



The photos in the image above depict, clockwise from the top, the mothers of four DMS faculty members—Drs. Katherine Little, Ira Byock, Dennis McCullough, and Deborah Peltier. The images on the succeeding pages are imagined still lifes suggested by each of their sagas, but the photos in them are actual family snapshots.

Lessons in Dying Well

By Deborah Lee Luskin

Physicians are trained not to share personal information with patients and most don't. They tend to keep their own counsel about everything from their health to family concerns.

But when a physician experiences the death of a parent, all bets are off. Physicians will often share such a close-to-the-heart loss with others—including their patients. Regardless of how many deaths a physician has attended, or how anticipated a parent's death may have been, when a parent dies it rocks a doctor's universe.

Their years of training, of applying evidence-based science to illness and injury, of supporting patients facing their own mortality—none of that offers any defense against the humanity that comes crashing down on us all when we face the loss of those who gave us life. Despite (or perhaps because of) that fact, the death of a parent seems to provide physicians with a new perspective on their work.

The poet William Blake wrote that someone "who would do good to another must do it in minute particulars." What follows are the "minute particulars" of several stories of parental loss experienced by members of the Dartmouth faculty. In each instance of death, whether due to illness or to advanced age, the physicians drew lessons from the experience—lessons they've since integrated into their daily delivery of patient care. In all these instances, "care" is the operative word. What these stories have in common is the realization that the dying need attentive care.

It is also clear from these stories that dying is a process, and that it can be a fruitful one for both the dying and the mourners left behind. Repeatedly, these are stories about a rich time in human devel-

opment, for the parent exiting life and for the child taking another step closer toward maturity—and his or her own death. What is also clear from these stories is that when the mourners are physicians, their patients—indeed, all of medicine—benefit.

Dying is a part of living

"What I really needed to know about care of the dying I learned not in medical school or my residency training but from the care my parents had given to Leah, my maternal grandmother," Dr. Ira Byock writes in his 1997 book, *Dying Well*. He was eight years old when his grandmother had a stroke. For the next year, she lived with Byock's family, receiving loving care until she was able to rejoin her husband in their own home. Byock, his sister, and their parents continued to visit them regularly and to help with shopping and household chores.

Years later, as Byock neared the end of his residency in family practice in California, he learned still more about the impact a terminal illness has on a family. "An individual receives a diagnosis," he says, "but illness happens to a family."

His father, Seymour Byock, had been diagnosed with and treated for pancreatic cancer at home, in New Jersey. With his wife, Ruth, Seymour Byock traveled to California to celebrate his 63rd birthday with their son, daughter-in-law, and first grandchild. No sooner had his parents arrived in California than Byock's father needed to be hospitalized. Instead of visiting for two weeks, he stayed for almost two months. Seymour Byock died at his son's home, a choice that was then very unusual.

As he recounts the experience of caring for his father at home, Byock explains the profound lesson he learned about the limits of medicine—especially hospital-based medicine, where death is considered a problem. "Medicine equates dying with death," Byock says. "But I've learned dying does not equal death. Dying is a part of living, with unique challenges and opportunities."

Learning from dying, and helping people die

Most physicians have far more experience with death than the average person does. Even so, when they experience the death of a parent, it shakes them personally and affects them professionally. Four physicians with Dartmouth ties share final, powerful lessons they learned from a parent—how best to care for someone facing the end of life.

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On the eve of his departure from Montana for New Hampshire, Ira Byock received a call from his sister. "It was the phone call we all dread," he remembers.

well, has become Byock's life work. While practicing family and emergency medicine in Montana, Byock helped lay the foundation for palliative care in this country. A past president of the American Academy of Hospice and Palliative Medicine, he was recruited to Dartmouth in 2003 to head DHMC's Palliative Care Program.

Literally on the eve of his departure from Montana for New Hampshire, Byock received a call from his sister. "It was the phone call we all dread," he remembers. At first, all they knew was that their mother had been in a car accident. They later learned that while stopped in traffic, she had suffered a fatal heart attack. Despite the chaos of the sudden death, Byock knows it could have been a lot worse. No one else had been injured. Nothing important had been left unsaid. And his mother had put all her legal and financial papers in order so that they were easy to find. "We felt cared for by my mother, again and again, even after her death. She was ready. She had done it for us. We continued to feel cared for into an uncertain future."

Before she died, Ruth Byock had read the galley-

of the most recent of her son's four books, *The Four Things That Matter Most*. Those four things, he explains in the book, can be reduced to 11 words: *Please forgive me. I forgive you. Thank you. I love you.* "I know this stuff works," Byock says. "I draw comfort [from] knowing nothing critical was left unsaid. I apologized for all the worry I caused her when I hitchhiked across country [as a teenager]. I thanked her. I told her I love her."

The fact that his mother left her affairs in such good order has also made Byock a big proponent of advance directives. He's quick to add that he thinks such documents are often misunderstood. "They are not prescriptions," he says. "They are a statement of values and preferences. It's a way for an individual to project their caring into the future." Byock wants to make having an advance directive routine for all patients at DHMC. This year, his department sponsored the first annual National Health-Care Decisions Day. It was held on April 16, the day after the income-tax deadline. "Death and taxes," Byock explains. "They're both part of life."

Byock has become an articulate and recognized proponent of the need for a shift in the country's cultural climate, from avoiding to accepting end-of-life issues. "It's time we boomers acknowledge we're mortal," he says. "We're going to die, and we need to integrate that with rich and healthy living."

Byock came to Dartmouth in order to advance the nation's appreciation for palliative care. "This is the place to change the system," he says, "to transform medicine by advancing both cutting-edge medical technology [and] the highest of human values. These are complementary goals, not competitive ones."

It's the getting there

Dr. Deborah Peltier's widowed mother, Peggy Peltier, put all four of her children through college and grad school as a teacher of junior high school English. After her kids left home, Peggy Peltier stayed active and independent and remained involved in church and community affairs. With savvy foresight, she had a ramp and grab bars installed in a ground-floor bathroom when she was only 75, long before she needed such aids. She cross-country skied into her eighties, until a series of strokes finally slowed her down. Well established in her community, she was able to stay in her own home even then. Deborah Peltier's sister, Mary, lived with their mother until she needed constant care, and then she moved to a nearby nursing home.

During the years their mother was at home, the four siblings supported her and one another. The three who lived elsewhere shared the cost of keep-

ing their mother and sister at home and took turns giving their sister regular respite. Peggy Peltier continued to enjoy a busy social life, accepting rides to weekly prayer meetings and welcoming friends, former students, and church members into her home. A niece and nephew delivered her groceries weekly. A cousin who is a physical therapist also visited regularly and helped provide care.

"I don't know what we would have done without our family visits of grands and great-grands," says Deborah Peltier. An associate professor of medicine at DMS, she credits her mother's cheerfulness as a tremendous asset. It drew friends to come visit when she could no longer go out; even after her mother moved to the nursing home, she remained cheerful, Peltier says. "Cheerful is a good kind of demented to be," she chuckles. "It's easier on your caregivers."

When Peggy Peltier entered the nursing home, all four siblings were comfortable with their mother's advance directive declining intensive medical intervention. She was in the nursing home for three years. The winter she was 94, she caught the flu. There was no ambulance, no hospitalization, no ventilator. She was kept comfortable at the nursing home. It was there, 10 hours after her diagnosis, that she died, with Mary at her bedside.

Participating in her mother's care during the last decade of her life reinforced for Deborah Peltier the importance of civility. "A parent will die, but sisters remain," she says. Knowing that her children would maintain good relationships after her death "is what my mother would have wanted," she adds. Peltier is grateful not only that she could help care for the parent who had supported her through college and medical school, but also for the lessons she learned as her mother's health declined—lessons she now applies daily in her practice of geriatrics.

After spending the first part of her career as a psychiatrist, Peltier completed a geriatrics fellowship at Dartmouth. She has now taught geriatrics at DMS for almost 20 years and is currently the director of the geriatrics and ambulatory-care clerkship. She also works at the VA Medical Center in White River Junction, Vt., in a new home-care program. "It's a delight," she says of the time she spends visiting elderly patients in their homes. She often shares her mother's story with new patients and their family members; she finds that it both breaks the ice and introduces many of the practical issues involved in end-of-life caregiving.

Peltier says she learns much more from a home visit than from an appointment at the clinic. A home visit provides cues for questions—about family photos on the wall, for instance—whose answers offer insight into the patient's past experiences and



current cognitive capabilities. Home visits also allow Peltier to find out who shovels the walk, what's in the fridge, and how far it is from the bedroom to the bathroom. She has a chance to ask caregivers (often spouses who themselves are aging) if their shoulders hurt, if their spirits are sagging, if they are getting adequate medical care.

As Peltier knows from her own experience, providing around-the-clock, live-in care to even a cheerful elderly person is physically and emotionally demanding for a healthy, middle-aged child. It is perforce much more difficult for an elderly spouse. So she realizes that aging patients and their aging spouses can't go it alone. She and her team—which includes a nurse, a social worker, a chaplain, and occupational and physical therapists—assess the depth and breadth of support available to each patient and arrange for more help as needed.

Peltier says her practice is richer since her mother's death. She feels closer to her patients since witnessing her mother's dementia—what Peltier calls "death by inches"—and seeing how it affects a loved one's personality and challenges relation-

Deborah Peltier's mother cross-country skied into her eighties, until a series of strokes finally slowed her down. Even then, she was able to stay in her own home.



Katie Little's mother was able to return home briefly, but more complications ensued. As per her wishes, Virginia Little received comfort measures only.

ships. "I'm more compassionate," she says. "I know how hard it can be, even with everyone wanting it to go in the same direction. It's not the death part that's so bad," she says. "It's the getting there."

Words they understand

Dr. Katherine Little's parents had signed up to live at Wake Robin, a continuing-care community in Shelburne, Vt., even before it was built. They were in their sixties, forward-thinking, and planning for retirement and eventual old age after careers that had evolved into a commuter marriage: Katie Little's mother had been a professor of social work at the University of Connecticut, and her father a professor of political science at the University of Vermont (UVM). Both had signed living wills many years earlier, and everyone in the family was comfortable with these advance directives.

Then, when she was only 64, Virginia Little was diagnosed with metastatic melanoma after she suffered a pathologic fracture—a break caused by illness-induced weakness in a bone. She was admitted

to UVM's Fletcher Allen Medical Center in Burlington, Vt., where Katie Little had just entered medical school. Little was able to visit her mother every day. She'd relate what she was learning in medical school, keeping her mother's intellect engaged while she was hospitalized.

Her mother was able to return home briefly, but more complications ensued and she was readmitted to Fletcher Allen. As per her wishes, Virginia Little received comfort measures only, and she died a few days later—the day after Thanksgiving.

After graduating from medical school, Katie Little went on to complete a residency in emergency medicine in 1991. She has worked in the Emergency Department at DHMC ever since.

All those hospital visits when her mother was ill don't count as formal training but definitely were part of making Little the physician she is today. "By making the time that fall to be with my mother," Little says, "I think I started to understand some of how patients feel."

One of the things she remembers was how her mother's caregivers talked. "My mother was a smart woman. She and my father were highly educated," Little says. "But they [found it] hard to understand what the medical personnel were saying. For example, I remember my mother saying, 'My doctors tell me that people in my situation have, on average, six months to live. But no one can tell me when the six-month clock started ticking.'"

And Virginia Little had the benefit of not just one but two family members in medicine, for one of Katie Little's two brothers is a family physician. Between the two of them, they tried to translate the medical jargon into language their parents could comprehend. Even so, it was hard. "The problem was twofold," Little says. "First was the medical complexity, and then there was the emotional involvement."

Today, Little keeps the lessons she learned back then in mind as she treats patients who come to the DHMC Emergency Department. One of those lessons concerns the value of advance directives. She feels that such documents are "critically helpful, . . . allowing us to navigate the hardest decisions about life and death of a loved one, with the loved one's guidance about their own wishes."

Little also learned during that tough time that "each patient brings his or her own life perspective" to an encounter with the medical system. For example, social scientists like her parents have "little interest in bodily diseases or mechanics, because their most engrossing thoughts are about political institutions and public policy ramifications." She recognizes, too, that patients' personalities affect the way they approach the end of their lives, "some

. . . with dignity, some with anger, some with forgetfulness, some with fear."

Her mother's illness also helped Little appreciate the fact that medicine can seem overwhelmingly technical to patients and their families. She thus knows "how important it is to explain everything in language at their level of comprehension. . . . Patients actually sometimes don't hear more than 10 percent of what their doctors say," she says.

"What my mother's hospitalization and death helped teach me," she concludes, "is about talking with patients and families. It really brought home to me in major fashion that I can reassure patients by speaking in words they understand. I try to take time with each patient, and with their family and friends, to explain as much as I can."

Care is what matters

With remarkable fortitude, Bertha McCullough fought her way back from several health crises when she was in her eighties. She worked resolutely to rehabilitate herself after each setback so she could return to her own apartment in a senior housing community, where she was surrounded by friends and neighbors who looked in on her. But her health problems continued to mount, and she lost the ability to walk. That necessitated a move into a nursing home, where she slowed down still more. One year, as December approached, she told her son she didn't think she'd make it to Christmas. "I just pray I'll die at night," he recalls her saying. She lost interest in eating but picked at her food to please the nursing home staff. Mostly, she wanted to be left alone. "Why is it so hard to die?" she asked.

Her son, Dr. Dennis McCullough, an associate professor of community and family medicine at Dartmouth, had both a personal and a professional interest in the answer to that question. After practicing family medicine for several years, he had combined his interests in community-based medicine and geriatric medicine as the medical director of Kendal at Hanover, a life-care community in Dartmouth Medical School's backyard.

As a result, McCullough understood that nursing homes are assessed by how long they keep their residents alive, and that his mother no longer wanted to live. So he moved her to a residential hospice facility, where she was permitted to follow her own changing rhythms. Rather than be woken and urged to eat regular meals, she was allowed to sleep for 24 hours at a time if she wanted to and was provided with coffee and toast when that's what she requested. For about five weeks, Bertha McCullough woke once a day for a couple of hours, enjoyed her snack, talked about her dreams, planned her funer-



al, and told stories in exquisite detail. "She was very connected while awake," Dennis McCullough recalls. And then she died.

During the last years of his mother's life, McCullough suffered some health problems of his own. Forced to give up clinical practice, he embarked on studying, and writing about, the many complex issues surrounding elder care. He is now committed to educating the public on the subject. "People over 80 are intense users of health resources," he says. "Why not focus on better care, with early intervention, so little ailments are stopped before they become health crises?"

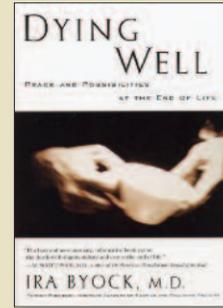
McCullough is one of many medical professionals who have come to recognize that this country's current health-care system swings between inflicting on the elderly too little care (not spending enough time listening and not stepping in early because of cost constraints) and too much care (recommending invasive diagnostic tests and treatments that may be inadvisable for someone who is frail or battling multiple ailments). It's a system, he and others have concluded, that is expensive, inefficient,

Dennis McCullough's mother was allowed to sleep for 24 hours at a time if she wanted to and was provided with coffee and toast when that's what she requested.

Narratives that illuminate end-of-life issues

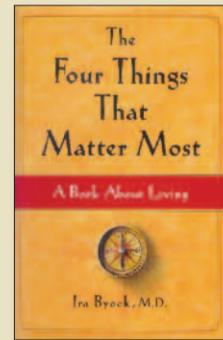
Medicine may be a science, but healing is an art. A doctor will surely poke and probe and order tests, but a healer listens as patients relate the stories of their illnesses. Healing, in other words, depends on narrative.

And physicians are not only receivers of narrative but, sometimes, storytellers themselves. Many physicians have used narrative to educate. Two of the DMS faculty members interviewed for the adjacent feature—Drs. Ira Byock and Dennis McCullough—have written very readable books about the end of life.

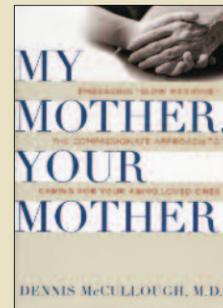


In both *Dying Well* and *The Four Things That Matter Most*, Byock tells patient stories that are not just about illness and death but also about the wisdom that can be received during the poignant time at the end of life. *Dying Well* begins with the story of how the intimacy of caring for his father during his last two months taught Byock what a rich and valuable time that period can be. Part of Byock's father's lasting legacy has been his son's interest in, commitment to, and promotion of hospice and palliative care.

The Four Things That Matter Most grew directly out of Byock's work in palliative care. One of the nation's most respected advocates for facing end-of-life issues in a forthright manner, Byock has been a member of the Dartmouth faculty for the past five years. Not content to simply provide physical comfort to the dying, he advises terminally ill patients and their survivors how to make the most of this spiritually ripe time of life: ask forgiveness; give forgiveness; apologize; say goodbye. His book tells the stories of patients and family members who struggle to complete these four conversations, and who inevitably feel a sense of spiritual ease once they do.



Dennis McCullough, for his part, has written a book laying out an approach to elder care that he calls "slow medicine." The concept is catching on fast. *My Mother, Your Mother* received a glowing review in the *New York Times* when it was published in February 2008. A feature in the *Times* in May has helped McCullough's concept gain traction among caregivers; among the elderly; and among middle-aged baby boomers who are, in increasing numbers, caring for their aging parents. Now, the term "slow medicine" is showing up in numerous articles and blogs.



Developed over a lifetime of practice, research, and education, slow medicine offers the promise of better—and less expensive—care for America's burgeoning geriatric population. McCullough explains in *My Mother, Your Mother* that elders often fare better with medicine based on face-to-face relationships that involve patients, their caregivers, and their families. He also narrates the story of his own mother's last years.

In addition to spreading the word about slow medicine through his book, McCullough is also promoting it at DHMC, where he is working with other faculty members to improve geriatric care throughout northern New England. D.L.L.

Deborah Lee Luskin, the author of both this sidebar and the adjacent feature, is a regular commentator for Vermont Public Radio as well as a freelance writer. One of her recent commentaries was a narrative about caring for her own aging parents. To read or hear it, go to <http://www.vpr.net/episode/44199/>.

and not particularly humane. "Care is what matters," McCullough says, "not intervention."

As part of his campaign to raise awareness about end-of-life care, McCullough has written a book titled *My Mother, Your Mother*. The book describes a concept he calls "slow medicine"—a "compassionate approach to caring for your aging loved ones." He suggests relying more on community and common sense and less on hurried decision-making, hospitalization, and invasive procedures. "I'm trying to help families understand what their options are," McCullough says. The approach—and the term he uses to describe it, borrowed from the "slow food" movement—seem to be resonating with both elderly patients and their families.

McCullough hopes that slow medicine will continue to spread. He's helping a group of DMS faculty members—headed by Dr. Stephen Bartels, a geriatric psychiatrist—launch a wide-ranging effort to improve care for the elderly throughout northern New England. He'd like to see a process for recognizing hospitals that deliver community-based care for the elderly—care that accounts for psychological as well as physical health. And he'd love to see Dartmouth-Hitchcock accredited as the nation's first Slow Medicine Hospital.

Open to the individual process

Just how hard it can be to negotiate the end-of-life process is illustrated by the fact that two additional physicians agreed to be interviewed for this article but then decided, on reflection, that they preferred not to make public the "minute particulars" of their personal stories.

But one of them—whom we'll call Dr. John Jones—was willing to share the lessons he learned when a parent facing metastatic cancer proved adamantly opposed to hospice care. Jones was initially surprised by the reaction. But a later conversation made him realize that some people prefer not to share with non-family something as intimate as their thoughts about dying.

Jones has since then come to believe that people nearing the end of life need a guide who knows them and listens to them but doesn't push ideas on them. He realizes now that helping his patients get the care they want sometimes means addressing a detailed list of ailments, but it sometimes means just helping them attain a general sense of well-being. The experience, Jones explains, "taught me to be more open to the individual process—that it was all right for a patient to choose not to deal with death, not to confront it head on.

"I learned," he concludes, "that 'my way or the highway' didn't work." ■