

Hospice Community Applauds Dementia Care Recommendations for End-of-Life Care Released by Alzheimer's Association

*NHPCO's Lund Person Speaks at
Alzheimer's Association Conference
in Chicago*

(Alexandria, Va) – The Alzheimer's Association released its third set of recommendations on improving care for people with Alzheimer's and other dementias – this set of recommendations focuses on care at the end of life. Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, offers concrete suggestions for addressing issues unique to people with dementia at the end of their lives.

The National Hospice and Palliative Care Organization is one of many national organizations supporting these recommendations. NHPCO extends its thanks to the Alzheimer's Association for addressing the needs of people at life's end and applauds its collaborative efforts in this ongoing work.

This new set of recommendations was released at the Alzheimer's Association's 15th annual Dementia Care Conference held in Chicago where Judi Lund Person, NHPCO vice president for quality, was a panelist at the opening plenary session.

"The mission of the Alzheimer's Association is consistent with that of NHPCO. Everyone living with Alzheimer's or other forms of dementia should be

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**SUMMARY BY JOHN C. TANGEMAN,
MD, FACP, HOSPICE STAFF PHYSICIAN**



John C. Tangeman, M.D., FACP

Recent Study Shows Palliative Care Shortens ICU Stays Without Adversely Affecting Mortality

A recent study in the *Journal of Critical Care Medicine* (2007, Volume 35, pp 1530-1535) examined the effect of proactive palliative care consultations on the length of stay and outcomes of high risk patients in the medical intensive care unit.

The University of Rochester study identified 191 patients as being seriously ill and at high risk for death. Two groups were formed; 65 patients received "usual care" and 126 patients received proactive palliative care consultation. In the usual care group, palliative care consultations occurred when requested by the attending physician. In the study group, a palliative care team consulted and followed these patients and their families proactively. Palliative care consultations provided patient/family centered care directed at improving the patient's quality of life through excellent pain and symptom management, goal clarification, assistance with medical decision making and support.

This study found that patients in the proactive palliative care intervention group had a significantly shorter ICU length of stay when compared to the "usual" care group, 8.96 days compared to 16.28 days. There were no differences between the groups with respect to mortality rates (55% vs. 59%), discharge disposition or total hospital length of stay.

Decreasing ICU length of stay has several potential implications for the hospital and the patient, including significant financial savings for the hospital. Enhanced patient comfort and improved communication regarding benefits vs. burdens of treatment allowed many patients and their families to decide to forgo unwanted or futile therapies. Traditionally, palliative care consultations tend to be initiated late in the hospital course, often after all aggressive treatments have failed, sometimes over weeks. This study underscored the need to consider palliative care input early in a serious illness, particularly when there are uncontrolled pain or other distressing symptoms. The palliative care consult team can also be very helpful in facilitating family discussions involving complex medical decisions.

The Palliative Care Physicians Group provides palliative care consultations at several WNY hospitals, including Buffalo General, Millard Suburban, and South Buffalo Mercy, with hopes of adding services at other area hospitals in the future. A palliative care consultation may be obtained by calling (716) 362-0505.

The **"Self Portraits"** holiday card was created by children served by Roswell Park and the Essential Care for Children program, a pediatric program of Home Care Buffalo, through The Center for Hospice and Palliative Care. The net proceeds from this card's sale will support both cancer research and medical and supportive services for children and families who are facing life-threatening illness.

A pack of 15 colorful cards (order #P1107) are \$10.50. To order call 800-959-5931 or go online to www.paintboxproject.com/Home/Catalog/HolidayCollection?ProductSKU=P1107.

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Local Hospices & VA Working Together to Help Veterans at End of Life

More than 1,800 veterans are dying every day but not much is known about end-of-life issues for this special population. The vast majority of veterans do not receive their health care from the VA but community healthcare providers and organizations often don't know who they are or how to reach out to them.

While significant barriers exist, the Hospice Veterans Partnership (HVP), a national initiative, is working to overcome barriers through communication and collaboration. According to the Veterans Administration, the number of veteran deaths reached an all-time high in 2006 of 687,500 veterans. At least 600,000 deaths a year are expected to occur through 2016. Only about 4% (approximately 23,000/yr) will occur in VA facilities. HVPs are solving care coordination problems at the local, state and national levels.

HVP's help the VA by:

- Honoring veterans' preferences
- Expanding the interdisciplinary team
- Increasing VA staff knowledge of the Medicare Hospice Benefit
- Freeing up inpatient beds for incoming veterans
- Sharing the job of caring for veterans with the community

The HVP helps veterans by:

- Honoring veterans' preferences
- Standardizing VA's response to community hospices
- Informing community response to veterans' unique end-of-life issues
- Contributing to continuity and quality of care
- Eliminating "charity care" for veterans

Hospice Buffalo is proud to be a member of HVP VISN 2 and encourages health care professionals to work collaboratively to ensure that veterans have timely access to the dignity and comfort provided in hospice care at end of life. For more information, visit the Hospice-Veteran Partnership Toolkit (on the National Hospice & Palliative Care Organization's (NHPCO) Veterans' Webpage) www.nhpc.org/veterans for rich information on this significant initiative for our area veterans.

"We in the VA depend on you, community hospice agencies to deliver home care for our terminally ill patients. The VA does not intend to replicate the excellent system that is already in place for home hospice care and we in the VA must learn to collaborate with and learn from you."

- Tom Edes

Department of Veterans Affairs

Hospice Community Applauds Dementia Care Recommendations for End-of-Life Care Released by Alzheimer's Association, Continued from page 2.

confident they will receive compassionate, quality care at the end of their lives," remarked Lund Person.

Key aspects of the recommendations include:

- The need for advance care planning as soon as possible after diagnosis of dementia. This includes documenting the person's wishes regarding medical treatments in advanced stages of dementia and designation of a proxy decision-maker.
- Provision of person-centered palliative care to people with advanced dementia.
- The importance of dementia-specific training for residential care workers on end-of-life issues – for example, signs of dying, pain management issues, and communicating with families.

The recommendations published by the Alzheimer's Association will be shared by NHPCO at its upcoming Clinical Team Conference in New Orleans set to begin November 29. Additionally, NHPCO staff and its dementia work group are reviewing criteria for hospice eligibility for people with dementia as first published in Medical Guidelines for Determining Prognosis in Selected Non Cancer Diseases (NHPCO, 1996).

"It's important that we provide practical tools and approaches to help providers implement the valuable recommendations that have been published by the Alzheimer's Association," Lund Person stated. "Also of importance is making sure that people living at home, outside of nursing facilities, find high-quality end-of-life care when it's needed. Hospice and palliative care providers at all levels must make sure they understand how to serve this growing population."

For more information or to download the Phase 3 Recommendations, visit the Alzheimer's Association Web site, www.alz.org.

Resources to help families with advance care planning – as suggested by the Phase 3 Recommendations – are available from NHPCO's Caring Connections. For state-specific advance directive forms and informational brochures, visit www.caringinfo.org or contact the HelpLine at 1-800-658-8898. You may also call Hospice Buffalo at 686-8070 to obtain free advance directives planning guides, entitled "Sharing your Wishes".

VISIT OUR WEBSITE AT WWW.HOSPICEBUFFALO.COM/NEW_INTOUCH

Beloved Physician Chooses to be with his Hospital Family

By Megan O. Farrell, M.D., Hospice staff physician

How do we define home? Who can be designated a patient's family? These are key questions that identify integral concepts in Hospice home care. We often care for individuals whose situations stretch the typical definitions, as their circumstances may only barely resemble our understanding of home and therefore home care.



Megan Farrell, M.D.

We recently cared for an elderly gentleman with advanced esophageal cancer. He had undergone chemotherapy and radiation concurrently; a treatment regimen which took its toll. When we were asked to consult, he was in an acute hospital setting with multiple symptom issues, related not only to his disease but his treatment. His clinical condition was deteriorating and it was unclear if he would survive the complications.

Eventually, he stabilized and would have been discharged to the Hospice home care program, but he was different, his situation unique. This soft spoken, unassuming man unknowingly challenged us to think creatively, to make a health care system which rarely waivers, bend and be flexible.

Our patient was an Irish born physician, a pediatric pathologist, who had devoted the bulk of his career to serving in a local pediatric hospital. As a rule, pathologists are a low profile group and are rarely seen and barely known by those outside the closed circle of the lab and operating room staff. This man, however, was not only well-known but was well-loved by the entire staff.

With no immediate family living locally, it was clear that home care, in the traditional sense, was not feasible. Through our conversations, it was obvious that he wished to spend his final days, however they would be numbered, in the institution in which he had spent his career. He wanted to die in his "home" surrounded and cared for by his "family".

Without hesitation, the administration and staff of the pediatric facility went to work to make the transfer possible. Likewise, Hospice staff designed a plan of care through which the expertise of its interdisciplinary team would work side-by-side with pediatric caregivers to provide quality palliative care for their elderly "family" member. The outpouring of support and affection was overwhelming, and he died peacefully where he was meant to, at "home" in his hospital.

Hospitals are in the business of caring but, too often, they are first and foremost businesses. The kindness shown and the care given to this beloved physician revealed the true potential of a health care institution that went to great lengths to care for its own. Our role at Hospice in helping him realize his final wish, demonstrated that organizations can be creative and flexible when the individuals involved remain constant and firm in their commitment to the cause.

Calendar of Events

The following workshops will be held at the Hospice Mitchell Campus Education Center, 225 Como Park Blvd., Cheektowaga, NY

Friday, October 12

Harvest Festival, Celebrate autumn with your family and friends at the Hospice Harvest Festival, a gala event presented by the Buffalo Bills on Friday, Oct 12 at 6 p.m. at the Adam's Mark Grand Ballroom. Featuring international wine tasting, gourmet sit-down dinner, a \$10,000 Ethan Allen drawing, silent and live auctions and live entertainment by Nik and the Nice Guys! Tickets are \$175 each or corporate tables of ten for \$2,500. Call 686-8090 for reservations or order your tickets online at www.hospicebuffalo.com.

November/December

Light-A-Life Memorial Tree, honor a loved one with an heirloom bell. With a gift of \$50 or more, you'll receive this year's commemorative bell, the 13th in our collectible series. Inscribed with the name of your loved one, it's sure to become a family heirloom. Order by Nov. 14 to ensure holiday delivery. Order online at www.hospicebuffalo.com or call the Hospice Foundation at (716) 686-8090.

Saturday, Dec. 1

19th Annual Light-A-Life Tree Lighting Ceremony, All are welcome to attend this beautiful outdoor event to welcome the holiday season. Free event and parking. The ceremony begins at 4:30 p.m. at CTG, 800 Delaware Ave., Buffalo. Presented by CTG, M&T Bank, and Amigone Funeral Home, Inc. For info, call (716) 686-8090.

InTouch

MISSION STATEMENT

The Center for Hospice & Palliative Care serves individuals with serious illness, and their families and caregivers through a continuum of care spanning the course of illness and bereavement.

The Center's specially-trained professionals, support staff and volunteers assist individuals to make choices about their care, support those who are grieving and educate the professional and lay communities about end-of-life issues.

Definitions of Hospice & Palliative Care

Palliative Care is comprehensive care, provided by an interdisciplinary team for patients living with a life-limiting illness and their families.

Care is focused on alleviating suffering and promoting quality of life. Major issues addressed are pain and symptom management, information regarding the illness, advance care planning, psychosocial and spiritual needs and coordinated care with other community resources.

Hospice Care is palliative care for terminally ill patients who have a prognosis of 6 months or less to live. Services are provided to the patient's family during their loved one's illness and through a period of bereavement.

RESEARCH NOTES

- **CareCircle builds web pages for families in crisis, allowing them to post information, calendars and photo albums for concerned friends and family.** Visitors to the sites may volunteer to help in specific ways, from delivering hot meals to arranging for delivery of meals from local restaurants. Only persons with passwords provided by the family have access to the pages and the pages do not show up in online searches. The article says, "The online presence of a CareCircle page helps stem the usual flood of phone calls that infiltrate a home following a crisis," and one family member adds, "It's a service in a time of need that allows the community to reach out to you in a way that's personal, while at the same time maintaining your privacy." The website is located at <http://www.carecircle.com/>. (Employee Benefit News, 7/1)
- **A study of withdrawal of life support of incapacitated ICU patients who do not have surrogate decision makers or advance directives found that doctors considered such action in 37 of 3011 patients in the seven medical centers surveyed. The authors "found wide variability in hospital policies, professional society guidelines, and state laws regarding who should make life-support decisions for this patient population.** Thirty-six of 37 life-support decisions were made in a manner inconsistent with American College of Physicians guidelines for judicial review." (Annals of Internal Medicine, 147(1):34-40)
- **A randomized, controlled trial examining the results of in-home palliative care for the terminally ill found "significantly increased patient satisfaction while reducing use of medical services and costs of medical care at the end of life."** Study participants were more likely to die at home and less likely to visit the ER or be admitted to the hospital. (Journal of the American Geriatrics Society, 2007;55(7):993-1000)
- **A study at a VA nursing home that modified its electronic medical records to specify resuscitation status at the time of admission and alerted primary physicians to complete advance directives resulted in a dramatic increase in both areas.** Before the intervention, primary clinicians wrote advance directive discussion notes for four percent of admissions. After the intervention, that number rose to 63%. When patients preferred DNR orders, they were written for 86% pre-intervention and 98% post-intervention. (Journal of the American Geriatrics Society, 2007;55(7):1001-1006)
- **A study of whether a group of seniors would be willing to "undergo high-burden therapy for a chance to avoid death" found that their preferences were inconsistent and changed over time.** "Variability in their health state over time explained this in part, although the frequency of inconsistent trajectories even in those with stable health states suggests that preferences are influenced by transient factors rather than representing stable core values." (Journal of the American Geriatrics Society, 2007;55(7):1007-1014)
- **Surveys of staff and family caregivers of recent decedents in residential care/assisted living facilities and nursing homes were used to validate two versions of a new measure, The Quality of Dying in Long-Term Care (QOD-LTC) for all decedents and the QOD-LTC-C for "cognitively intact decedents."** Both were found to be "psychometrically acceptable measures of the quality of the dying experience, developed for and tested in LTC settings. Use of these measures can increase understanding of the dying experience in LTC." (Blackwell Synergy Online Early Article from a future Journal of the American Geriatrics Society, doi: 10.1111/j.1532-5415.2007.01293.x)

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