

Living well. **DYING***well.*

CENTER FOR **SPIRITUALITY & HEALING**

Empowering **COMMUNICATION** at the End of Life

*Supporting Individuals,
Families, and
Loved Ones*

*Sustaining Skills
for the Health Care Team*

*Improving Wellbeing
for Communities*



UNIVERSITY OF MINNESOTA

Driven to DiscoverSM

Living well.

dying well.

A new initiative aims to regain the **LANGUAGE** and **SKILLS** needed to **EMPOWER**, **NURTURE**, and **CARE FOR PEOPLE** at the end of life.

When Frank Bennett was a chaplain resident at a Twin Cities hospital, he checked in on a woman who had end-stage lung cancer. She knew she only had a few days left to live, but she wasn't able to acknowledge to her husband and daughters that her time was short, much less that she had specific wishes for how she wanted to live while she was actively dying.



Frank Bennett, MDiv, BS

Her family wasn't blind to her condition. In fact, they'd told Bennett that they could see her "shrinking before their eyes." They wanted to talk about it, but worried that bringing up the specter of death would frighten her. So they said nothing.

Bennett was early into his career as a chaplain, but he could tell everyone was suffering from not being able to have a difficult but crucial conversation. "I was amazed that the patient, family, and providers felt like they couldn't talk to each other," he says. So, with the patient's encouragement and the permission of everyone involved, he convened a meeting in her hospital room.

The patient was first to speak. She told her husband and daughters that she knew she was dying and wanted to go home and be with her family. She hoped to work up enough energy to be able to get

out of bed and make pies, an activity that had always made her happy.

"There were tears of both sadness and love all around the room," says Bennett, who is now an associate minister at large for pastoral care at Wayzata Community Church. "Then she went home, made her pies, and died."

Since that experience, Bennett has facilitated numerous conversations in a variety of settings to help the elderly and terminally ill communicate with their loved ones and healthcare providers about what really matters as life winds down. He stresses, however, that he is not a miracle worker. "I have no magic," he says. "It's just that, as a culture, we've gotten out of the practice of talking about dying. If patients, caregivers, and healthcare providers are empowered to speak openly and are given some tools for how to start these conversations, they could do it without me."

Providing those tools to a broad range of people — individuals facing serious health challenges, elderly citizens, family members, caregivers, doctors, nurses, hospital aides, hospice workers, and others — is the goal of a new initiative that has launched at the Center for Spirituality & Healing. Called Living Well/Dying Well, the program combines university-level coursework, community forums, workshops, and pilot programs in senior living settings to help us regain the language and skills needed to empower, nurture, and care for people at the end of life.

The program is a natural fit for the Center. “We want to support wellbeing at every stage of life,” says Mary Jo Kreitzer, PhD, RN, FAAN, founder and director of the Center. “Focusing on living well and dying well is an exciting new program area for us.” The initiative reframes end-of-life deliberations from focusing only on death and dying to looking more broadly at life’s values, goals, and aspirations.

That’s no small task when you consider that at a time when medicine has forestalled death, Americans are so skittish about the D-word they put off talking about it for as long as possible. While an estimated 1.5 to 1.6 million Americans receive hospice care in the United States each year, over 35 percent of those patients are there for less than seven days before they die, according to a 2013 report by the National Hospice and Palliative Care Organization. Experts say that waiting so long to access hospice care is a lost opportunity to provide comfort care and symptom management to people who want and need to focus their remaining energy on their relationships.

In fact, honest conversations actually facilitate the emotional work that can happen when a person is close to dying. “There are some deep questions that are asked as a person enters the very last stage of life,” according to Louise Delagran, MA, MED, education specialist and instructional designer at the Center, who developed the program’s first academic course, “Empowering Patients in Living Well/Dying Well: Providing Humane Care at the End of Life.”

What makes life meaningful to me?

When are the tradeoffs too great to want to stay alive?

At what point can I no longer stand the pain?

Answering those questions can provide important guideposts to make a person’s death as comfortable and meaningful as possible. Take Bennett’s lung cancer patient. Like most people who are dying, she wasn’t thinking about work or unrealized ambitions. She was primarily concerned with being at home with her family and enjoying simple pleasures, in her case, making pies. If she hadn’t discussed what she wanted with her family and caregivers, chances are she would have died in the hospital. “If you talk to enough healthcare providers, most will tell you a story about a person who is at the end of their life

and how, once they were able to communicate about what they wanted and clean up unfinished business, they were able to have the death they needed,” says Bennett.

The 5000-level course Delagran designed began in the Fall 2015 semester. It’s geared toward healthcare professionals — including students studying medicine, nursing, and social work — who often have little to no training about how to facilitate these conversations, and other students who are interested in this important topic.

“Nurses at the bedsides of people who are dying often witness a lot of suffering and want to provide holistic care, but can’t due to healthcare system barriers,” says Susan O’Conner-Von PhD, RN-BC, an Associate Professor in the University’s School of Nursing who teaches about palliative and end-of-life care. Sometimes, healthcare teams want to try yet another treatment, even when the patient is ready to die. It can also be the case that families, in their grief and fear about a loved one’s death, want to delay the death, although the patient is suffering from the harmful effects of treatments.

Navigating these dynamics without education and ongoing support can cause burnout for physicians, nurses and other healthcare providers who struggle to make the best decisions when they are in the face of something as frightening and emotionally fraught as death. O’Conner-Von remembers a past nursing student now working in hospice who called her cell phone, worried because a patient who was actively dying didn’t have adequate pain management. “The patient’s family wanted her to be comfortable,” says O’Conner-Von. “But some family members were worried that morphine would hasten her death. The novice nurse felt she needed to advocate for the patient so she could lessen her pain.”

With O’Conner-Von’s coaching, the novice nurse was able to talk with the family, who all agreed that they didn’t want their loved one to suffer from pain. She was given morphine, which made her comfortable enough to relax and realize that she desperately wanted to phone a family member and ask them for forgiveness. She died within 24 hours after the phone call. “The family was so appreciative of this nurse’s guidance,” says O’Conner-Von. “They were too afraid [of what was happening] to call the physician to help with her pain management.”

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Living Well/Dying Well builds upon a growing cultural awareness about the value of having a “good death.” Not only are Baby Boomers advocating for more control of their healthcare at all stages of life, but the popularity of surgeon and public health researcher Atul Gawande’s book *Being Mortal: Medicine and What Matters in the End* — which reached No. 1 on The New York Times Nonfiction Best Seller List — signals that people are hungry for these conversations.

“Being present with a person at the end of their life is a job description for which everyone is qualified,” says Bennett. “Whether we’re the person facing mortality, a care partner or loved one, a clinician, or staff of a care facility, celebrating these extraordinary moments can open doors to healing, wholeness, and even peace.”

“Dying isn’t a medical or even spiritual condition” says Bennett. “It’s a human condition.”

The Living Well/Dying Well initiative focuses on four areas, including
ACADEMIC CURRICULUM,
COMMUNITY ENGAGEMENT,
CONTINUING EDUCATION FOR HEALTHCARE PROFESSIONALS,
and **EMERGING SCHOLARSHIP.**

Living Well/Dying Well: **The Initiative**

The Center seeks to bring scholarship, new skills, and innovative tools to a broad range of people whose interests and expertise intersect at the end of someone’s life. In fall 2015, we launched a new course called **“Empowering Patients in Living Well/Dying Well: Humane Care at the End of Life.”** The course is also available as modules that can facilitate online learning.

Living Well/Dying Well: **Our Leadership**

The Center is pleased to welcome two seasoned professionals to this new initiative.

Frank Bennett is a Senior Fellow with the Center, and program lead of the Living Well/Dying Well initiative. He is an ordained UCC minister, chaplain, and teacher. He is an advanced healthcare directive facilitator and has worked in acute, palliative, and hospice healthcare settings.

Susan O’Conner-Von PhD, RN-BC, is Director of Graduate Studies at the Center and an Associate Professor in the UMN School of Nursing. Susan teaches courses on spirituality, palliative and end of life care. She is a member of the Board of Directors for the Minnesota Network of Hospice and Palliative Care and the American Society for Pain Management Nursing. She is also a long-time hospice volunteer.

Living Well/Dying Well: **Opportunities and Contacts**

We are eager to co-create with you a Living Well/Dying Well program tailored to your needs. Programs can be customized for audiences including individuals and families facing end-of-life, community organizations, healthcare professionals, academic institutions, student groups and more. To learn more about how we can support you in achieving your goals, please contact the Center’s new Director of Business Development and Community Relations, Sue Nankivell at sue@umn.edu or **612-626-2395**.

There also are many ways that philanthropic support can advance the initiative. These include pilot programs, technology-enhanced education tools and public awareness strategies. The Center’s Development Director, Dianne Lev, is available to talk more about how your giving can make a profound difference; she can be reached at dlev@umn.edu or **612-624-1121**.