



2007 Annual Report

Creating knowledge, rediscovering old wisdoms about care at life's end

A Groundswell

ICEOL sees a surge in interest and progress in 2007



Richard Payne, M.D.

The year 2007 saw significant progress in the work of the Institute on Care at the End of Life at Duke University. "The planning and stage-setting of earlier years really took root in 2007," said ICEOL deputy director Jeanne Sheils Twohig, M.P.A. "The year was full of powerful examples of how we can best attend to our niche: the intersection of spirituality and healthcare at the end of life."

"The progress we made shows a clarity of mission," added ICEOL director Dr. Richard Payne, "and the way that mission has affected people's lives through educational forums, trainings, and dialogue."



Jeanne Sheils Twohig, M.P.A.

One illustration of that progress is the "Magnified and Sanctified: Jewish Ritual, Reality and Response" conference hosted at Duke in May 2007. Nearly 160 Jewish and non-Jewish clinicians, community members, chaplains, scholars and rabbis came together to explore Judaism's approach to life's end and the implications for caregiving. Each participant left with a copy of the guidebook *Jewish Ritual, Reality and Response at the End of Life: A Guide to Caring for Jewish Patients and Their Families*," an ICEOL publication that was debuted at the event.

Thanks to the Institute's marketing plan, and the appeal of the information within, the guidebook enjoyed great demand after the conference. Offices of Vitas Innovative Hospice, for example, placed bulk orders. NHPCO president and CEO J. Donald Schumacher held up the book as an example of effective outreach efforts during his organization's national conference. The Hospice of the Florida Suncoast and The Hospice Institute of the Florida Suncoast celebrated the guidebook in the cover story of its newsletter, and is also marketing the book in its 2008 products and services catalog. "This guidebook is a great resource for our own chaplains," said Susan Bruno, director of institute outreach for The Hospice Institute of the Florida Suncoast. Twohig pointed out that organizations see the book as a gateway to partnership between themselves and ICEOL.

The success of the *Jewish Ritual* book hints at one facet of ICEOL's future organizational strategy. "Learning and training are important, but to leave with a durable product in your hand extends what happens at a conference," said Twohig. "Going forward, a key part of conference and event planning will be making sure the learning has legs. Doing so creates a foundation for sustained learning while expanding ICEOL's product line and our reputation."

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The year 2007 was a time of significant progress for the ICEOL as a catalyst for growth and transformation. The Institute strengthened its position as a national resource to improve care for those who are at life's end.

This annual report spotlights ICEOL's recent activities and achievements, as well as discussions with key partners and clinical pastoral education residents.

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JEWISH
RITUAL, REALITY
AND RESPONSE
AT THE END
OF LIFE

A GUIDE TO
CARING FOR
JEWISH PATIENTS
AND THEIR FAMILIES



ICEOL had similar success in the Initiative to Integrate Practical Theology and End-of-Life Care, which first brought together theologians and clinicians for two days of intense discussions based on faith, hope and love as foundational aspects of caring. In 2007, those discussions became the springboard for *Living Well, Dying Faithfully: The Role of Christian Practices in End-of-Life Care*, a collaborative book project due out in 2008 by ICEOL and 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 in Scotland. “This first-of-its-kind initiative recognizes, explores and ultimately will describe how theology and medicine can learn from one another to improve the health and well-being of people who are dying and their loved ones,” said Swinton.

Support of scholarship

In 2007, ICEOL also enhanced its commitment to scholarship. The Institute rekindled a suspended grant program by making two awards last year to faculty who wish to explore end-of-life issues through a spiritual lens, using applied research. Dr. Donald H. Taylor, Jr., assistant professor of public policy at Duke, was awarded a grant to support his project titled “Same Sex Caregiving Pilot Study: How Care Is Provided and to What Effect,” which Taylor said deals with an understudied topic. “The ICEOL grant program is allowing my project team to investigate this important topic,” added Taylor, “and to determine the feasibility of a larger study of this type.” Also, ICEOL awarded a grant to Dr. Richard Lischer, the James T. and Alice Mead Cleland Professor of Preaching at Duke Divinity School, for his study “Doing the Stations: Suffering and Dying Well as a Practice of the Church.”

ICEOL faculty member Dr. Allen Verhey was named a Henry Luce III Fellow in Theology for 2008–2009. He will work on a project titled *Ars Moriendi: Jesus’ Death and the Christian’s Dying*. “The *Ars Moriendi* literature, now much neglected, was popular in the fourteenth through the eighteenth centuries,” said Verhey. “It nurtured and guided both ‘the art of dying’ and care for the dying.” Verhey plans to identify strengths and weaknesses of that tradition and to retrieve especially the attention to Jesus’ death within that tradition as a model and source of consolation.

ICEOL is committed to the continuation of these kinds of activities in the Divinity School and greater university to support faculty and students in their research and educational tasks.

Responding to demands

A 2007 survey conducted by ICEOL tapped more than 900 clergy from across the country to learn about their needs regarding end-of-life care. “We found that clergy want and need more education, information and resources on serious illness, end of life and grief to better support their congregations,” said Payne of the findings, which were presented at the July 2007 conference of NHPCO. Among the findings: Only 39 percent of respondents were very comfortable training lay leaders to provide support or organizing lay caregiving support for practical, emotional and spiritual needs. “We are using these and other findings to develop a tool-kit of resources for clergy and lay leaders,” said Twohig, “so that they can better address end-of-life care issues in their congregations.”

It is results like those that help focus the future work of ICEOL. To lay the future path, Institute leaders continue to clarify programmatic and organizational approaches to the mission. Perhaps the best example of that work is the refinement of a three-year strategic plan, including a business plan to describe the Institute’s financial and fiscal status and provide a stronger basis for financial forecasting, diversification of funding, and a strategy for revenue generation from programs, products and services. Another example of programmatic work is the efforts of Merry Davis, associate director of programs and communications, in the organization of events, marketing and communications plans. Davis also stepped up communications efforts in 2007, from more frequent publication of e-newsletters to expanded online offerings of papers, brochures and other communications.

“When you look back on the past year’s work, you start to see that the mosaic really has a picture to it,” said Twohig. “It is so good to see our programmatic and administrative efforts continue to take shape. We can’t wait to implement the next steps of our vision.”

*“Publications like
this guidebook help
position ICEOL as a
partner, an opportunity
to mutually enhance
work in end-of-life care.”*

— ICEOL Deputy Director
Jeanne Sheils Twohig

Significant Strides

Creating and testing new models of care

In 2007, the Palliative Care Collaboration between ICEOL and St. John's Health System (Detroit) made great progress in improving access to and quality of palliative care for all patients. Based on a survey of SJH staff on how institutional culture influences development of palliative care initiatives, the project team is now strengthening policies and practices related to palliative care. The Collaborative is also piloting a screening tool to identify patients systemwide in need of palliative care and is launching education initiatives for physicians, nurses, chaplains and clergy.

Duke and SJH capped off 2007 with a ceremony recognizing the original trainees, dubbed Palliative Care Champions. The event spurred an article in the January 2008 *St. John Health Physician* newsletter. "I have been so inspired by these medical professionals who have answered the call and become so passionate about palliative care," said Rhonda Bishop, R.N., SJH project director, in the article.

Education initiatives reached outside the SJH system as well. A community forum brought together clergy to learn about end-of-life issues. The community training was modeled after a program called Compassion Sabbath, created by the Practical Bioethics Center in Kansas City, of which ICEOL board member Myra Christopher is president and CEO.

Producing resource material

Following the success of the "Magnified and Sanctified: Jewish Ritual, Reality and Response" conference in May 2007, ICEOL published a guide that dives deep into the topics of the conference. Titled *Jewish Ritual, Reality and Response at the End of Life: A Guide to Caring for Jewish Patients and Their Families*, the guide has garnered attention from hospices, clergy, divinity schools and similar organizations. The book, which is available for sale, continues to enjoy high demand and is now in its second printing.

In 2007, ICEOL undertook a new project: the Toolkit of End-of-Life Care Resources for Clergy. A collaboration among ICEOL, Project Compassion, an organization that supports people living with serious illness, and NHPCO's Caring Connections initiative, the toolkit strengthens the ability of faith communities to address end-of-life issues. Caring Connections is creating a companion guide to help hospices and end-of-life coalitions reach out to and support faith communities in such efforts.

ICEOL also partnered with NHPCO on presenting the brochure "Offering Spiritual Support for Family or Friends," with information and suggestions for providing spiritual support to loved ones facing serious illnesses. "You do not have to be an expert in spiritual care to offer support," said ICEOL deputy director Jeanne Sheils Twohig. "This pamphlet has tips for anyone acting as a companion to someone with a serious illness."

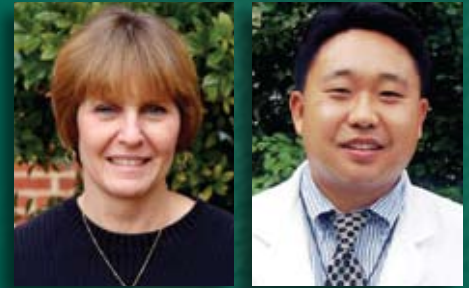
Encouraging new thinking & dialogue

In 2007, Victor Dzau, M.D., chancellor for health affairs at Duke University and president and CEO of Duke University Health System, asked ICEOL director Dr. Richard Payne to spearhead the creation of a vision for palliative care for Duke. To that end, Payne is bringing together parties who work in palliative care and end-of-life issues to design an academic model of palliative and end-of-life care which integrates patient care, teaching and research. "This request demonstrates our role as a convener and a facilitator of discussion," said Payne.

For "Partners in Caring: Strengthening Clergy and Clinician Collaboration at the End of Life" in October, ICEOL collaborated with Hospice of Harnett County (NC), which hosted the discussion, as well as Campbell University Divinity School. "As Harnett County's oldest non-profit agency, we are always seeking to improve communication between the agency and our patients and families, as well as between professional caregivers," said Gordon Clapp, director of marketing at Hospice of Harnett County. For the conference, ICEOL developed a case study that became the heart of the program, raising issues that can happen when the spiritual and medical sides of end-of-life care intersect. "This event was created for the community, but is also a model for other hospices and organizations to follow to generate dialogue around these important issues," said Payne.

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Specializing in Spiritual Care



Miriam Saxon

Stanley Kim

Miriam Saxon and **Stanley Kim** are spending the year as chaplain residents in the Duke University Health System, where they are learning how to provide spiritual support to patients and families at the end of life. This residency is offered through the hospital's Clinical Pastoral Education (CPE) program. In 2007, ICEOL provided financial support to these CPE residents and connected them with resources and learning opportunities. Selected through a nationally competitive process, they have split their pastoral care training between Duke University Hospital and Duke Hospice, where they are chaplain trainees under a certified CPE supervisor.

For Saxon, who earned her Master's of Divinity at Duke and is an ordained Episcopal priest, clinical pastoral training began with an internship at Alamance (NC) Regional Medical Center in 2005. For Kim, the process was more extensive—his family transferred from Buffalo, New York, where he spent three years as a staff chaplain at Buffalo Sisters' Hospital, to take advantage of the opportunities at Duke. "Duke understands how important that spiritual component is to end-of-life care," said Kim.

ICEOL has contributed to the residents' education and networking opportunities—for instance, sponsoring their attendance at the NHPCO's Clinical Team Conference in New Orleans, and inviting them to APPEAL training sessions and the "Magnified and Sanctified" conference at Duke. The residents say they will carry the ICEOL mission into their future work. Saxon enjoys a half-time pastoral position at an Episcopal church in Raleigh, where she says she will continue to work with the congregation on end-of-life issues. She will also seek part-time hospice work.

Kim will embark on a research project studying disparities in access to health care, particularly spiritual care at the end of life, the role of chaplains, and the potential for care by home pastors. "I'm Korean, and in my community people approach pastors to seek end-of-life support," said Kim, "but often pastors have limited knowledge about end-of-life care and resources." He also plans to train to become a certified CPE supervisor himself.

ICEOL Advisory Board

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Conducting trainings & educational conferences

ICEOL provided training on end-of-life issues to pastors with “Through the Valley of the Shadow: Pastoral Ministry and End-of-Life Care,” a multi-district meeting of Methodist clergy in February 2007. ICEOL saw the event as an opportunity to create a 10-hour, modular curriculum to teach clergy about death and dying and how to build capacity within their congregations to attend to end-of-life issues. The Center for Continuing Education at Duke Divinity School collaborated with ICEOL on the training. The course will become a signature training offering of the Institute. In addition, this forum sparked lasting interest and gave rise to the “Partners in Caring” discussion and dinner in Harnett County, NC, later in the year.

The Institute enhanced understanding of denominationally specific care through two conferences in 2007. In March, Duke joined with Presbyterian Church USA to host “In Life and Death We Belong to God,” attended by more than 300 participants. The conference inspired related discussion on North Carolina public radio, with Dr. Payne as a featured guest. In May, attendees from 14 states participated in a one-day conference, “Magnified and Sanctified: Jewish Ritual, Reality and Response.” Participants listened to nationally known keynote speaker Rabbi Elliot N. Dorff, Ph.D., rector and professor at the Jewish Theological Seminary and author of 12 books and more than 150 articles on Jewish thought, law and ethics. Attendees also benefited from sessions led by experts in Judaism’s approach to life’s end and experienced artistic interpretation of Jewish traditions through song and dance.

As part of the continuing APPEAL initiative (A Progressive Palliative Care Education Curriculum for the Care of African-Americans at Life’s End), ICEOL convened another in a series of trainings in November 2007 at Duke. Nearly 120 health care, social service and spiritual care providers from around the country attended. APPEAL training helps build a community of trained caregivers to provide physical, social, emotional and spiritual support to African-American patients and families facing live-ending illness.

Supporting student development

ICEOL continues to foster the spiritual formation of students. Its 2007 Westbrook Scholarship supported Aaron Klink, a Duke Divinity School Th.M. student who is interested in end-of-life issues. ICEOL supported the creation of the Spiritual Formation Group, a group of second- and third-year Duke Divinity School students who explore spiritual issues regarding the end of life. ICEOL also assists the student group HOLD (Helping Others and Ourselves in Life and Death). At 78 members strong, HOLD links ICEOL with the wider Divinity School community.

ICEOL enhanced Duke Divinity student education by sponsoring eight Field Education students in 2007, in placements ranging from Butner Federal Prison to several hospices. One Field Education participant, Cari Willis, compiled her learnings from Butner Federal Prison into a book titled *The Overwhelming Grace and Mercy of Christ*. ICEOL also supported two Clinical Pastoral Education (CPE) residents who are concentrating on end-of-life care: Miriam Saxon and Stanley Kim. And, faculty members who work with ICEOL, including Allen Verhey, Ph.D., Professor of Christian Ethics, and Tonya Armstrong, M.S.W., Ph.D., offered courses in Duke Divinity School addressing topics around spirituality and the end of life.

Building strategic relationships

ICEOL continued to partner with like-minded organizations to conduct numerous events nationwide in 2007. Examples include the partnership with Hospice of Harnett County and the Campbell University Divinity School for “Partners in Caring,” as well as the partnership with NHPCO for the conference “Caring for Mind, Body, and Spirit: Psychological, Bereavement and Spiritual Needs at the End of Life.”

The Institute is also forming multiple partnerships for APPEAL training sites. “Given the high demand for APPEAL training,” said APPEAL coordinator Valerie Chestnut, “we are building partnerships that will allow us to take the program deep into the communities where it can have the largest impact. The opportunities are nearly limitless.”