



# The ACE Project Newsletter

- Advocating for Clinical Excellence - Transdisciplinary Palliative Care Education -

## Reunion Conference Update!



We are very excited to announce that we are finalizing the details of our Reunion Conference!

The Reunion Conference will take place October 24-26, 2010 at the Westin in Pasadena. (Note change in date).

It has been four years since we began the ACE Project and 300 of you have now been involved in this educational effort. Through these years we have heard many amazing stories on how attending this course has empowered you to make a difference in your area of influence. We are excited to be planning for our Reunion Conference for October 24-26, 2010 where we will bring together all four cohorts to give you an opportunity to share your accomplishments with your colleagues through a poster presentation. This will give you an opportunity to display your ACE goals, your advocacy efforts and share progress made toward your goals. (On page 3 of this newsletter you will find more info on developing and preparing a poster). Each of you attending the Reunion Conference will receive the **Palliative Care Advocate Award** at the last day of this conference. This award recognizes your successful completion of the course and its requirements, (if you attended an annual course and the Reunion Conference, completed the 6 and 12-month post-course follow-up and professionally presented a poster highlighting your change efforts, you will receive this honor). Supervisors will be notified of this accomplishment and each of you will receive a certificate indicating this achievement. Two additional awards will be given to recognize the accomplishment of exceptional participants. Twenty attendees will be given the **Awards of Merit** and ten outstanding participants will be recognized for **Advocacy Honors**. In addition to receiving a certificate, a monetary award will be given to those who have been selected to receive these honors.

This will be a rewarding time for all of us as we come together to share, discuss and learn ways to better serve those in our care. Although the Reunion Conference had been tentatively scheduled for October 20-22, 2010, we were able to secure more affordable hotel rates by changing the date. Please mark your calendar to join us next year at the Westin Pasadena October 24-26, 2010! Check out the ACE Project's website periodically for updates at [www.cityofhope.org/aceproject](http://www.cityofhope.org/aceproject).

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## Participant Goals and Highlights

### James Maudlin, MDiv – Course 1

*Advanced Illness/Palliative Care (AIPC) Program, Jacksonville, FL*

**Goal:** Develop a bereavement education program with three levels of training available to all VA Palliative Care Consult Teams (PCCT), medical staff and volunteers in VISN 8 (Florida, South Georgia, Puerto Rico).

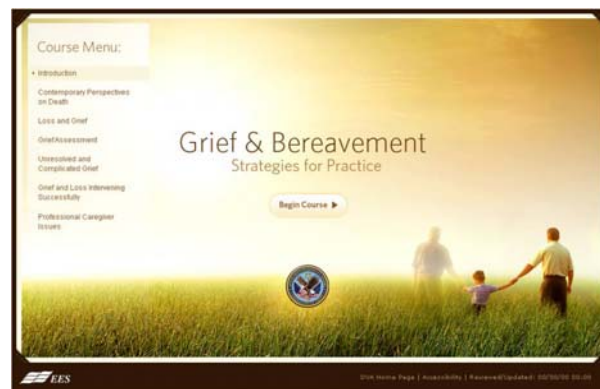


After participating in the first cohort in 2007, James Maudlin was inspired to do his part in creating his own ripple effect in the VA community in his district (Florida, South Georgia and Puerto Rico). His initial goal was to create a program for his region that would offer, via internet to staff, fundamentals on bereavement with tools for assessment. His aim was to provide a foundation to better understand the bereavement process within his local region. The response Jim received when providing a copy of the course in storyboard form to the VA National Director of Hospice and Palliative Care went beyond his expectations. The national director's feedback was not only positive but they encouraged him to expand this program to the national level where all CEUs, SW, Physician, CME and even Cemetery staff of the VA would have access to this course!

As you can imagine, developing this program took longer than expected. Funding and not knowing what to expect made this task a more difficult to accomplish. Much time, effort and pride was put into the project, even though the development process ran behind schedule. Materials adopted from ACE, End-of-Life Nursing Education Consortium (ELNEC) and National Health and Palliative Care Organization were used to create the modules and proper pilot testing was needed to help evaluate validation and timing to complete the course. Finally through much hard labor, the modules were created, funding was offered and a pilot test was run on an online model. What initially may have been hurdles, as far as the development of the program, resulted in opportunities to hold multiple training courses. As efforts were made in the development of the project, organizations became aware of the work Jim was doing. He was invited many times to speak at different events and also hold training courses using the transdisciplinary model for VA chaplains and community chaplains.

The program is still in progress with plans to launch for the VA in 2010. Even before the project has completed, Jim has already impacted many lives and has done an incredible job in creating awareness on these issues. We can expect more lives to be touched as we eagerly anticipate the implementation of his hard work.

*Thank you Jim for your effort and dedication to improving the delivery of care to our veterans and their families!*



# Guidelines for Preparation of Posters

## General Information

As you may recall, the investment from the NIH in support of the ACE Program recognizes the importance of participants sharing what they have learned with their colleagues. We are invested in you as a palliative care change agent and are eager to learn from you. The ACE Reunion Conference gives you an opportunity to share your strategies, ideas, and lessons-learned from your Ace experience through a dynamic poster-sharing sessions. Your poster should describe goals before, during and after attending ACE. Your poster should be self-explanatory, concise and illustrate a compelling message that describes how you overcame barriers and worked to create meaningful institutional change in your setting. The poster session offers an opportunity for discussion and networking and a chance to practice your "elevator talk" regarding your change experience. We encourage your poster to highlight your leadership efforts in incorporating transdisciplinary care in a palliative care setting.

Below are some guidelines to help you as you begin thinking about what you want to include in your poster. Further details will be sent closer to the Reunion Conference.

## Development of Poster

- Prepare a label for the top of your poster indicating the title, authors, and affiliations. Lettering should be at least one inch high.
- It is best to arrange written materials in columns. Text should supplement graphics - the poster is primarily a visual, rather than a written, presentation. It is helpful to use arrows to indicate the direction in which the poster is meant to be viewed.
- An introduction should be placed at the upper left and a conclusion at the lower right.
- No material should extend beyond the perimeters of the board (above, below or on the sides).
- Posters should include a statement of the goals, education and intervention, methods, obstacles/barriers/strategies to address and what happened, and implications for clinical practice.

## Illustrations

- Use large font size that can be easily read at a distance of 6'.
- Be sure graphs and charts can be easily read at a distance of 6'.
- Each figure or table should have a heading of one or two lines in large type stating the point of its message. Detailed information can be provided in a legend in smaller font below the figure. These legends should be brief, yet informative.



# New Resources

We are excited to announce that **PainEDU** has updated their content to include a new website for patients with cancer pain in Spanish.

Inflexion is introducing a free Spanish language website for Hispanics coping with cancer pain, called Pain ACTION: Dolor de Cáncer. The website provides patients with different ways to learn about key pain self-management issues and features personal stories, educational lessons, interactive tools, and self-assessment questionnaires.

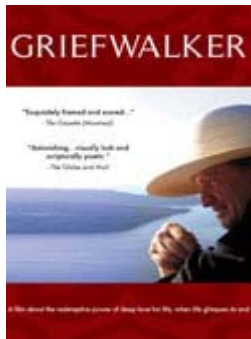
Visit the site and refer your Spanish-speaking patients to: [www.dolordecancer.com](http://www.dolordecancer.com).



The National Institute on Aging and the National Institutes of Health has published a booklet titled **End-of-Life: Helping With Comfort and Care** with aims to better equip those caring for someone nearing the end of life. This publication is based on research, such as that supported by the National Institute on Aging and augmented with suggestions from practitioners with expertise in helping individuals and families through this difficult time. All too often a sense of hopelessness and surrender floods the mind of the individual and family when they are told that nothing else can be done. This may be true for the possibility of a cure but not for medical support or the involvement of family and friends. This booklet is an overview of issues faced during these last moments and provides tips on how to work with health care providers to complement their medical and care giving efforts.



Order or download at: <http://www.nia.nih.gov/HealthInformation/Publications/endoflife/>



## Griefwalker - a New Film on End-Of-Life Care

Stephen Jenkinson has been called the "Angel of Death." Perhaps not a title well embraced by many but for him it is his calling as he shares a message that most people do not want to hear: that our deaths are not something to be denied or avoided, but "befriended."

This film, directed by Tim Walker is an account framed by Walker's own wrestling with denial of his own death after he nearly surrenders to a sudden illness and also dealing with the death of someone very close to him. The film follows Harvard trained theologian and palliative care educator Stephen Jenkinson as he provides compassionate grief counseling to the dying, their friends and family.

To learn more go to: <http://www.alivemindmedia.com/films/griefwalker/>



## Light In The Wood

Harpist Lisa Lynne has once again teamed up with George Tortorelli and his flutes to create another peaceful CD. In addition to Celtic harp, Lisa Lynne also plays bandura, mandolin, bouzouki, dulcimer and guitars on some of the tracks. George's instruments include bamboo flutes, recorders, and Irish whistles.

For ordering information please visit: <http://www.lisalynne.com/music.html>



## New Guidelines for Incorporating Spirituality in End-of-Life Care

New Rochelle, NY, October 6, 2009—Guidelines derived from a recent Consensus Conference, including recommendations on the role of healthcare providers in the assurance of quality spiritual care to patients in a palliative care setting, are published in a comprehensive report in *Journal of Palliative Medicine*, a peer-reviewed publication from **Mary Ann Liebert, Inc.** ([www.liebertpub.com](http://www.liebertpub.com)). *Journal of Palliative Medicine* is the official journal of the Center to Advance Palliative Care (CAPC) and an official journal of the Hospice and Palliative Nurses Association (HPNA). The article is available free online at [www.liebertpub.com/jpm](http://www.liebertpub.com/jpm)

The article, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," represents the final Consensus Report of a conference sponsored by the Archstone Foundation of Long Beach, CA. According to **Joseph F. Prevratil, JD**, President and CEO, "The report's recommendations seek to ensure that spiritual care is a fundamental component of quality palliative care, which strives to prevent and relieve suffering for seriously ill patients and their families."

"For the first time we have a practical model for the implementation of inter-professional spiritual care which will result in improved healthcare outcomes for patients," says **Christina Puchalski, MD, MS, FACP**, Co-Principal Investigator and lead author of the Consensus Report, from The George Washington Institute for Spirituality and Health (GWish) at the George Washington University Medical Center.

The Consensus Report outlines seven key areas for improving spiritual care: Spiritual Care Models; Spiritual Assessment; Spiritual Treatment/Care Plans; Interprofessional Team; Training/Certification; Personal and Professional Development; and Quality Improvement. Co-authors **Christina Puchalski, MD, MS, FACP**, and **Betty Ferrell, PhD, MA, FAAN, FPCN**, Principal Investigator from the City of Hope and colleagues from City of Hope National Medical Center present practical recommendations for implementing spiritual care in palliative care, hospice, long-term care, and other clinical settings. The guidelines provide spiritual care models, recommendations for professional training, advice on how to develop accountability measures to ensure integration of spiritual care, and guidance on engaging community clergy and spiritual leaders in the care of patients and families.

"Of the physical, emotional, practical, and spiritual dimensions of hospice and palliative medicine, spirituality has been least well addressed. This report aims to improve that situation," says **Charles F. von Gunten, MD, PhD**, Editor-in-Chief of *Journal of Palliative Medicine*, and Provost, Institute for Palliative Medicine at San Diego Hospice.

*Journal of Palliative Medicine*, published monthly in print and online, is an interdisciplinary journal that reports on the clinical, educational, legal, and ethical aspects of care for seriously ill and dying patients. The Journal includes coverage of the latest developments in drug and non-drug treatments for patients with life-threatening diseases including cancer, AIDS, cardiac disease, pulmonary, neurologic, respiratory conditions, and other diseases. The Journal reports on the development of palliative care programs around the United States and the world, and on innovations in palliative care education. Tables of contents and a free sample issue may be viewed online at [www.liebertpub.com/jpm](http://www.liebertpub.com/jpm)

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### The National Consensus Project (NCP) is pleased to present the newly revised NCP *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*



Published in January 2009, this second edition offers the most current information on the field of palliative care and can serve as a blueprint to build optimal palliative care practice. The publication was edited by Constance Dahlin, MSN, ANP, BC, ACHPN, who chaired the NCP Revision Task Force, with input from representatives of each of the four major organizations in palliative Care Organization, and the Center for Palliative Care.

This newly revised publication has been updated to make it more inclusive and expansive to all settings that provide quality palliative care. It can serve as a resource not only for practitioners but for legislators, payers, and others involved in and who have an impact on the field of palliative care. The website can be viewed at [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)

# *Congrats to the Participants of the 4<sup>th</sup> ACE Course!*

The 4<sup>th</sup> ACE Course was a great success and we want to extend a thank you to all for making it happen! We shared laughter and moments of serenity as we remembered those who have touched our lives, and explored ways to improve services for those in our care. We were re-energized to go back out and continue to offer the best care to our patients and their families.



# Follow-Up Info from Course 4

## *The Nine Contemplations of Atisha*

From: Betty Kramer, Ph.D, MSSW – Module 3 “Personal Death Awareness” Day 1

### **The First Contemplation**

Death is inevitable; no one is exempt.

Holding this thought in mind, I abide in the breath.

### **The Second Contemplation**

Our life span is ever-decreasing; each breath brings us closer to death.

Holding this thought in mind, I delve deeply into its truth.

### **The Third Contemplation**

Death will indeed come, whether or not we are prepared.

Holding this thought in mind, I enter fully into the body of life.

### **The Fourth Contemplation**

Human life expectancy is uncertain; death can come at any time.

Holding this thought in mind, I am attentive to each moment.

### **The Fifth Contemplation**

There are many causes of death – even habits, desires, and accidents are precipitants.

Holding this thought in mind, I consider the endless possibilities.

### **The Sixth Contemplation**

The human body is fragile and vulnerable; our life hangs by a breath.

Holding this thought in mind, I attend to my inhale and exhale.

### **The Seventh Contemplation**

At the time of death, material resources are of no use to us.

Holding this thought in mind, I invest wholeheartedly in practice.

### **The Eighth Contemplation**

Our loved ones cannot keep us from death; there is no delaying its advent.

Holding this thought in mind, I exercise non-grasping.

### **The Ninth Contemplation**

Our body cannot help us at the time of death; it too will be lost at that moment.

Holding this thought in mind, I learn to let go.

— Atisa Dipankara Shrijnana



## Follow-Up Info from Course 4



### They're Singing Your Song From a story told by Alan Cohen in his book: Wisdom of the Heart From: Reverend Pamela Baird's Centering Exercise Day 3

When a woman in a certain African tribe knows she is pregnant, she goes out into the wilderness with a few friends and together they pray and meditate until they hear the song of the child. They recognize that every soul has its own vibration that expresses its unique flavor and purpose. When the women attune to the song, they sing it out loud. Then they return to the tribe and teach it to everyone else. When the child is born, the community gathers and sings the child's song to him or her. Later, when the child enters education, the village gathers and chants the child's song. When the child passes through the initiation to adulthood, the people again come together and sing. At the time of marriage, the person hears his or her song. Finally, when the soul is about to pass from this world, the family and friends gather at the person's bed, just as they did at their birth, and they sing the person to the next life. To the African tribe there is one other occasion upon which the villagers sing to the child. If at any time during his or her life, the person commits a crime or aberrant social act, the individual is called to the center of the village and the people in the community form a circle around them. Then they sing their song to them. The tribe recognizes that the correction for antisocial behavior is not punishment; it is love and the remembrance of identity. When you recognize your own song, you have no desire or need to do anything that would hurt another. A friend is someone who knows your song and sings it to you when you have forgotten it. Those who love you are not fooled by mistakes you have made or dark images you hold about yourself. They remember your beauty when you feel ugly; your wholeness when you are broken; your innocence when you feel guilty; and your purpose when you are confused. You may not have grown up in an African tribe that sings your song to you at crucial life transitions, but life is always reminding you when you are in tune with yourself and when you are not. When you feel good, what you are doing matches your song, and when you feel awful, it doesn't. In the end, we shall all recognize our song and sing it well. You may feel a little warbly at the moment, but so have all the great singers. Just keep singing and you'll find your way home. May each who is here, discover, if we haven't already, our song...and may we sing it well. May each who is here, listen carefully for the other's song and sing to that other every chance we get.

## Resources from Colleagues



- ❖ Participant Hillel Bodek from Course 4 wanted share an article from Medscape called "Veterans with PTSD Twice as Likely to Die after Surgery" by Janis C. Kelly. This article may be of interest especially to those who work directly with veterans. To view the article please go to: <http://www.medscape.com/viewarticle/710808?src=mpnews&spon=12&uac=89474MT>
- ❖ Participant Peg McGonigal from Course 4 is a Chaplain from Aurora St. Luke's Medical Center in Wisconsin. She wanted to share her department's spiritual care website, hoping this could be helpful and a resource for everyone. To learn more go to: <http://www.aurorahealthcare.org/services/spiritual-care/index.asp>
- ❖ Participant Geoffrey Tyrrell from Course 4 wants to invite all ACE Chaplains to join the email group Palliative\_Care\_Chaplains. Currently, there are 7 Chaplains participating in this email group. If you are interested in joining this group please send an email to Geoffrey Tyrrell at [geofftyrrell@yahoo.com](mailto:geofftyrrell@yahoo.com). Also, to all ACE participants, Geoffrey's major ACE project is to write a book of blessings suitable for palliative care context. If you have any favorite prayers, readings or quotes please submit them directly to Geoffrey.
- ❖ Please join us for the Social Work Course "Promoting Excellence in Pain Management and Palliative Care for Social Workers" on July 30, 2010 with Keynote Speaker Guadalupe Palos, RN, LMSW, DrPh from MD Anderson. Anyone interested in psychosocial palliative care is welcome to attend. More information can be found at <http://sccpi.coh.org/2010%20SWC/SWC10.htm>

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We are excited to welcome two new members to our ACE family!



"I am fortunate enough to join the ACE Project team at City of Hope just in time to help coordinate the 2010 Reunion Conference! As a former Massachusetts resident and teacher, I know how important it is to enact change across our country. As someone who is very passionate about education, I feel that the efforts you are taking in your institutions and communities will undoubtedly bring about the necessary change that patients and their families are so desperately seeking. What a privilege to work with so many passionate and driven minds! I am here to learn from the best and to assist in any way possible. I look forward to speaking with all participants in the coming days leading up to the Reunion. Many thanks to all, and best wishes for the work you are doing in your area."

-Lisa Marie Kilburn

***Lisa Kilburn** - Originally from Boston, Lisa recently moved out to sunny Southern California with plans to pursue her passion in healthcare and education. She graduated from the University of Rhode Island and completed her BA in Political Science and Spanish. She then went to work for two years in Barcelona, Spain where she sharpened her Spanish speaking skills and is currently a licensed ESL and Spanish Teacher in MA.*



"It is an honor and privilege to join the ACE Project team at City of Hope! I am excited to be working with you and hope that I can help you achieve your goals of serving and helping patients and their families. Please do not hesitate to contact me for assistance and good luck to everyone in your work!"

-Eunice Yang

***Eunice Yang** - Born and raised in Atlanta, Eunice graduated from the University of Georgia with a BA in Political Science and minor in Korean. After graduating from college, Eunice went on her first trip to Africa on a medical mission, which changed her career path to public health and humanitarian efforts. Eunice graduated from the George Washington University with a MPH in Global Health this summer. She recently returned from a three-month trip to Uganda working with the AIDS Support Organization on a global health fellowship through her university.*

Thanks to Licet Garcia for her work as Interim ACE Coordinator in Maren's absence—tiding us over until Lisa and Eunice were on board.