



OHSU CENTER *for* ETHICS *in* HEALTH CARE



Days of Grace

A dying poet's powerful teaching about life-threatening illness

Dennis Bleything was a man of words. They were the tools of his trade as a professional writer; the jewels of his gift for poetic expression; and the currency of his role as teacher of many things to many people. He was a communicator, whose eloquence, wit and wisdom changed lives, lifted spirits and touched souls.

It was entirely in character, then, that at the very end of his life – even with a body ravaged and diminished by the devastating effects of Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease) – Dennis would choose to continue his teaching and giving of self. He did this through his foundational role in the creation of a new OHSU course, adapted from a similar course at Harvard University, that offers first-year medical students an unprecedented window of understanding into life-threatening illness.

His physical energies had become a profoundly precious resource. His ability to form words was reduced to the slow, hollow unwieldiness of a computerized voice system. But the spirit expressed through his vividly sparkling eyes was the spirit of a man who elected to live completely and purposefully every minute that was given to him.

"I want to do it all!" he said to Susan Tolle, MD, director of the Center for Ethics in Health Care, in response to her question about his participation in the course. And – while sadly he didn't live long enough to fulfill his vision of becoming one of the first patient/teachers to meet weekly with a first-year medical student – his ability to be deeply present to his own

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photo on cover:
Teaching was second nature to Dennis Bleything even as his illness progressed

(continued from cover)

experience, and his understanding of what that experience could teach others, became the bedrock of the thinking behind this powerful new course.

“ALS is not for wimps,” asserted Dennis in his typically succinct and understated fashion. Certainly, this is not the stuff of which medical textbook prose is made. But it cuts straight to the heart of what ALS is - a terminal disease, an unrelenting progression of losses and indignities.

“Dennis knew that simple truths spoken from the heart could offer students some of their deepest learning about illness and its effects on patients and their families,” said Dr. Tolle.

“This is the kind of teaching that will become the foundation of a doctor’s education. The profound way in which our students are learning directly from people who truly know about what it is to be living with illness is in large part because of what Dennis showed us this course could be.”

Dennis mourned the losses of his independence, the taste of the good food he liked to cook and could no longer eat, and the lithe strength of his once-athletic body – along with so many other losses that were the inexorable progression of his disease.

“You can persist anyway,” he concluded though. And he was sustained by the unconditional love and support of his family and friends, his own strength – which surprised him in its depth

“Dennis knew that simple truths spoken from the heart could offer students some of their deepest learning about illness and its effects on patients and their families.” Susan Tolle, MD

and steadiness – and his fervent belief that experiences like his, impossibly difficult though they might be, had meaning and purpose because of what they could teach others.

Susan Tolle met with Dennis six times to brainstorm what the Living with Life Threatening Illness course could be at OHSU. And each visit provided new insight and new ideas about how the teaching might unfold.

Diane Bleything shares her experience and insights with first-year medical student Sharl Azar



Even after his death, Dennis' teaching voice was still clearly heard thanks to the courage and generosity of his wife, Diane. Offering precious insight into her husband's experience with ALS and her own as caregiver, she urged students to bring their whole heart to their work, to maintain their authenticity and honesty. "Look people in the eye," she said. "And above all – listen." Because that it was Dennis would have taught.

One student in particular, Sharl Azar, who had been assigned to meet with Dennis, recalled both the shock he felt at the news of Dennis' death (his reaction being the first of many profound lessons he was to learn during the course of the program), and how the time he was able to spend with Diane a few weeks later was "one of the most life-changing experiences of [his] life."

A future oncologist, Sharl had no idea what to expect from the program or from his meeting with Diane. What he learned reshaped entirely his perspective on medicine.

"I understood how the care Dennis was getting affected every aspect of his life," Sharl explained. "Illness is so often treated as something static, limited to the 15-minute doctor visit – but it's really a dynamic process that extends far beyond, into the whole family circle. Dennis taught me to listen. I learned that what he needed most was to know that people could still hear him."

Sharl summed up his experience this way: "We're so engrossed in the science that we forget the art of medicine. This program was a remarkable gift. It reminded me why I am doing what I'm doing."



The Living with Life Threatening Illness course is directed by Erik Fromme MD and co-directed by Susan Tolle, MD

“Dennis taught me to listen. I learned that what he needed most was to know that people could still hear him.” Sharl Azar, first-year medical student

This is exactly the teaching that Dennis would have hoped for. "He was so excited about this class," Diane remembered. "It gave him a surge of new hope, a real boost, that he could be part of it."

A few weeks before he died Dennis remarked how pleased he was that he could still make people laugh, "though not as often as before," he added wryly. He described himself as "bursting all the time" with what he wanted to share. And, just the day before his death, he was able to attend a reading of his poems. He was a communicator always.

With every means available to him – his deeply expressive eyes, his broad smile, his elegant fingers on the keyboard – he found ways to give expression and meaning to his life with ALS. Generations of new doctors and their patients will have reason to be deeply grateful that he did.

The Living with Life Threatening Illness course is one of several new education programs that will be funded through the Miles J. Edwards Chair in Professionalism and Comfort Care (currently almost \$1.8 million has been raised toward the \$2.5 million needed to complete the Chair). In the meantime, this program is made possible through the vision and generosity of The Collins Foundation.



A message from
Center for Ethics in Health Care
donors Cornelia Stevens and
Lisa Andrus-Rivera

UPCOMING *events*

JUNE 15, 2007

*Statewide Palliative Care Conference,
“In Patient Palliative Care:
Moving to the Next Level.”*

Co Host: Legacy Health Systems
Red Lion Jantzen Beach, Portland, OR

JULY 27, 2007

*Regional Palliative Care Conference,
“Practical Palliative Care:
Symptom Management in Serious Illness”*

Co Host: Bay Area Hospital
Southwestern Oregon Community College
Hales Center for the Performance Arts
Coos Bay, Oregon

SEPTEMBER 21, 2007

Regional Palliative Care Conference
Co Host: Sky Lakes Medical Center
(formerly Merle West Medical Center)

Sky Lakes Medical Center
Klamath Falls, OR

On May 21st, an article by Don Colburn appeared on the front page of the Oregonian. This article featured first year medical student, Natasha Fewkes, visiting another patient teacher, Gordon Waters, to learn what facing a life threatening illness is like from a patient's point of view. Their six conversations addressed whatever the patient teacher, Mr. Waters, wanted to talk about, and it was extremely moving for both of them: for him he was given a sense of purpose, and for her, a life-altering experience about what medical practice can be.

There were six student/patient teams in the Living With Life Threatening Illness course which was modeled on a similar curriculum started at Harvard University, and unique to the West Coast. This course is the latest example of what the Center is doing to enrich the curriculum at OHSU by innovative methods.

Our Center and the amazing work it's doing in several areas didn't happen overnight. Since 1989, innovative programs and techniques in End-of-Life issues made the Center the national leader in this area today. It started from an office with no funding. It was all of you who are reading this letter who made this happen, brick by brick; dollar by dollar. We are thankful that so many people both faculty and community volunteers have also given generously of their time and deeply of themselves as Dennis and Diane Bleything and Gordon Waters have done. Community volunteers help find just the right people to serve as our patient teachers. The gift of sharing their wisdom when they have so much to teach but so little energy to spare is remarkable. In one way or another, dozens of people partnered with us to make this new course a reality.

Moreover, hundreds of people have shown their support through these fifteen years, and we thank you from our hearts. It takes teamwork and dedication on the part of all of us to educate the next generation of health care professionals.



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