice care included:

- Escalating needs for home care (49%)
- A decision to withhold/withdraw life support (26%)
- Difficulty with pain and symptom management (23%)

While 51% of caregivers reported that discussion of hospice was initiated by the patient's physician, only 22% said they and the patient obtained their pre-enrollment information about hospice care from the physician. Discussions initiated by physicians were more likely to result in immediate enrollment than were discussions initiated by the patient, family, or others.

"Many family members did not recall a process of deliberation and careful consideration of hospice services, and 21% could not describe any features of hospice that motivated them to enroll," the authors write. "A consideration of potential benefits motivated their hospice choice less than did the perceived absence of alternatives."

The authors suggest that physicians can help improve the hospice referral process by describing hospice care during advance care planning discussions and by explaining the major features and benefits of hospice to both patients and their families.

"Clinicians would be able to describe the benefits of hospice enrollment more effectively if

they could highlight features of hospice that are most important to patients and families," comment the authors. "This might also decrease the discomfort that many clinicians experience when they initiate these discussions."

The authors note that "...physicians play a key role as gatekeepers in the hospice referral process."

Source: "How Should Clinicians Describe Hospice to Patients and Families?" Journal of the American Geriatrics Society; November 2004; 52(11):1923-1928. Casarett DJ, Crowley RL, Hirschman KB; Center for Health Equity Research and Promotion at the Philadelphia Veterans Affairs Medical Center; Center for Bioethics, Division of Geriatrics, Leonard Davis Institute of Health Economics; and School of Social Work, University of Pennsylvania, Philadelphia.

HOSPICE BENEFITS FOUND IMPORTANT TO PATIENTS AND FAMILIES

Aspects of hospice care that motivated enrollment include:

- ✓ Terminal care at home
- ✓ Pain and symptom management
- ✓ Caregiver support

Aspects of hospice care that would have motivated earlier enrollment include:

- ✓ Spiritual and emotional support
- ✓ 24-hour-a-day help by phone
- ✓ Regular visits by a nurse
- ✓ Patient/family education about physical care and the dying process
- ✓ Coordination of care and case management

— Casarett, Crowley, and Hirschman
Journal of the American Geriatrics Society

Short Hospice Stay Increases Caregiver Risk of Post-Loss Depression

Caregivers of patients with a hospice enrollment of three or fewer days before death are at an increased risk for subsequent major depressive disorder, “a disabling and costly disease for both the individual sufferers and society,” a team of researchers at the Yale School of Medicine has found.

‘Earlier hospice enrollment may help reduce the risk of major depressive disorder...’

— Bradley, Prigerson, et al
American Journal of Psychiatry

reavement,” write the authors in their report in the *American Journal of Psychiatry*.

The team conducted a prospective cohort study of 174 caregivers of hospice patients with cancer between October 1999 and September 2001. Participants were interviewed at hospice enrollment and at follow-up, six to eight months after

“Research on bereavement and depression has identified a lack of preparation for death as a risk factor for post-loss depression, and if fewer days of hospice care is related to inadequate preparation for death, then shorter hospice enrollment might be a risk factor for elevated caregiver depression during be-

the patient’s death.

Key findings include:

- 16.7% of patients received ≤ 3 days of hospice care; mean length of stay for all study patients was 34.7 days
- Caregivers of patients with ≤ 3 days in hospice were significantly more likely than caregivers of patients with longer stays to have post-loss major depressive disorder (prevalence rate, 24.1% vs 9.0% [fully adjusted odds ratio, 4.35; 95% confidence interval, 1.13-16.75])
- Caregivers of patients with ≤ 3 days of hospice care were first told by a physician that the disease was incurable 8.1 weeks before hospice enrollment, compared with 26.4 weeks for caregivers of patients with longer enrollments

“Earlier hospice enrollment may help reduce the risk of major depressive disorder during the first six to eight months of bereavement. Furthermore, those whose loved one dies within the first days of hospice enrollment might be a target group for bereavement interventions to alleviate the risk of subsequent major depressive disorder,” the authors conclude.

Source: “Depression among Surviving Caregivers: Does Length of Hospice Enrollment Matter?” *American Journal of Psychiatry*; December 2004; 161(12):2257-2262. Bradley EH, Prigerson H, Carlson MDA, Cherlin E, Johnson-Hurzeler R, Kasl SV; Department of Epidemiology and Public Health, Yale School of Medicine, New Haven, Connecticut.

Referring Patients for Spiritual Care: Practical Advice for Clinicians

Referral to Clergy Can Be As Routine As Referral to Other Colleagues

To the layperson, “cancer” is one of the most terrifying words in the English language, and a patient diagnosed with the disease experiences challenges and changes not only in the physical, psychological, and practical areas of life, but in the spiritual dimension as well.

That is according to the authors of an article published in the *Journal of Clinical Oncology*. While many oncologists feel confident addressing the first three issues, they may need help in knowing when and how to access the services of religious ministers or chaplains for the spiritual support of their patients.

“A physician or health care professional who shows interest in spiritual care expresses concern for the ‘whole person’ who has cancer,” the authors write. “Physicians should have the same confidence in referring their patients to clergy as they

do in referring them to other colleagues.”

The article offers advice on when in the course of cancer care to suggest spiritual support and how to introduce a referral to clergy or chaplains, explaining the distinctions between the two. Often just a simple screening question (“*What role does faith play in your life?*”) is needed to assess the dimension of patients’ spirituality and to help in guiding them to the support they may require throughout the cancer journey.

AT DIAGNOSIS OF CANCER physicians can suggest that patients who are members of a faith community involve their pastors. Some patients find the cancer experience to be both frightening and spiritually enriching; religious rites can act as powerful interventions, and even some nonreligious persons find

Continued on Page 5

End-of-Life Care Content in National Clinical Guidelines Found Lacking

An assessment of current treatment guidelines for nine common, chronic, life-limiting diseases has revealed that, while most disease-specific guidelines acknowledge the mortality of the illness, little clinical information on palliation or end-of-life care is presented.

A team of Pittsburgh researchers reviewed major national compendia to identify treatment guidelines on congestive heart failure, cancer (breast, colon, lung, prostate), cerebrovascular accident, chronic obstructive pulmonary disease (COPD), end-stage liver disease, end-stage renal disease, amyotrophic lateral sclerosis (ALS), human immunodeficiency virus, and dementia.

The resulting 91 guidelines were assessed and rated for the degree to which end-of-life and palliative care content was integrated into their information.

Overall, 10% of guidelines were classified as having significant palliative care content; 26% had moderate content; and 64%, minimal. Among the least addressed domains were physician advocacy (3%), spiritual issues (4%), ethics (10%), and family roles and responsibilities (11%). The highest percent-

KEY FINDINGS:

- Only 14% of guidelines advised physicians at what point in the disease course palliative care should be considered.
- While 91% mentioned death, dying, end of life, mortality, or terminal illness, only 36% mentioned palliation or hospice. The authors comment: **"...the lack of mention of hospice is worrisome."**
- Only 5% of guidelines addressed pain assessment and management in the context of end-of-life care.

— Mast, Salama, et al
Journal of Palliative Medicine

ages of guidelines with significant palliative care content included those on ALS, dementia, renal disease, and COPD.

"Some of the diseases with the worst prognosis (e.g., cancer) had the least end-of-life content," write the authors. It could be that physicians are expected to learn about end-of-life care from other sources, such as stand-alone palliative care guides, they note, but **"the lack of clear criteria for when these [palliative care] guidelines should be integrated into patient care means that, like hospice, they are likely to be referred to only when the patient is actively dying."**

The authors add, "Guidelines should provide advice on when... the probability of increased mortality or decreased quality of life should lead the doctor and patient to reassess their goals and to think about a more palliative emphasis."

Source: "End-of-Life Content in Treatment Guidelines for Life-Limiting Diseases," Journal of Palliative Medicine; December 2004; 7(6):754-773. Mast KR, Salama M, Silverman GK, Arnold RM; Mercy Hospital, Pittsburgh; The Western Pennsylvania Hospital, Temple University School of Medicine, Pittsburgh; and University of Pittsburgh School of Medicine.

Referring Patients for Spiritual Care

Continued from Page 4

that prayer is much appreciated. "Many of my patients find the support of their clergy or rabbi to be helpful at this time. I suggest that you call him or her."

DURING THE COURSE OF TREATMENT physicians can check on their patients' spiritual status. "How is the treatment affecting you?" Or, "What sense do you make of this experience?" Patients may be struggling with self-image or self worth due to changes in appearance and social or family roles.

AFTER COMPLETION OF TREATMENT patients may wish for spiritual support in expressing their thanksgiving or joy. Nonetheless, a chaplain or minister might check in with patients every two weeks to monitor for signs of possible stress or anxiety.

AT CANCER RECURRENCE physicians can refer patients to professional chaplains, who are trained to help people find

realistic hope in the midst of tragedy and to "be present" during spiritual suffering. "I can see how distressed you are, and I'd like to ask the chaplain who works with me to see you. She has experience and training beyond what I can offer. Many of my patients have found her to be helpful."

"Because spiritual support is a routine and expected component of comprehensive care during the last months of life, hospice care requires the participation of trained chaplains," comment the authors.

In closing, the authors offer the following quotation: "The most precious possession any human being has is their spirit, their will to love, their sense of dignity and personality. **Though technically we may be concerned with tendons, bones, and nerve endings, we must not lose sight of the person we are treating."**

Source: "Addressing Spiritual Care: Calling Help," Journal of Clinical Oncology; December 1, 2004; 22(23):4856-4858. Steer JC, Lee C; First Baptist Church, Rochester, Minnesota; The Royal Marsden Hospital, London, England.

PHYSICIAN RESOURCES

Tips for Preparing for End-of-Life Care Discussions with Patients

Physician preparation for discussing end-of-life and hospice care with patients who are terminally ill “is the key to helping patients and families during this time of transition, loss, and change,” according to a team of Florida end-of-life care experts.

“The ability to compassionately communicate difficult or ‘bad’ news to a patient and family is essential to the provision of quality care at the end of life,” write the authors in *The American Journal of Geriatric Cardiology*. “**In preparing our patients for the end of their journey, we will serve best when we prepare ourselves.**”

More than 90% of Americans want to know if their disease is terminal and desire clear and accurate information about it, the authors note. Their article explores a “deliberate approach” physicians can use to prepare themselves to initiate and conduct an end-of-life conversation with their patients.

Understand your own attitudes towards death and dying

The authors suggest that physicians first ask themselves what they mean by “the end of life,” and explore their own thoughts and feelings about death and dying. Self-awareness will allow physicians to monitor personal attitudes that may unconsciously interfere with the ability to talk comfortably to patients. “Your ability to project your comfort and confidence supports the pa-

tient and family while clearly communicating your desire to offer hope, support them, and assure their comfort,” they write.

Become aware of palliative care and hospice options

Prior to introducing the topic of end-of-life care with patients, physicians would do well to familiarize themselves with the hospice and palliative care resources available in their community. The authors recommend hospice as a valuable option for quality palliative care.

Know when to think about hospice

For patients with life-limiting diseases that do not follow the typical cancer trajectory, it can be difficult to predict six-month survival. The decision to begin hospice care will be influenced by the general physical status of the patient, the patient’s goals of care, concurrent comorbidities, and the response to treatment. Certain patient situations can also indicate the need for a hospice assessment. [See sidebar.]

Introduce the topic of end-of-life care with compassion

Hospice can be introduced in a caring manner by validating patients’ and families’ questions, concerns, and fears, and by assuring them that the physician will continue to support them. A physician might say:

“There is a service in our community that I collaborate with to help patients and families during this time that I would like you to consider. It is called hospice care, and my patients and families have told me that it has been very helpful. May I ask them to come and talk with you to explain their services? If you are not sure, you can always decide later whether you want their help.”

One way for physicians to broach the topic of palliative care earlier in the course of a noncancer, life-limiting illness is to review an existing living will with the patient and family. If no living will exists, physicians can suggest that one be completed.

“I’d like to talk about the future, to give you time to think about some things and to make some decisions. As your disease progresses, you may be faced with decisions about what type of care you do or do not want. It is important to think about these possibilities before a crisis occurs and let your family know your wishes. This could be a gift to your family, so that they will not be faced with having to guess what your wishes would be.”

Source: “Breaking the ‘Bad’ News to Patients and Families: Preparing to Have the Conversation about End-of-Life and Hospice Care,” *The American Journal of Geriatric Cardiology*; Nov-Dec 2004; 13(6):307-312. Arnold RL, Egan K; *The Hospice Institute of the Florida Suncoast, Largo, Florida.*

WHEN TO CONSIDER HOSPICE CARE

- The patient has sought treatment in an emergency room or been hospitalized for a disease-related episode twice in the past year
- The physician is receiving an increased number of calls and requests from family caregivers
- Family members appear to be overburdened with or fatigued by caregiving
- After hospitalization, the patient cannot return home and is admitted to a nursing facility
- The patient has had a weight loss of 10% or more in the past six months
- The patient’s appetite has been steadily declining, unrelated to any other medical condition

— Arnold and Egan
The American Journal of Geriatric Cardiology

PHYSICIAN RESOURCES

PDA Downloads for Clinicians

More than 40% of practicing physicians own a personal digital assistant (PDA) — up from just 19% in 2001 — according to a report in the January 17, 2005, issue of the *American Medical News*, a publication of the American Medical Association.

Below are two medical reference resources physicians and other clinicians can access free of charge and download to their PDAs.

'FAST FACTS' ON END-OF-LIFE CARE

A current collection of Fast Facts and Concepts, the brief, peer-reviewed summaries of clinical information on end-of-life care topics stored on the End of Life/Palliative Education Resource Center (EPERC) website, is now available for free download to PDAs.

Included with the Fast Facts are the documents "Medicare: Hospice Eligibility" and "Medicare: Hospice Manual." When viewed on the EPERC website, the one-page Fast Facts can also be printed or downloaded as text or PDF files.

Recent titles in the Fast Facts index include:

- Pediatric Pain Assessment Scales
- Pain Assessment in the Cognitively Impaired
- Substance Use Disorders in the Palliative Care Patient
- Physicians and Prayer Requests

To download all current Fast Facts to a PDA, go to www.infigo.com/mninfo.htm. To access the complete listing of Fast Facts as a text or PDF file, go to www.eperc.mcw.edu.

OPIOID CONVERSION TOOL

The Hopkins Opioid Program, a medical conversion tool for use on a PDA, is offered free online to clinicians by the Sidney Kimmel Comprehensive Cancer Center at the Johns Hopkins Center for Cancer Pain Research.

The tool was designed to facilitate appropriate conversions from one opioid or route of administration to another, using standard conversion information drawn from such sources as: peer-reviewed literature; the Physicians' Desk Reference; and patient care guidelines published by national organizations dedicated to promoting quality health care for patients with cancer.

Features include:

- A complete listing of pain medications used in hospitals
- Information on dosage forms available in pharmacies
- Cautionary notes regarding drug choices
- References to more comprehensive information
- A glossary of abbreviations

The program was developed by neuro-oncologist Stuart Grossman, MD, and colleagues. Grossman, who is director of the Kimmel Cancer Center's Cancer Pain Service, notes that more than 90% of cancer patients identify pain as one of their top concerns.

"If a patient is not getting relief on a particular medication, it is common for his physician to switch him to a stronger pain medication," Grossman notes. "Some physicians encountered problems with calculations that convert the patient's current medication to a more potent pain reliever, and patients ended up receiving less total pain medication than they were getting from the original ineffective drug."

For more information, visit www.hopkinsopioidprogram.org.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

The EPEC Project (Education on Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Center for Palliative Care Studies

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/pallmed/

Palliative Medicine Program at the Medical College of Wisconsin

www.medsch.wisc.edu/painpolicy/

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

www.growthhouse.org

An online community for end-of-life care

End-of-Life Care Meetings for Clinicians

Opening Doors, Building Bridges. August 1-3, 2005, St. Louis, MO. Sponsors: National Hospice and Palliative Care Organization and Missouri Hospice and Palliative Care Association. First National Conference on Access to Hospice and Palliative Care. Phone: 703-837-1500; Email: conferences@nhpco; Website: www.nhpco.org/access2005

Leading with Passion: Revolutionizing End-of-Life Care. September 22-24, 2005, Hollywood, FL. Sponsor: National Hospice and Palliative Care Organization. 20th Management and Leadership Conference. Phone: 703-837-1500; Website: www.nhpco.org/mlc2005

Kaleidoscope: Dialogue & Diversity in Hospice Palliative Care. September 25-28, 2005, Edmonton, Alberta, Canada. Sponsors: The Canadian Hospice Palliative Care Association and The Palliative Care Association of Alberta. Phone: 613-241-3663; Email: info@chpca.net; Website: www.chpca.net

Children's Hospice International's 17th World Congress. September 29-October 2, 2005, Salt Lake City, UT. Phone: 800-242-4453; Email: info@chionline.org; Website: www.chionline.org

Annual Assembly of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. February 8-11, 2006, Nashville, TN. Phone: 847-375-4712; Fax: 877-734-8671; Email: info@aahpm.org; Website: www.aahpm.org

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