



The ACE Project Newsletter

- Advocating for Clinical Excellence - Transdisciplinary Palliative Care Education -



from the ACE Project
Office!

Be Not Afraid

Charles von Gunten, the editor-in-chief of the Journal of Palliative Medicine (2008, Vol 11(9): 1179) recently wrote a powerful editorial reminding readers of the importance of palliative care professionals applying the “scientific method” to hospice and palliative medicine. We developed the ACE Project with a similar view in mind. Our goal is to encourage ACE participants to apply the scientific method to the “psychological, social and spiritual dimensions of the care we provide” to build an evidence base for our efforts to “relieve suffering and improve quality of life” for the patients that we serve.

Excerpts from “Be Not Afraid”

“I sometimes have the impression that science scares people working in hospice and palliative care. ... Science (from the Latin scientia, meaning “knowledge”) is simply the effort to discover new knowledge- to increase human understanding.¹ In our field, we want to discover new knowledge that helps us relieve suffering and improve quality of life of people who are sick enough to die. ... We must not be afraid of science. We must not be afraid of applying the scientific method to hospice and palliative medicine. We need to be seen as leading the efforts to develop new knowledge so that our abilities to relieve suffering and improve quality of life are better in 10 years that they are today. ... That means being willing to expose our biases and put our beliefs to the test. The Journal of Palliative Medicine publishes work that helps evaluate and disseminate new knowledge. ... To that end, we are initiating a series devoted to applying the scientific methods to palliative medicine.³ I hope that more work like that of Steinhauer and colleagues- science applied to the psychological, social and spiritual dimensions of the care we provide, not just the physical- will be forthcoming.

1. Science. Wikipedia <http://en.wikipedia.org/wiki/Science> (Last accessed August 12, 2008).
2. Steinhauer K, Alexander S, Byock I, George L, Olsen M, Tulsy J: Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? A pilot randomized controlled trial. Journal of Palliative Medicine 2008;9:1234-1240.
3. Carlson MDA, Morrison RS: The what and why of observational and quasi-experimental research. Journal of Palliative Medicine 2008;9:1258-1261.

We look forward to reading about the work of ACE participants in upcoming professional journals such as this!

Issue: January 2009

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Comments,
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Awards at the Reunion Conference



Having completed three of the four ACE Project courses, we wanted to send out a notice to remind our participants know about the awards that will be announced at the Reunion Conference- October 20-22, 2010. While we are still deciding on the location, we do know how we will honor all the incredible work of the ACE participants. The **Palliative Care Advocate Award** will be given to participants at the end of the Reunion Conference to recognize their goal work and successful completion of the course content. Each participant who has attended an annual course and the Reunion Conference, completed their 6- and 12-month post-course follow-up and professionally presented a poster highlighting their change efforts will receive this honor. Supervisors will be notified of this accomplishment and each participant will receive a certificate indicating this achievement!

Additionally, there will also be monetary awards given in two different categories recognizing participants' outstanding achievements:

- Twenty participants will be selected for **Awards of Merit** and will each receive \$500. This award recognizes outstanding goal work conducted following attendance at ACE.
- Ten participants will be selected for **Advocacy Honors** and will each receive \$1,000. These participants will be identified by the ACE Project Team as the most innovative and successful in achieving their post-course goals.

We hope that these thirty awards will offer both incentive to competitively participate in the poster session and offer prestige for the selected recipients. Employers will be notified of these honors and encouraged to share the news, locally announcing these achievements. Additionally, regardless of award status, we encourage all ACE participants to present your advocacy activities as posters or presentations to other audiences (either in your own setting or at local, regional or national meetings).



NHPCO Distinguished Research Award to ACE Faculty Member!

The National Hospice and Palliative Care Organization presented awards to leaders in the field at its 9th Clinical Team Conference, October 23 - 25, 2008, in Dallas, Texas. Awards were given recognizing outstanding clinical care, team work, research and volunteerism.

The Distinguished Research Award was presented to **Betty Kramer, PhD, MSSW**, a Professor in the School of Social Work and a member of the Comprehensive Cancer Center at the University of Wisconsin-Madison.

A primary aim of Dr. Kramer's research has been to understand the experience and variation found among family members caring for older adults with chronic and terminal illnesses in order to enhance service provision.

For more information, see the NHPCO press release of October 31st at:
<http://www.nhpc.org/i4a/pages/index.cfm?pageid=5756>



Congratulations Betty!

Honoring Florence Wald

ACE is dedicated to supporting participant efforts to be change agents in your institutions. We pause to reflect upon the achievements of a palliative care pioneer, Florence Wald, who died November 8, 2008. Her efforts changed the delivery of care across the nation. We honor her inspiration!



By [Patricia Sullivan](#)

Washington Post Staff Writer

Thursday, November 13, 2008; Page B06

Florence S. Wald, 91, a former Yale University nursing school dean who brought the hospice movement to the United States and started the first American hospice unit, died Nov. 8 at her home in Branford, Conn. No cause of death was reported.

Her interest in end-of-life issues was sparked in 1963. Cicely Saunders, an English physician who was a pioneer in the field, gave a lecture at Yale describing her approach to treating terminally ill cancer patients by easing pain and suffering in the final stages of life so they could concentrate on their relationships and prepare for death. "She made an indelible impression on me, for until then I had thought nurses were the only people troubled by how a terminal illness was treated," wrote Dean Wald, who informally retained the title of dean after she left the Yale post in 1966. After hearing Saunders's lecture, Dean Wald immediately sought to revamp nursing education to focus on patients and their families and involve them in the patients' care. She resigned from the deanship to educate herself about the hospice movement.

In 1969, she spent a month at St. Christopher's Hospice in London, the hospice founded by Saunders. When she returned to the United States, she formed an interdisciplinary team of doctors, clergy and nurses to study the needs of dying patients. In 1974, that team founded the first U.S. hospice, Connecticut Hospice in Branford. At first it provided only home care; by 1980, it had an inpatient facility.

The hospice movement took off, with programs sprouting by the dozens, then hundreds. In 1982, Congress required Medicare to pay for hospice care, which put the treatment in mainstream medical practice. Today, about 3,200 hospice programs serve about 900,000 patients a year in the United States. "Hospice care for the terminally ill is the end piece of how to care for patients from birth on," Dean Wald once wrote. "As more and more people . . . are exposed to this new model of how to approach end-of-life care, we are taking what was essentially a hidden scene -- death, an unknown, and making it a reality. We are showing people that there are meaningful ways to cope with this very difficult situation."

During the 1990s, Dean Wald joined the board of the National Prison Hospice Association. She also declared her support for physician-assisted suicide. "There are cases in which either the pain or the debilitation the patient is experiencing is more than can be borne, whether it be economically, physically, emotionally, or socially," she said. "For this reason, I feel a range of options should be available to the patient, and this should include assisted suicide."

Dean Wald was born Florence Sophie Schorske on April 19, 1917, in New York City. When she was young, she spent months in a hospital because of a chronic respiratory ailment, an experience that inspired her to enter nursing. She graduated from Mount Holyoke College in Massachusetts in 1938 and received a master's degree in nursing from Yale in 1941. During World War II, she worked as a research technician with the Army Signal Corps. After the war, Dean Wald became a staff nurse with the Visiting Nurse Service of New York and a research assistant in the surgical metabolism unit of the College of Physicians and Surgeons in New York. She also spent two years as an instructor at Rutgers University's nursing school in New Jersey. She returned to Yale and received a second master's degree in mental health nursing in 1956, then became an instructor in the nursing program. In 1958, she was appointed acting dean of the school, a position that became permanent a year later. At Yale, Dean Wald was credited with making the study of nursing more academically rigorous, and she revamped nursing education to focus on involving patients and their families in the patients' medical care. Dean Wald was inducted into the National Women's Hall of Fame in 1998. She was also named a "living legend" by the American Academy of Nursing.

<http://www.washingtonpost.com/wp-dyn/content/article/2008/11/12/AR2008111202953.html>





In the News

At the Edge of Life: Life and Death in 21st Century Medicine

The Dallas Morning News spent a year exploring efforts to improve end-of-life medical care. Reporter Lee Hancock interviewed experts and attended national and regional conferences and trainings in palliative care. Ms. Hancock and photographer Sonya N. Hebert gained unprecedented access to Baylor University Medical Center's palliative-care team, spending months attending team meetings, observing patient visits and interviewing clinicians, patients and families. In late May and early June, they shadowed the team around the clock for three weeks. Every patient, family member and staffer named or photographed gave prior permission, and unless indicated, the stories are presented in the order that events occurred.

Explore efforts to improve end-of-life medical care through our five-part series, interactive tools and behind-the-scenes videos:

- Part 1: Saying the "D-word"
- Part 2: Fighting the medical machine
- Part 3: Healing beyond technology
- Part 4: End of life choices
- Part 5: Healing the whole family

The Dallas Morning News

Series available at: <http://www.dallasnews.com/sharedcontent/dws/spe/2008/edgeoflife/>

Children's Hospice and Palliative Care Coalition

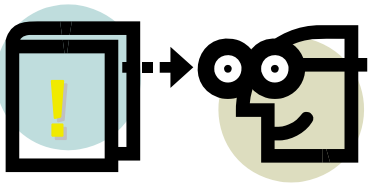


Beginning in early 2009, thirteen California counties will pilot the program and unite families, healthcare providers, and communities toward the common goal of providing comprehensive, family-centered healthcare to children with life-threatening conditions.

[The Nick Snow Children's Hospice and Palliative Care Act of 2006/ Assembly Bill 1745](#) requires the State Department of Health to submit a waiver to the federal government that allows children with life limiting or life threatening conditions to receive concurrent curative and palliative care. Currently, full service palliative care i.e. Hospice Care, is only provided to children when 1) a physician determines that the child has 6 months or less to live and 2) that the child forgoes curative therapy. The Children's Medical Services (CMS) Branch has been designated as the lead agency to write the waiver and will work with the Children's Hospice and Palliative Care Coalition www.ChildrensHospice.org, the Medi-Cal Waiver Analysis Branch, and other stakeholders in developing the waiver. The CMS Branch will also oversee the administration and evaluation of the waiver. The goal of the waiver is to promote the development of comprehensive Pediatric Palliative Care demonstration programs that allow for the provision of expanded hospice type services and curative care concurrently. These programs should improve quality of life for children with life limiting or life threatening conditions, and their family members. Cost neutrality should be achieved by reducing hospital stays and other unnecessary services. The email address for collaboration on this topic is ccsppc@dhs.ca.gov.

This waiver, which was mandated by the Nick Snow Children's Hospice and Palliative Care Act, was signed into law in September 2006. Nick's vision is finally spreading across the country, touching children and families with hope for a cure while simultaneously receiving support from hospice and palliative care teams.

More info about implementation: <http://www.childrenshospice.org/benefit/ccs-medi-cal-information/>



Recent Publications of Interest

Professional Chaplains and Health Care Quality Improvement

The March/June 2008 issue of the *Hastings Center Report* includes an essay set, "Can We Measure Good Chaplaincy?," from the Center's research collaboration, *Professional Chaplains and Health Care Quality Improvement*, funded by the Arthur Vining Davis Foundations. The full text of the essay set can be downloaded free from the project's web page:

<http://www.thehastingscenter.org/Research/Detail.aspx?id=1212>



The Hastings Center

a nonpartisan research institution dedicated to bioethics and the public interest since 1969

The essay set is structured in response to requests from chaplains for short, clear pieces they can easily share with colleagues and administrators, to prompt fresh conversations about patient-centered care, and the role of the chaplain in providing that care. Other forthcoming research products include journal articles reporting on the collaboration's focus group study involving chaplains in New York, Chicago, San Francisco, and Phoenix.

New Pediatric Resource: Faces of Hope: Stories of Inspiration and Strength during the Journey through Childhood Cancer

Dana-Farber/Children's Hospital Cancer Care has published a new book for the pediatric oncology community. "Faces of Hope: Stories of Inspiration and Strength during the Journey through Childhood Cancer," is a moving publication detailing the strength, courage and grace seen everyday within pediatric oncology patients and families. It presents powerful images of 51 pediatric cancer patients along with patient/family-submitted stories explaining their sources of encouragement and hope.



This book would be great for Resource Centers and hospital libraries. Copies are \$20.00 and can be purchased at www.childrenshospital.org/facesofhope.

Charting the Course for the Future of Social Work in End-of-Life and Palliative Care: A Report of the 2nd Social Work Summit on End-of Life and Palliative Care

Editors: Susan Blacker, MSW, RSW, Grace H. Christ, DSW, Sallie Lynch, MA

Contributors (listed in alphabetical order): **Terry Altilio, LCSW, ACSW**; Mercedes Bern-Klug, PhD, MSW; Ellen L. Csikai, MSW, MPH, PhD; Gary Gardia, Med, LCSW; Richard B. Francoeur, PhD, MSW, MS; **Betty J. Kramer, PhD, MSSW**; **Shirley Otis-Green, MSW, LCSW, ACSW, OSW-C**; Patricia A. Sherman, PhD, LCSW; Gary L. Stein, JD, MSW; Katherine Walsh, PhD, MSW

This monograph examines the state of palliative and end-of-life care social work. Creating a proactive vision is essential to realizing the profession's potential in this area and to improving care at the end of life. This was the working goal of two Social Work Summits on End-of-Life and Palliative Care. A priority item identified at the 1st Summit in 2002 and the overarching consideration of the 2nd Summit in 2005 was to create a social work
(Continued on following page)

coalition of experts, institutions, organizations involved with end-of-life and palliative care to promote advocacy, education, research and networking.. Such a network of organizations would centralize activities, enhance collaboration and maintain the momentum of recent efforts in social work in end-of-life and palliative care. State of the field presentations at the 2nd Summit and the Priority Map of the 1st Summit made it possible to identify key priority initiatives related to those four areas and to develop action plans with the potential to continue to move the field forward. The Social Work in Hospice and Palliative Care Network (SWHPN) was developed after the 2nd Summit to create a forum through which to advance the action steps identified in the areas of practice, research, education and policy. In July 2007 SWHPN was formally launched as a nonprofit 501(c)(3) organization and invited individuals to join as founding members in December 2007. SWHPN now has a large subscriber base for public website updates and growing membership base in its private online community. SWHPN continues to build on the past collaborations with many social work and other organizations working to care for the seriously ill and the bereaved. Complete monograph available at <http://www.swhpn.org/monograph.pdf>



Educational Opportunities

ACE Project Course 4- October 13-16, 2009



We are now accepting applications for the fourth and **FINAL** ACE course!
Please alert your colleagues- the application deadline is June 20th.



www.cityofhope.org/ACEproject

Internet-Based Education on End-of-Life Issues for Mental Health Care Providers

Earn up to 20 hours of CE credit
at your convenience, at your home or office

AVAILABLE EARLY 2009

This innovative program uses text, audio, and video clips to deliver course content derived from recent research. Case examples, graphs, tables and practice tools are used to illustrate critical course content. Psychologists, counselors, grief and bereavement specialists, clergy, nurses, and other mental health providers can engage in this interactive 1 - 10 module program that focuses on the following End-of-Life issues:

Overview of End-of-Life Issues Assessment & Treatment of Psychological Distress Assessment
& Treatment of Pain Diagnosis & Treatment of Cognitive Changes Grief & Bereavement
Religious & Spiritual Issues Family Caregiving Issues Multidisciplinary Teamwork Ethical &
Legal Considerations Advance Care Planning

This program is approved by the American Psychological Association to offer CE credit to psychologists; other CE approvals are pending, please check website for updates.

For information, contact Martha Mihaly, PhD, mmihaly@apa.org; 202-336-6042, or website found at <http://www.apa.org/pi/eol/homepage.html>

Think Cultural Health: Bridging the Health Care Gap through Cultural Competency Continuing Education Programs

<http://www.thinkculturalhealth.org>



From the website: "With growing concerns about racial and ethnic disparities in health the need for health care systems to accommodate increasingly diverse patient populations, cultural competence has become more and more a matter of national concern and attention.

Providers can take the first step to improve the quality of health care services given to diverse populations. By learning to be more aware of their own cultural beliefs and more responsive to those of their patients, providers can think in ways they might not have before. That can lead to self-awareness, and over time, changed beliefs and attitudes that will translate into better health care.

This site, sponsored by the Office of Minority Health (OMH), offers the latest resources and tools to promote cultural competency in health care. You may access free online courses accredited for continuing education credit as well as supplementary tools to help you and your organization promote respectful, understandable, and effective care to your increasingly diverse patients.

A Physician's Practical Guide to Culturally Competent Care, is a free online educational program accredited for physicians, physician assistants, nurse practitioners, and pharmacists.

Culturally Competent Nursing Care: A Cornerstone of Caring, is a free online educational program designed specifically for nurses and is accredited by the American Nurses Credentialing Center and the National Association of Social Workers."

PROMOTING EXCELLENCE IN PAIN MANAGEMENT & PALLIATIVE CARE FOR SOCIAL WORKERS



July 31, 2009- City of Hope, Duarte, CA

Social workers and other psychosocial professionals from across the country are invited to attend the 4th Annual Conference: *Promoting Excellence in Pain Management & Palliative Care for Social Workers*. The featured lecturer will be Mercedes Bern-Klug, PhD, MSW, MA.

For more information, and/or to apply, go to: <http://sccpi.coh.org>.

SURVIVORSHIP EDUCATION FOR QUALITY CANCER CARE CONFERENCE

July 15-18, 2009- Sheraton Universal Hotel, Universal City, CA

City of Hope Department of Nursing Research & Education provides an annual program to educate competitively chosen multi-disciplinary teams from cancer settings across the nation in cancer survivorship.

For more information go to: <http://www.cityofhope.org/education/health-professional-education/nursing-education/survivorship-conference>

PAIN RESOURCE NURSE COURSE

September 2-4, 2009 City of Hope, Duarte, CA

The annual PRN course is in its 18th year of preparing individual nurses, as well as other disciplines, in developing the role of the Pain Resource Nurse.

For more information see; <http://sccpi.coh.org/2009%20PRN%20Course/PRN09.htm>

Alert Your Nursing Colleagues: ELNEC Courses in 2009

ELNEC (End-of-Life Nursing Education Consortium) is a national education initiative to improve end-of-life care in the United States. The project provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in end-of-life care so they can teach this essential information to nursing students and practicing nurses.

ELNEC-Core

- [April 21-22, 2009, Oklahoma City, OK](#) (in collaboration with Mercy Health Center)
- [June 25-26, 2009, Minneapolis, MN](#) (co-sponsored by the Hospice and Palliative Nurses Association [HPNA])
- [August 13-14, 2009, Orlando, FL](#) (co-sponsored by HPNA)
- [September 24-25, 2009, Boston, MA](#) (co-sponsored by HPNA)

ELNEC-Critical Care

- October 23-24, 2009, Washington, DC
Registration form will be available January 2009.

ELNEC-Geriatric

- [March 11-12, 2009, Richmond VA](#) (Sponsored by Massey Cancer Center and The Virginia Association of Nonprofit Homes for the Aging)

May 15-16, 2009, Pasadena, CA

[California Registration](#) - free registration for California nurses provided by the Archstone Foundation

[Non-California Registration](#) - nurses from all states are invited to register

ELNEC-Pediatric Palliative Care

- [February 20-21, 2009, Sacramento, CA](#)

Images from ACE Course 3

