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 development, 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 sisters, 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 lessons 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
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 father had been in a car accident. They later learned that while stopped in traffic, he had suffered a fatal heart attack. Despite the chaos of the sudden death, Byock knew 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 until she needed constant care, and then. Deborah Peltier’s mother, Peggy Peltier, put all four of her children 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 palliative medicine 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 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 person’s family. “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 they 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 ambulances, no hospitalization, no ventilator. She was kept comfortable in 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 palliative medicine 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 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-
Katie Little’s mother was able to return home briefly, but more complications ensued. 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 all 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 that they were highly educated and had academic complexity, and then there was the emotional involvement.”

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 love and that’s guidance about what our 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 ‘littl[e] interest in bodily diseases or mechanics, because their most energizing work is 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 forgiveness, some with fear.”

Her mother’s illness also helped Little appreciate the fact that medicine can seem overwhelming-ly 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 home assessments are based by how long they keep their residents alive, and that his mother no longer wanted to do 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 funeral, 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 (recommend- ing invasive diagnostic tests and treatments that may be inadequate for someone who is frail or but- tling multiple ailments). It’s a system, he and oth- ers have concluded, that is expensive, inefficient, to UVM’s Fletcher Allen Medical Center in Burt- lington, 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 en- gaged while she was hospitalized.

Her mother was able to return home briefly, but more complications ensued and she was readmit- ted 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 all 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 that they were highly educated and had academic complexity, and then there was the emotional in- volvement.”

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 help- ful, . . . allowing us to navigate the hardest deci- sions about life and death of a loved one, with the love and that’s guidance about what our 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 ‘littl[e] interest in bodily diseases or mechanics, because their most energizing work is 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 for- gentleness, some with fear.”

Her mother’s illness also helped Little appreci- ate the fact that medicine can seem overwhelm- ing-ly technical to patients and their families. She thus knows “how important it is to explain everything in language at their level of comprehension. . . . Pa- tients 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 nurs- ing 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 in- terest 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 prac- ticing family medicine for several years, he had combined his interests in community-based medi- cine 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 nurs- ing home assessments are based by how long they keep their residents alive, and that his mother no longer wanted to do 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 funeral, 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, Mc- Cullough suffered some health problems of his own. Forced to give up clinical practice, he embarked on studying, and writing about, the many complex is- sues 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 interven- tion, so little ailments are stopped before they become health crises?”

McCullough is one of many medical profes- sionals 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 (recommend- ing invasive diagnostic tests and treatments that may be inadequate for someone who is frail or but- tling multiple ailments). It’s a system, he and oth- ers have concluded, that is expensive, inefficient, 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 profes- sionals 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 (recommend- ing invasive diagnostic tests and treatments that may be inadequate for someone who is frail or but- tling multiple ailments). It’s a system, he and oth-
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—Dr. 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. The Four Things That Matter Most is showing up in numerous articles and blogs.

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 processes 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 despair, not to confront it head on.

“I learned,” he concludes, “that ‘my way or the highway’ didn’t work.”