Continuing Education—May 2009

DR. RICHARD PAYNE AND
DUKE’S INSTITUTE ON CARE AT THE END OF LIFE

(On April 29, 2009, Richard Payne, MD, participated in the 2009 National Bereavement Teleconference, “Diversity and End-of-Life Care,” sponsored by the Hospice Foundation of America. This teleconference was broadcast to many sites nationwide, including the Duke HomeCare and Hospice office in Durham. While Dr. Payne has gracefully spoken to Duke Hospice staff and volunteers at any number of events over the years, we’re taking this opportunity to formally introduce him and the Duke Institute on Care at the End of Life to our volunteers to inform them of the resources for their hospice work that are available in our community.)

Before taking the reins as director of the Duke Institute on Care at the End of Life (ICEOL), Richard Payne was Dr. Payne the Pain Doctor, chief of the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City, and distinguished researcher, author, and lecturer. Today, holding joint appointments at Duke Medical and Divinity Schools, Payne continues his campaign to bring comfort and quality of life to those whose lives are in the final stages or whose lives are limited by pain. Under his direction the Duke ICEOL has developed a broad vision to focus attention on and improve the quality of EOL care for all patients, particularly the underserved.

The Institute is founded on the conviction that good care for the dying and the grieving includes, but goes far beyond, sophisticated medical technology, medical expertise, and business efficiency. Rather, the notion of "dying well" flows from the traditional virtues of charity and compassion. When death is seen as a basic part of life, care for the dying becomes a ritual focus for families, friends and community members. By contrast, too many of us today see death as a failure. If we hope to recover the practice of dying well, we must attend to the complexities of the social, cultural, moral, theological, public policy and economic issues involved in living and dying.

This vision depends upon the cooperative efforts of many disciplines. To that end, the constituents of the Institute will work collaboratively through research efforts, educational initiatives, and outreach programs. The core faculty is drawn from theology, medicine, nursing, social work, and the humanities at Duke and other partnering institutions.

The Institute is dedicated to including previously under-represented and diverse groups. The Institute recognizes that access to palliative care for the African-American and other minority communities has been insufficient, and that there are many cultural distinctions and societal issues that have limited the use of that care. The Institute hopes to learn how to best meet the end-of-life needs of all communities. A better understanding of the distinctive religious and spiritual practices of diverse communities as they relate to end-of-life care is a primary commitment of the Institute.
Finally, the Institute is committed to enhancing meaningful public dialogue around issues related to care at the end of life through education and the dissemination of information. The Institute will make an effort to include public education as a component of all of its programs.¹

This seems at first blush to be an enormous undertaking. It is. But a review of the substantial projects, products, and resources developed, coordinated, and distributed by the Institute and available widely to organizations and individuals (including Hospice volunteers) in the Triangle area, nationally, and worldwide proves that Payne’s personal energy, expertise, and passion for quality care of the dying translates well to skill-training for those working at bedsides. Here’s an overview, by no means comprehensive, of the range of resources available to us through the ICEOL. For more information on these and other ICEOL programs, go to their website at www.iceol.duke.edu

**BOOKS AND WRITTEN/WEB MATERIALS**

- Annotated Bibliography of Articles on Spirituality at the End of Life, drawing from academic and clinical journals from 1998 – 2008. The abstracts were taken directly from the journals where the articles were published. Topics include Buddhism, culturally effective EOL care, assessing patients’ spiritual needs, African Americans, HIV+ patients, and caring for spiritual pain.²

- A list of Web resources involving organizations that works in end-of-life care and related areas, including professional medical associations, hospice and palliative care organizations, professional education, pastoral and religious organizations, and academic organizations.³

- *Living Well, Dying Faithfully: The Role of Christian Practices in End-of-Life Care*, Eerdmans Publishing. 2006 ICEOL gathering of theologians and clinicians and their intense discussions of faith, hope and love as foundational aspects of caring. This book is a collaborative project with the Rev. John Swinton, B.D., Ph.D., R.N., professor in practical theology and pastoral care in the School of Divinity, History and Philosophy in Kings College at the University of Aberdeen, Scotland.⁴

- ICEOL and St. John Health (Detroit, MI) Partner on Palliative Care Resources for Churches to provide free articles on palliative care to over 300 Detroit area churches. Designed to work as worship program inserts and congregational newsletter items during the weeks of Advent, the articles address the difficult but important topics of advance directives, palliative care, hospice and bereavement. The series is titled “A Different Kind of Holiday Gift” and was developed to support faith community expansion of end-of-life ministries. This work is part of three-year collaboration between ICEOL and St. John Health to improve access to palliative care. Topics are “Conversation that is Courageous and Caring,” “Comfort for Those Who Don’t Want to Hurt,” “Comfort Care with Competence and Compassion,” and “Grieving Individually, But Not All Alone.”⁵

³ http://www.iceol.duke.edu/resources/index.html  
⁴ http://www.iceol.duke.edu/about/programs/theology.html  
• “Key Topics on End-of-Life Care,” resource on caring for African Americans at the end of life. Topics include spiritual, sociological and cultural perspectives on death and dying. Also included are case studies of communities working to improve care.6

• Jewish Ritual, Reality and Response: A Guide to Caring for Jewish Patients and Families by Rabbi Mark A. Popovsky. Introduces Jewish beliefs and practices around illness, death, and loss, and provides practical suggestions for responding to the sometimes complicated situations where the clinical, religious, and cultural are entwined.7

RESEARCH/SURVEYS

• ICEOL and Project Compassion partnered to survey faith leaders about how they address issues of serious illness, end of life, and grief in their congregations and what resources they need to help them do this important work. Over 900 faith leaders nationwide completed the survey. Survey results and the survey tool can be downloaded from ICEOL’s website.8

• “Local Scholars Grant Program” focuses on funding in three areas: spiritual care at the end of life, disparity in end-of-life care, and theological, literary or historical aspects of suffering, death and dying. To promote a multi-disciplinary perspective, proposals are encouraged from scholars who work in any discipline and are associated with Duke University, the University of North Carolina at Chapel Hill, or North Carolina Central University.9

SEMINARS

• “In Life and in Death We Belong to God: The Congregational Continuum of Care in the Presbyterian Church”

• “Magnified & Sanctified: Jewish Perspectives on Care at the End of Life”

• “Caring for Mind, Body and Spirit: Psychological, Bereavement and Spiritual Needs at the End of Life”

• “Leading When You Are Not Sure of the Way”

TRAINING

• APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life’s End) This training is designed for those working with African American patients and families facing serious illness in hospitals, hospices, outpatient clinics, nursing homes and office-based settings. Expected participants include physicians, nurses, social

6 http://www.iceol.duke.edu/resources/lastmiles/toc.html
7 http://www.iceol.duke.edu/news/jewishpatientsguide.html
9 http://www.iceol.duke.edu/about/programs/scholars.html
workers, medical chaplains and other clergy, psychologists, counselors, hospice and hospital administrators, pharmacists and family caregivers.  

- The Unbroken Circle: A Toolkit for Congregations Around Illness, End of Life and Grief, developed for clergy, faith community nurses, and congregational lay leaders interested in addressing end-of-life care issues in their congregations. Features practical guidance for developing innovative ministries for members facing illness, dying and grieving, and a comprehensive vision for weaving end-of-life care into the fabric of congregational life from tips for worship to model programs for education and leadership development.

**Speakers**

- Death, Politics, and Hope - A Conversation with Eleanor Clift The discussion with Eleanor Clift, author of the recently published Two Weeks of Life: A Memoir of Love, Death, and Politics, provided insights into the current atmosphere surrounding dying in America. Ms. Clift answered such questions as “Does health care reform have a chance this time around with President Obama?”, “What is hope for a stage IV cancer patient?”, and “Does the public really care about federal funding for hospice?”

**Arts**

- Vesta This Bryan Harnetiaux play offers a warm and often funny exploration of a family’s struggle with a variety of end-of-life issues as they come to terms with the eventual loss of their matriarch, Vesta. This 90-minute drama can be used by hospices, churches, divinity schools, medical schools and other organizations as an educational tool and as a vehicle for creating public dialogue about end-of-life issues.

**Education**

- Field education through Duke Divinity School. Projects have included ministering to inmates with life-threatening illnesses at Butner Prison, developing community-based care teams through Project Compassion in Chapel Hill, Duke HomeCare and Hospice chaplaincy.

- Chaplain trainees working with Duke University Hospital and Duke Hospice, in collaboration with Duke University Hospital’s Clinical Pastoral Education program.

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10 http://www.iceol.duke.edu/events/2009appealtraining.html