



# Dying

# Well

**Slowly but surely, Americans are coming to see death not as a failure on the part of medicine but as a natural part of life. DHMC is leading the way in this movement, as described here. And a pair of related stories recount deaths realized in this manner.**

I have learned from my patients and their families a surprising truth about dying: this stage of life holds remarkable possibilities,” wrote Ira Byock, M.D., in his 1997 book, *Dying Well*. To Byock, director of DHMC’s Palliative Care Program, dying well means dying free of pain and fear while having one’s emotional, social, and spiritual needs, as well as medical needs, attended to.

Byock has been a hospice physician for more than 20 years. His research and advocacy, plus his service as president of the American Academy of Hospice and Palliative Medicine, have earned him a national reputation. Since coming to Dartmouth in 2003, he has been working to improve DHMC’s already strong palliative-care program—to bring an even more holistic approach to caring for the terminally ill and injured. “Medicine, as powerful as it is, is just an instrument,” he says. “If all we do is improve *medical* care for people who are dying, all we can hope to achieve is better medicalized dying.”

Instead, what Byock wants to do is ensure that people who are close to death still have a high quality of life. Many palliative-care programs focus solely on relieving physical suffering. Byock and his colleagues take a different approach. The DHMC palliative-care team—which includes physicians, pain specialists, nurses, social workers, and a pastoral caregiver—helps patients and their families to better understand the illness at hand and to identify the values and beliefs that will guide their choices. “We then assist with the personal—meaning the emotional, social, and spiritual—adjustment to their condition, their often uncertain prognosis, and to perhaps progressive illness, disability, and the knowledge that their life expectancy is short,” explains Byock. “But it’s highly individualized.” The team is also reaching out to area hospice programs. Byock says he and his staff have visited almost every hospice program in the region to improve continuity between DHMC and community programs.

“Often people wait until there is no hope of living longer before being referred to or accepting hospice care,” says Byock. “We’re now trying to use hospice care to give them the very best supportive services so that they have a chance of living longer.” For example, some insurance plans require that an individual who accepts hospice care must forgo potentially life-extending treatments. “People shouldn’t have to choose between a treatment that might give them a few quality months to live and treatment or care directed at their comfort and quality of life,” Byock maintains. Dartmouth has a chance “to lead a constructive revolution in health care, where attention to the personal needs of the individual patient and family become part of the mainstream,” he adds.

Byock’s hope is to make dying really about living, to temper what he calls the “shrill, piercing, overwhelming amplitude” of grief for those left behind. When counseling people who have just lost a loved one, he often tells them to “just remember to breathe—at this moment, all you have to do is take the next breath.”

In the two stories that follow, the authors describe wrestling with their hopes and fears about an imminent death—one after a life measured in decades, one after a life measured in hours. Death at an advanced age, Byock says, is sad but “offers an opportunity to celebrate . . . a full life,” while the death of a child can leave “an overwhelming sense of loss, not only for what has been but for all that might have been.” Yet “at some point, parents often are able to look back and acknowledge the gift that their child was in their lives,” he adds. “In a sense, we are all transient gifts to one another.” JENNIFER DURGIN



**A few months ago, going through some things Rad had packed away in a suitcase, I came across that homemade banner—intact 82 years after its creation—the banner that money couldn't buy.**

## Radford Chapple Tanzer

By Sheila Harvey Tanzer

*The widow of a DMS faculty member recaps a long life well lived, and its peaceful conclusion.*

**A**lthough we had lived in the same neighborhood for 30 years, Rad Tanzer and I did not meet until Nardi and Tom Campion invited us both to dinner in the fall of 1994. By then, my years as a widow had taught me self-reliance; I took my single identity for granted, presuming it to be a permanent state.

I looked forward to that evening in October because parties at the Campions' were always lively. When I opened the front door, I heard Nardi's greeting: "Sheila, come in. This is our other guest, Rad Tanzer." He stood up, we shook hands, and I sat down near the warmth of the fire, next to a person who appeared to "feel comfortable in his skin," as the French expression goes. He put me immediately at ease.

Around the dinner table, as we talked about the book he was reading—Doris Kearns Goodwin's biography of FDR—other aspects of Rad's personality emerged: intelligence, wit, and kindness. He was attentive to what each of us had to say, and we learned more about him, as well—that his wife had died four years previously, that he continued to work out regularly at Dartmouth's Berry Sports Center, and that he had just celebrated his 89th birthday. "And still riding your bike to town," Nardi laughed. Rad Tanzer clearly had the vitality of a much younger man.

When the party was over, I gave Rad a ride back to his house; as we shook hands and said good-bye, I remember hoping that this would not be our last conversation. Fortunately, it was not. But little did I know then that just three months later we would again share dinner—this time at a party for two. He would broil steaks and bake a pair of slender sweet potatoes in his toaster oven. And as we sat together at his kitchen table, there would be no hesitation on my part when he asked me to marry him (even before our first kiss).

Our decision elicited amazement from most of

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our friends, and some of them had reservations because of the difference in our ages. The disparity of 22 years was a factor neither of us could ignore, but our joint willingness to take a leap of faith was based on a rapport we discovered soon after our initial meeting—a harmony of souls that quickly deepened into devoted love. It would be durable enough, we believed, to face whatever the future might hold. It was a choice we never regretted.

I look back now and realize how Rad's tolerance was put to the test when I moved into his house, brimming over with new ideas. "How about putting a fresh coat of paint on the living room walls and replacing the threadbare rug?" I suggested. "And what if we moved the washing machine out of the kitchen? With just an inch to spare, it would fit right into the large bathroom closet." He would have been justified in vetoing the whole proposed upheaval, but instead he entered into decisions involving every room. But his study would stay the same, we agreed. That was his domain.

The resolve with which Rad approached any task was something that I soon came to admire. Regardless of whether it was a large or small undertaking, he paid scrupulous attention to every detail. Nothing was ever left untended. He balanced his checkbook to the penny until just three months before his death. He maintained in impeccable order a large archive of professional and personal papers, filling drawers and drawers of file cabinets. Everything was in its place—an inspiration as well as a challenge to the disorganization that most of us live with.

I had an opportunity to work with Rad on a project one summer after we'd put in a new perennial bed. The gray paint on the nearby basement bulkhead was peeling off, so I offered to help him repaint it and suggested a change to green. How useful I thought I was—the spry, young wife coming to the rescue of her elderly husband, then close to his 94th birthday.

Yet I learned that his high standards applied to even a simple painting project. His large basement was meticulously organized, just like the rest of his one-story house. Behind the workbench, on the shelves of an old bookcase, were rows and rows of glass bottles—scores of them—filled with short, long, square-headed, thick, and thin nails of every conceivable type. Then screws, bolts, hinges, hooks, and brackets. There were open boxes piled high with faucet handles, old bicycle seats, rolled up rope, and other odds and ends to round out a handyman's paradise. Nearby stood a trestle table on which, the morning we were planning to tackle the bulkhead, he had already laid out the supplies we would need. He was wearing his twill



Radford Tanzer: Top, in his twill Army shirt during WWII; above, with his mother and sisters; upper right, as a youngster; right, his homemade banner.

World War II Army shirt, still in service 55 years later. We both put on cotton gloves and ventured out to the yard.

It was early afternoon on a fair July day by the time we finished the laborious task of scraping and sanding. After Rad had wiped down the bulkhead surface, we began to apply a coat of dark green enamel. On and on he worked, as I eyed his slow, even brushstrokes that seemed effortless. I wanted to keep up with him, but spasms were settling into my back and all I could think of was lying down on the cool grass and closing my eyes. Finally, when the lower right corner of my door was finished, I felt the exhilaration of a job well done. But that was when Rad looked up at me with what could have been a gleam in his eyes and said, “Well, now that we’ve finished this part, let’s prop them up and put a fresh coat of paint on the undersides, too.”

Like the Army shirt, some of his other clothes were old friends he could not abandon. One day, noticing the worn canvas around the toes of his ancient sneakers, I offered to treat him to some new ones. “But why in the world would I want them?” he asked in wonderment. “I already have a pair of tennis shoes.”

**I**n Rad’s devout Episcopalian family, unselfish commitment was a way of life. Talent was to be used not to advance oneself but to help others; frugality was a given. His father, a dentist, sang in the choir, was a member of the vestry, and served two terms as mayor of Little Falls, N.Y. His mother entered Vassar in 1901, when few women went to college. Two years later, at age 21, she left school to marry Rad’s father, but her zest for learning never ceased. Elected the first woman president of the Little Falls board of education, she also taught Sunday School and for years shared her love of good books by reading aloud classics such as *David Copperfield* and *King Arthur and His Knights*. Rad and his four sisters learned to identify songbirds, wild-

flowers, and constellations. Every August, his mother held a Perseid picnic on the hill behind the family’s house—spreading blankets on the ground so the children could lie down and gaze up, waiting for the dazzling shooting-star spectacle to begin.

That the family bond was strong and abiding became evident in the late 1930s, when Rad first started to earn a full-time salary. He immediately began sending money home to help pay for the college tuition of his younger sisters.

A poignant example of how scarce money was for him when he was a student came to light recently as I read through a box of letters in Rad’s study, including some he had written home as a freshman in college. Arriving at Dartmouth in September of 1921, a few days after he turned 16, he moved his belongings into his dorm room in North Massachusetts Hall. Though it is not likely that Rad ever coveted any material object, the large Dartmouth banner that his roommate had hung on his side of the room clearly caught Rad’s fancy. In a letter written on his mother’s hand-me-down typewriter, he described the events of September 20, 1921:

“Billy and I waited for three hours to register this morning. . . . I had to write a check for \$185 for board and tuition, so together with the Morris chair, my funds are pretty low. I have \$58 left, but I think this will last me till Christmas. I went to the Christian Association to see about a job typewriting. He advised me not to work the first month, but to study. He says he may be able to get me a job after that.

“Last night about 20 fellows came into the room selling different things. I stalled them off as best I could. I would like a Dartmouth banner, but the little ones are \$3.00, medium \$5.70, and the large ones \$9.00. I wonder if it would be much trouble to make one?”

For comparison’s sake, a large such banner costs \$78 today. Rad knew that buying one was impossible. Still, the question that he asked led his mother to respond as he must have known she would. He sent a sample of green felt, and when she had located a match, she mailed a piece for his approval. “Yes, proceed,” he wrote back, providing her with the exact measurements of the green rectangle with its white letters and class numerals.

I like to picture Rad admiring his mother’s handiwork before he hung it on his wall—an emblem of the college to which he was loyal for the rest of his long life. A few months ago, going through some things Rad had packed away in a suitcase, I came across that homemade banner—intact 82 years after its creation—the banner that money couldn’t buy.

After he retired, Rad endowed two scholarship funds at Dartmouth Medical School. And toward the end of his life, he willed over \$1 million—an amount that amazed everyone, because he had lived so simply—to establish an educational endowment for the DHMC Section of Plastic Surgery, which he had founded. When Rad joined the Dartmouth faculty in 1939, he was only the 16th doctor and fifth surgeon at the Hitchcock Clinic and the only plastic surgeon in all of northern New England.

To be in Rad’s company was to be in the presence of extraordinary kindness. During our eight years together, never once did I hear him make a critical remark about another person (even when one might have been called for!). In the last few years of his life, in spite of hearing aids, it was hard for him to understand everything. But instead of grumbling, “Speak up! I can’t hear!” he never failed to convey exquisite courtesy in his response: “I’m sorry, I didn’t quite catch what

**The next day, Dr. Diane Palac came to Rad's room in her palliative-care capacity. She sat down next to his bed. "Rad," she said gently, "I do believe death is drawing near." He opened his eyes wide as if to confirm that what he had just been told was true. Their eyes met, and it was clear Rad understood that he was dying.**

you said. Would you mind repeating it for me?"

The ideal of ever-present courtesy had entered his imagination as a child when he listened to his mother read about King Arthur and his worthy minions. A well-worn copy of Howard Pyle's 1912 edition of *The Story of King Arthur and His Knights*, a gift to Rad on his eighth birthday, still sits on a bookshelf behind his wing chair. Pyle pointed out that one becomes a true knight not by wearing a suit of armor but by the constant practice of virtues such as courage, honor, and fidelity, until they become integrated into one's identity.

Those virtues were tested during the last two years of Rad's life. His whole body grew gradually more frail as intermittent bladder infections took their toll. Yet his inner equilibrium never wavered. One morning, not long before his death, we were sitting at the kitchen table having breakfast. I mentioned my astonishment that he did not seem to have a shred of negativity in his makeup, nor did he have any need for self-aggrandizement. "How can you never be in a bad mood?" I asked.

"Well," he smiled, "you never can tell when I might start."

Poverty of spirit is one of those virtues which, if you think you possess it, you can be certain you don't. As everyone who knew him would agree, humility was an intrinsic part of Rad's nature. On the evening that I met him at Nardi and Tom Campion's house, I remember asking him about ear reconstruction because I remembered, as a volunteer in the Mary Hitchcock Hospital pediatrics ward during the 1960s, being able to tell at a glance which young patients were his: their head bandages looked like soft white football helmets.

But I knew nothing about the complexity of the operation. Nor did I realize that he had been the first doctor anywhere to devise an effective method to construct an outer ear for a child who had been born without one. No one would have guessed from the modest account he gave us that night that his contributions to the field of reconstructive surgery had been seminal and that he was a figure of international renown.

Dr. Rocco Addante, who joined the DMS surgery department shortly before Rad's retirement, once wrote him a letter recalling an exhibit at the old hospital that explained various surgical techniques: "I saw you coming down the hallway, but my attention was diverted and the next thing I knew one of the new plastics OR nurses noticed you looking at the posters and proceeded to 'explain' to you the different steps involved in ear reconstruction. You were dressed in street clothes, listening attentively, never making her look foolish or uninformed. As you went on to the next surgical

service, I walked up to her and said, 'Do you know who that man is?' 'No,' she replied, 'but he was very pleasant.' She was shocked to learn that the humble man she was talking to was the one who pioneered the technique that she was describing. True story, and one of my most memorable. I can still recall your peaceful demeanor studying that poster. A tribute to you, Rad: humility and intelligence—a rare combination to find."

**T**he morning that Rad went by ambulance to DHMC we were both calm. Other bouts of acute cystitis and kidney failure had brought us to the emergency room, and he had always returned home, a little less strong but still in possession of his usual good humor. This trip was in early June of 2003—three days after the eighth wedding anniversary party that friends had thrown for us in our own living room. Rad had sat in his wing chair with a blanket over his legs, chatting and laughing.

In the hospital, his infection responded to antibiotics and his internist, Dr. Ed Merrens, said it was likely Rad could be discharged in a few days. Then, on the evening of June 8, Rad developed acute shortness of breath. X-rays and an ultrasound the next day revealed bilateral pulmonary embolisms as well as clots in both legs.

Suddenly his condition was grave, Dr. Merrens warned, adding that the embolisms could also cause severe pain. Uppermost in my mind was keeping Rad comfortable at all times. Dr. Merrens said he would order morphine on demand and asked whether I would like him to contact the palliative-care team. I was quick to say yes, because as a former hospice volunteer I had genuine admiration for the sensitivity of the hospice approach. Yet even so, I was unable to acknowledge the gravity of Rad's condition. I screened out all thoughts that palliative care was about anything except pain management, completely bypassing its role in the care of the dying.

The next day—while I was out of the room, unfortunately—Dr. Diane Palac came to Rad's room in her palliative-care capacity. By coincidence, she had been my primary-care doctor for several years and had met Rad. She was aware of the fact that he had been growing weaker over the previous year. She quickly determined (she later told me) that even though Rad was not moving at all as he lay there, he was calm, comfortable, and right with her in alertness. Yet it was also clear to her that he would not survive this illness. He was exceedingly weak and was on high-flow oxygen through a face mask. Simply opening his eyes required more energy than he could spare. Because of the blood



Top, Rad and Sheila Tanzer on their wedding day—June 2, 1995. Above, Tanzer on his bike in 1969. At right, Tanzer (center) with a young patient.

clots in his lungs, the least physical effort made him short of breath.

After greeting Rad, she sat down next to his bed and asked him whether he was comfortable. He was not in any pain, he said, though sometimes it was hard to breathe. “Do you have any unfinished business?” she asked next. “No,” he responded, “I can’t think of any.” Pause. “Are there any changes you might want to make in your will?” “No, thank you, I have taken care of that.” Long pause. “Rad,” she said gently, “I do believe death is drawing near.” He opened his eyes wide as if to confirm that what he had just been told was true. Their eyes met, and it was clear Rad understood that he was dying.

She asked how he felt about that. His only comment was, “It will be very hard to leave Sheila.” Dr. Palac responded, “Yes, Rad, I know,” and he closed his eyes again. She explained that the morphine he was receiving would help with his shortness of breath. She reminded his nurse of this as well.

That afternoon, he was alert and carried on conversations with several friends. Two fellow plastic surgeons stopped in to see him, and a member of the church choir came by to sing a few hymns in her beautiful soprano voice. At suppertime he took only a few mouthfuls of food and a few sips of fluid. Because I had spent the previous night on a cot in his room and had hardly slept, I was now being advised to go home to get some rest. Later in that evening, when the hospital “patient sitter” arrived, I leaned over the bed to give him a good-night kiss. He looked me straight in the eye and held my hand. “I’m so in love with you,” he murmured.

When I telephoned early the next morning, I was relieved to hear that he had had a calm night. Arriving at the hospital a little after 7:00 a.m., I found him struggling for breath and glad to see me. I sat on the bed holding his hand, talking to him, praying for healing on the deepest level, assuring him of a love that would be steadfast through illness

and death. Soon he drifted off to sleep, his face utterly peaceful and his breathing even. Then the gentle breaths began to space out. They came ever further apart until, at last, there were no more. I continued to sit there, not wanting to move, surrounded by the awe of death, that moment of silence when the spirit begins its mysterious journey.

At 8:30, Ann Lawrence, one of the day nurses, came in and gently placed her stethoscope on his chest. “Yes,” she said, “I cannot get a heartbeat.” I felt numb, as if psychic novocaine had sealed me off from reality. I was watching myself feel gratitude for Rad’s peaceful death and for the excellent care that Dr. Merrens, Dr. Palac, and his nurses had given him.

Within a short time, others arrived: two good friends, Nardi Campion and Marie Kirn, and Father Jim Bresnahan, one of the Hospital’s chaplains and a member of the palliative-care team. For two hours we kept a vigil around Rad’s bed, taking turns reading psalms and prayers.

Then Ann Lawrence returned with another nurse. With tender care, they washed his body and placed it in a white body bag. Soon two members of the transport team arrived. One, who had taken Rad down to get an x-ray a few days before, looked over at us and said, “I’m so sorry.” Then they transferred his body to a gurney and as they started to leave the room, we all stood up spontaneously in silent tribute.

In the months that followed Rad’s memorial service, an intense longing for his earthly presence was always with me. I recalled words that a French friend had used to describe her husband’s death: “*C’est une vraie amputation*,” or “It is just like an amputation.” She meant not just the cutting off of a single limb but rather the severing of a substantial part of our own sense of self. She could have been speaking for me, I believed, not realizing then that by concentrating on my own loss I had entered into a dark labyrinth. It seemed impossible that I’d ever find a path connected to the outside world.

Not long after Rad’s proposal in early 1995, I had stopped by his house to bring him a present—a homemade heart-shaped cookie. I was touched to notice on later visits that he continued to keep it in the same place, on the table in his kitchen where he ate.

Several weeks later, I stopped to see Rad on my way to the cemetery, explaining that it was the seventh anniversary of my late husband’s death. He said he’d like to come along. So we drove out to Pine Knoll together, parked the car, and trudged toward a granite monument with “Harvey” chiseled into it. After we’d stood there in the February snow for several minutes, each of us absorbed in thought, I turned to go. Then he stepped forward, reached into his coat pocket, and placed something on top of the stone. Glancing back, I was startled to realize it was the cookie. “I wanted to leave something for Larry,” was all he said as we headed back to the car.

At first the gesture bewildered me. Then I understood. The simple act was one of kindness and selflessness.

On a bitterly cold morning in January of 2004, about six months after Rad’s death, I awoke in our bed. Before I’d opened my eyes, an unexpected shift of inner perspective led me out of my confining labyrinth into a clearing—a place where possibility existed once again. Suddenly able to embrace Rad’s life as having moved from the seen to the unseen, I became aware of the heart-shaped cookie there before me. Almost transparent, it stayed for a luminous moment, revealing the gifts of an immeasurable love. ■



**“Couldn’t this be a false positive?” I asked. I was grasping for anything that might indicate a different diagnosis and a better outcome for our son. But it was definite—he had trisomy 18.**

## Ethan Bennett Gagné

By Lynda Hynes Gagné

*A DMS alumna writes about her son’s all-too-short life, and the blessings he left behind.*

I’ll never forget that Friday. It was a beautiful August afternoon in 2003. I was four and a half months pregnant, and my husband, Josh, was meeting my daughter and me at the doctor’s office for my second ultrasound. Emma, two and a half years old, was excited about seeing the baby. Although I’d already had an ultrasound, the first one had been done at eight weeks simply to establish a due date. This one would mark a turning point, for we would not only verify that everything was all right but also learn if we were having a boy or a girl. I remembered Emma’s ultrasound at four and a half months. Once we saw her image on the screen, saw her little fingers and toes and watched her move, she suddenly became real. She was no longer “it” or “the baby.”

In addition to Emma, I had a 14-year-old stepdaughter, Katie, and an 11-year-old stepson, Sam. I was secretly hoping for a boy this time, for that would make our family perfectly symmetrical—two boys and two girls; two older children and two little ones.

Soon after the technician began guiding the ultrasound probe over my belly, she told us that the baby was a boy! I squeezed my husband’s hand. Emma didn’t seem very interested in the black-and-white pictures on the screen, however. I realized that she had probably been expecting to see a roly-poly infant like the ones in diaper commercials. Then the technician took some measurements to evaluate the baby’s growth.

When she finished, she explained that she’d found two anomalies but quickly added that neither of them seemed significant. There were two choroid plexus cysts on the baby’s brain, but she said such cysts are not that unusual. And the baby had an inflamed kidney, but she said that could be because he was already eliminating waste. She told us the doctor would look at the results and then come in to talk with us. I had just transferred to Dr. Cecilia Clemans, a 1994 graduate of Dartmouth

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Medical School as it happens, because my previous ob-gyn was on leave.

As we waited for Dr. Clemans to come in, I began crying. I knew something was wrong. Josh tried to reassure me, saying that Emma had probably had some anomalies on her ultrasound, too. “No, no,” I said, “there was nothing wrong on Emma’s ultrasound. This is not normal.”

The wait seemed forever and intensified my fear that something was terribly wrong. Finally Dr. Clemans came in, greeted us, sat down, and said in a very gentle manner that we needed to talk about the ultrasound. We told her that we knew the baby had some cysts on his brain and a problem with his kidney. Carefully choosing her words, she said that in addition to those problems, the baby was very small, below the 10th percentile for his gestational age, and that his arms and legs were smaller than his head and body. She also told us that his hands were clenched. Any of these factors alone, she went on, would not necessarily be reason for alarm, but taken together they indicated that our son had trisomy 18—a chromosomal abnormality that causes severe mental and physical problems. Most trisomy-18 babies, she said, die before birth or shortly thereafter.

We were stunned. Neither of us had even heard of trisomy 18. Since none of the problems on the ultrasound were necessarily significant individually, I asked her what made her think it was trisomy 18. Dr. Clemans clenched her own hand as she explained that the baby’s clenched fists—a position that had been unvarying during the entire ultrasound—were the most telling sign. She added that trisomy 18 is a random event, not caused by anything that I had done or not done.

This could not be happening, I thought to myself. What did she mean that our baby was going to die? He’d looked perfectly fine to me on the ultrasound. I’d always thought the worst thing that could happen would be spina bifida or Down syndrome. *This is the 21st century*, I wanted to shout. *Isn’t there something we can do, when babies weighing less than a pound survive?*

The ultrasound findings pointed strongly to trisomy 18, but the only way to know for sure was by examining the DNA of cells in my amniotic fluid. Dr. Clemans said I could have the amniocentesis as early as Monday morning and the results by the end of the week. Before we left, she handed us a description of trisomy 18 from one of her medical books and encouraged me to phone the doctor on call if I had any questions over the weekend.

As we stood outside the office, Josh gave me a hug and I told him I was sorry. I felt numb. What had I done wrong? When I’d learned I was pregnant with Emma, I’d been thrilled because we’d



Top, from the left, Dr. Cecilia Clemans; Josh Gagné; Lynda Gagné, holding Ethan; Dr. Elizabeth Keane; and one of the hospital nurses. Above left, baby Ethan. Above right, Ethan with his parents and two of his siblings, Katie and Sam.

been trying to conceive for many months. When I'd learned I was pregnant with this baby, however, I was not expecting it; had I not wanted him enough?

I spent much of the weekend on the Internet, reading everything I could about trisomy 18. It was all bad. Of babies who were born alive, average survival was three days in one study, five days in another. Most sources said 95% of trisomy-18 babies die within a year, but most of the published studies had even higher figures—up to 100%. And even when trisomy-18 babies lived beyond a year, all were severely mentally retarded and had significant physical problems, including heart disease, severe apnea, cleft palate, club foot—the list seemed endless.

**B**ut after poring over everything I could find, I began to hope that our son might not have this horrible condition after all. The ultrasound had not revealed a heart defect, but the literature indicated that 90% of babies with trisomy 18 have a heart defect. The ultrasound had also not shown any of the other physical anomalies commonly associated with trisomy 18. Most encouraging of all, our child was a boy and trisomy 18 is four to five times more common in girls. However, I couldn't ignore those clenched fists, which are common among trisomy-18 babies. Yet trisomy 18 is very rare—occurring in only 1 out of 5,000 to 8,000 births; there had to be another explanation for those fists, I kept thinking. I did find a relationship between cocaine use by an expectant mother and clenched fists. Maybe he was clenching his fists because I drank too much diet Coke. And maybe his kidney problem was what was restricting his growth. *We can certainly do something about a kidney problem, can't we?* I thought. Perhaps the ultrasound was just a false positive, and all my anxiety would be for naught. I began feeling hopeful.

On the other hand, Dr. Clemans had seemed sure. She had not

said, "There is only a slight chance of trisomy 18—let's do the amnio to rule it out." I remembered her saying that if I had any questions over the weekend, I could get in touch with the practice's doctor on call. I decided to phone her. "Couldn't this be a false positive?" I asked, after explaining the hopeful signs I'd found. I was grasping for anything that might indicate a different diagnosis and a better outcome than trisomy 18 had to offer. The doctor on call was familiar with my case. She explained that it was all the anomalies collectively, not any of them individually, that strongly indicated trisomy 18 or another chromosomal disorder. As I hung up the phone, I fell to the floor, crying, "No, please no, don't let this be happening."

Because we had already learned that many trisomy babies are miscarried during the first trimester, we decided to name our son right away. We called him Ethan, which means strong. Later, we searched for a middle name fitting for our Ethan and decided on Bennett, which is Latin for "little blessed one."

On Monday morning, I met Dr. Clemans for the amniocentesis. She used ultrasound to determine the baby's position, then inserted a long needle into my belly to draw out a sample of the fluid within the amniotic sac. It was not painful. But I was afraid to look at the ultrasound. I had been praying that Ethan's fists would not be clenched this time. Unfortunately, they were. So, anticipating that the results of the test would be positive, I decided to tell Dr. Clemans then and there that regardless of the outcome of the amnio, we planned to continue with the pregnancy.

The time between the amnio and the results seemed interminable. On Thursday, Josh and I returned to get the definitive word. We were soon ushered into Dr. Clemans's office, where she was waiting for us. In a soft-spoken and compassionate manner, she told us that the results had revealed what they'd thought. She showed us the diagram of Ethan's chromosomes, and sure enough there were three on his 18th pair. All of the other sets had only two. The report outlined the poor prognosis for trisomy-18 babies and recommended genetic counseling. Although we knew this was the likely result of the amnio, the news still fell on us like a bomb, shattering all hope that we would have a healthy son. My tears came gushing out.

With damp eyes himself, Josh said, "Well, we are going to have a son, his name is Ethan, and we will have him as long as we have him." Suddenly I did not feel so bereft; we were going to see this through together. So, I asked Dr. Clemans, what happens now? Would I be followed like other expectant mothers or was there little point in regular visits? She was very reassuring and said that she would actually want to follow me more closely than the usual mother.

I cried all the way home. It was definite—our son had trisomy 18 and would probably not live long. He might not even be born alive. In the days and weeks that followed, I could not help but think about Ethan. I'd see kids playing soccer and be reminded that he would never kick a soccer ball. I'd look at Emma and know that she might never meet her brother. Oh, how I wished my precious little boy were going to be all right.

At my next prenatal visit, I talked with Dr. Clemans about having a level-II ultrasound and an electrocardiogram to learn more about Ethan's prognosis. I wanted to know as much as possible so we could make good decisions. The office scheduled an appointment with a radiologist in Boston who specialized in diagnostic ultrasound.

About two weeks later, Josh and Emma and I headed for Boston. I

**December was an extremely difficult month. I was eager and terrified at the same time—I wanted so much to hold Ethan in my arms but was so afraid of losing him. I kept second-guessing all my decisions and was on the Internet constantly looking for answers, but I found few. I felt powerless and alone.**

was hopeful that we'd learn more about the likely course of my pregnancy and Ethan's life. There was also part of me, the irrational part, which still nurtured a fantasy that the level-II ultrasound would not find anything wrong with Ethan, or at least would indicate that his condition might not be lethal; maybe he'd have unusually mild physical anomalies for a trisomy-18 baby. After battling through Boston traffic, finding a parking space, and locating the correct building, we arrived just in time for the appointment.

**W**e were brought into a dimly lit room by a technician. As she examined the images of Ethan, I eagerly asked her questions: "Are there still cysts on his head?" "Are his hands clenched?" "How often do you see trisomy-18 babies?" "What characteristics do you often see?" I was hoping to hear that Ethan was better off than most trisomy-18 babies. Instead, the technician repeatedly told me that the doctor would answer my questions—she was "not allowed to comment on the ultrasound." I tried to think of other conversational topics to break the obvious tension in the room. But she was clearly not interested in idle chatter.

When the doctor arrived, she introduced herself and said she understood we'd had a previous ultrasound finding of trisomy 18. "Yes," I said, "and we also had a positive amniocentesis for trisomy 18." I went on to explain that we were there to learn as much as we could about our son's condition so we'd know what to expect. She then turned away from us and began examining the ultrasound screen. After a few minutes of silence, she said that everything she could see was consistent with trisomy 18: he was small, he had clenched fists, and he had a heart defect. "What kind of a heart defect?" I asked, since the previous ultrasound had not shown one. "He has a hole in his heart and also has a valve defect," she responded, adding that the hole was "big." He had a 50% chance of dying before birth, the doctor went on, and if he was born alive he would die shortly thereafter. She added that 95% of people in our position would terminate the pregnancy.

I explained that I understood the outcomes associated with trisomy 18 and that we had decided we wouldn't engage in any heroic measures such as "life support" (we didn't want to be in a position where we'd have to choose to turn it off). But if there were things we could do to increase our chance of having time with him, we wanted to do whatever we could. I also told her that I needed to make some decisions regarding his birth, such as whether or not I would have a caesarean section. I explained that if, for instance, his heart condition

caused him to go into distress during labor, I planned to have a c-section. She replied that she did not think it would be ethical to do a caesarean section on a woman with a trisomy-18 baby since the baby would not live anyway. "If you are going to let nature take its course," she said bluntly, "you need to let nature take its course." She did not seem to understand that although I knew Ethan had a poor prognosis, his life, however long or short, was precious to me. Before we left, the doctor asked if we'd like an ultrasound image. I said I would, and she gave me a small, black-and-white picture of Ethan's profile, similar to the one we'd received at the routine ultrasound.

As we left the office, another couple walked out of a different exam room and we waited together for the elevator. As we stood there, the other couple was talking and laughing as they looked at the ultrasound pictures they'd received—great big pictures with three-dimensional images as well as some smaller, two-dimensional ones. It was obvious that they were having a healthy baby, and it seemed almost cruel that all we'd received was a single, small, two-dimensional black-and-white image; I would have treasured similar pictures of Ethan.

I was disappointed and frustrated. Not only had I hoped to gain more insight into Ethan's prognosis, but I'd been made to feel my questions were an annoyance. The doctor seemed to believe that because Ethan was going to die, either before birth or shortly thereafter, there was no point in determining what his particular problems were. Even when I'd specifically asked about his heart condition, I was told merely that he had "a big hole." How could I look up "big hole" on Medline or the Internet? Isn't that why we'd had a level-II ultrasound?

In the days that followed I grew more and more angry at the suggestion that I should do what "95% of other women in this position do—terminate." Was I supposed to just turn off my love for my child? Pretend that he never existed? Regardless of Ethan's prognosis, he was my child, not a fetus with trisomy 18, a statistic, an anomaly. The experience left me feeling violated and depressed.

At my next visit to Dr. Clemans, she explained Ethan's heart defect and said that it would not affect him until after he was born. We also discussed hospital options. I explained that although we did not want heroic measures, we would like him to receive any care that would be given to a normal baby who needs assistance—such as oxygen. I compared what I wanted for Ethan to the care that would be given to an elderly person who has decided against invasive procedures but does desire hospice or palliative care.

After much deliberation, I decided to have



Top, "big sister" Emma holds Ethan. Above left and right, Ethan's paternal grandparents take their turns with him.

Ethan at a community hospital with no neonatal intensive care unit. Although I wanted to have as much time with him as possible, whatever time I had I wanted to be good. I also wanted our entire family, particularly our three other children, to be able to spend time with him, which would be much easier if we were close to home. And since it is not unusual for trisomy-18 babies to die during the last few weeks of pregnancy, Dr. Clemans and I also discussed whether to induce labor shortly before my due date—and we eventually settled on December 26 as an inducement date.

**D**ecember was an extremely difficult month. I was eager and terrified at the same time—I wanted so much to hold Ethan in my arms but was so afraid of losing him. I kept second-guessing all my decisions and was on the Internet constantly looking for answers, but I found few. I felt powerless and alone.

The Saturday before Christmas, Katie asked me to drive her to church for a youth group event. When we got there, she said I needed to go in to sign a permission form. As we entered the room, I heard a loud cry of "Surprise!" I saw lots of people I knew, mostly women, but it still didn't dawn on me what was going on. I thought maybe we were in the wrong room and looked behind me for the person they were all waiting for. There was nobody there. When I turned back, I heard someone say, "This is a shower for you and Ethan." I was stunned. Once I realized that all of these people had put together this surprise party for me, less than a week before Christmas, I was extremely touched. Soon my husband arrived with Sam and Emma. He had known about it all along! What a blessing. For the rest of the day and the days that followed, I no longer felt so alone.

Late on Christmas Day, I began to have contractions. The doctor said I should head for the hospital. When we got there, the nurse who

checked us in was warm and reassuring. I was terrified: I wasn't ready to have Ethan, to have the clock start ticking on his life, to lose him. The doctor on call soon arrived and determined that I was not in active labor and could go home for the night. We arrived back at the hospital about 8:00 the next morning. This was the day I would finally meet my son, but maybe also the day I'd have to say goodbye to him.

The nurse gave me an IV and after a little while I began having mild contractions. They gradually increased in severity but remained well spaced, so Josh and I were able to relax and chat. Carolyn, the nurse, spent a lot of time with us during this period, and we enjoyed getting to know her. Soon Dr. Clemans said it was time and told a nurse to call Dr. Elizabeth Keane, our pediatrician. By this time the pain was extreme. Then, suddenly, the contractions slowed down. Was he stuck? Could he breathe? Would he not be born alive? Finally, there was another contraction and he was out. It was 1:47 p.m.

The doctors and nurses huddled around Ethan right away. There were no baby sounds. I held Josh's hand and said to myself, *Breathe, please breathe . . .* Josh later told me that at the same time he was saying to himself, *Scream, scream . . .* Finally, Dr. Clemans turned to us and said that he was beautiful. That's when I was finally able to look—they were weighing him: 3 lbs., 9.9 ounces. They immediately gave him to me. He was beautiful—he had all his fingers and toes. He was tiny and his color was very dark—almost purple. When he breathed, his chest contracted deeply. As I held him, I kept hoping that the doctor would say that because he was breathing on his own she expected that he would do extremely well for a trisomy-18 baby. But she said nothing about how he was doing compared to other babies or what we could expect.

Since we didn't know how long Ethan would live, I wanted our family—especially Emma, Sam, and Katie—to come to the hospital as soon as possible. Josh began making phone calls—first to Kara, my sister-in-law, who was taking care of Emma, and next to his parents, who would bring Sam and Katie with them.

Soon Kara arrived with Emma. Emma was a bit apprehensive at first. She crawled up on my lap while I held Ethan and just stared at him. After a while, she held Ethan's hand and gave him a kiss. Kara was very excited to meet Ethan. Of all our relatives, she had spent the most time researching Ethan's condition and talking with me about possible outcomes. As a result, she seemed to really understand the gift that any time with him would be.

Then my mother-in-law arrived, prepared to baptize Ethan. She recited some prayers in French and placed the sign of the cross with oil on his forehead; she was so nervous she did it twice, afraid that she might have missed something the first time. Then she relaxed and became the quintessential proud grandmother, not wanting to let go once she had Ethan in her arms. By now his coloring was lighter and his breathing less labored.

Soon more family members and friends arrived. It was a room filled with joy rather than sadness. Kara snapped pictures all afternoon, recording the precious moments for us. I was delighted that so many people wanted to meet Ethan and was thrilled to show him off. He was a beautiful angel.

Around 7:00 that evening, with our room still filled with well-wishers, Ethan began getting darker and his breathing grew more labored. The room fell silent. Dr. Keane examined Ethan as I held him

*continued on page 66*

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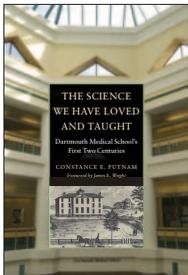
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## Dying Well: Ethan Gagné

*continued from page 51*

and said that death was probably imminent. Tears streamed down my face. Everybody stood around my bed, including both doctors, but nobody said a word. I could not stop sobbing and kept thinking, *Hang on, Ethan. I love you and am not ready to let you go.*

For 45 minutes, we believed Ethan was likely to die at any minute. Then his breathing and coloring slowly began to improve. He would be with us at least a little longer. I realized that nobody could tell us exactly how much time we'd have with him.

Our last visitors left about midnight, but I stayed up most of the night—holding Ethan, watching him, talking to him. I told him about our family, how Emma had been waiting for him, how much I loved him, how beautiful he was. All night long, I thanked God for my little baby and the privilege of holding him. Finally, I dozed off for an hour or two with Ethan in my arms.

The next morning, I anxiously awaited the doctor's arrival. Ethan seemed dehydrated and we were approaching the 24-hour mark. At about noon, Dr. Keane examined Ethan and explained to us the possible complications of feeding him: his internal system might not be developed, and ingesting food could cause his intestines to perforate. In addition, his anus was underdeveloped, so it was not clear if he could have a bowel movement. What a position to be in as parents—feeding him might cause his demise, but so might not feeding him. Oh, my son—I did not want him to suffer. He looked so frail.

Dr. Keane suggested feeding him a tiny bit of formula through a tube. And since he'd survived for 24 hours, she thought we could begin making plans to bring him home the next day—Sunday. I was thrilled! My heartfelt desire before having Ethan was to have the opportunity to bring him home, although I knew there was only a small chance of that.

A nurse put a very narrow feeding tube down Ethan's throat into his stomach. The first feeding went extremely well, and there seemed to be an immediate improvement in Ethan's condition.

Like the previous day, our room was filled with visitors; at times it seemed more like a convention center than a hospital room. But by Saturday evening, almost everyone had left. It had been wonderful to have so many

people share in Ethan's life and support us, but it was also nice to have some quiet time. Josh and I relaxed and talked and took turns holding Ethan as *The Sound of Music* played on the television in the background. I have fond memories of that interlude.

Later in the evening, poor little Ethan began grunting as he tried to pass his meconium; I desperately wished I could help him. By 2:00 a.m. Sunday, it was clear he wasn't digesting his food—it was coming back up through the tube and his nose. There was also some blood in the tube. The nurse decided to pull out the tube. Ethan's color and breathing had also changed. He was much darker and was now struggling to breathe; his chest rose and fell deeply with each breath. His condition continued to deteriorate over the next few hours, and the nurse explained that his lungs were beginning to fill with fluid—the beginning of congestive heart failure. She placed Ethan on my chest as tears poured down my cheeks. I was losing my little boy. I told him it was all right—I understood if he had to go, I loved him so much but did not want him to hurt any longer.

**A**s the sun rose, his heartbeat slowed. It was 6:27 a.m. when he stopped breathing. My beautiful little boy was gone. I wished I could turn the clock back to the day before, when we were talking about taking him home.

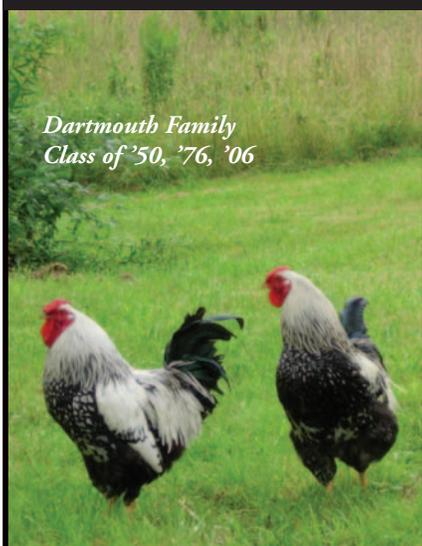
After some time had passed, Josh called his parents, the kids, and our pastor. I called my sister and a couple of close friends. As we waited for Josh's parents to get there with the kids, we talked with Carolyn, the nurse who had helped us through labor, about how to prepare for Sam, Katie, and Emma's arrival. We decided to wait for them in our room so they would not be afraid of seeing Ethan. They were a little apprehensive at first, but eventually all three of them, as well as my in-laws, held him for a while.

In mid-morning, a man from the funeral home arrived. He would take Ethan's body with him, as well as the clothes he would be buried in. We'd picked the christening outfit my sister-in-law had made for him—a tiny off-white embroidered dress and a matching bonnet. Now came the hardest part—I had to leave the hospital without my son. I wrapped him in a baby blanket with tears pouring from my eyes. I did not want to let him go and finally gave him to Carolyn, who

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would give him to the man from the funeral home after we left. My heart was broken.

On December 31, Josh and I drove to church for the service. I wanted to get there early enough to decide whether to have an open casket. I wanted it open so everybody could see how beautiful my baby was. But everyone else thought it was not a good idea—the funeral director, my in-laws, our pastor. They felt Ethan was so dark that it would detract from the service. So the little white coffin was closed and a framed picture of Ethan was positioned so everyone could see it. The service was lovely: a friend read a devotion she had written, we sang several uplifting songs, and the pastor delivered a comforting and hopeful message. I turned and looked at Josh at one point during the service and saw that tears were rolling down his cheeks; I held his hand a little tighter.

It meant a great deal to me that Dr. Clemans, several members of her staff, Dr. Keane, and several nurses from the hospital all came to the funeral. In fact, Dr. Clemans's counsel before, during, and after Ethan's birth and death was truly extraordinary. When we first met and learned that we were both Dartmouth alumni, it was a nice connection. But after we walked through the birth and death of my son together, we shared so much more. Not only is she a technically skilled ob-gyn, but she is wonderfully adept at the personal side of medicine.

After the service, I went back to the front of the church to look at my son for the last time. I stroked his face and touched his hair and told him I loved him.

We buried Ethan five months later, on May 22. The weeks leading up to the graveside service were hard. I had not expected to feel intense grief all over again. The day of the service was cold and rainy, but the service itself was beautiful.

At its conclusion, I distributed balloons—blue and yellow—to those who had come, explaining that there were 40 balloons because Ethan had lived for 40 hours. We then gathered around Ethan's tiny white coffin and released all the balloons at the same time. We watched as they raced skyward, a blue and yellow cloud that became smaller with each passing second. As I watched the balloons soar skyward, I felt peace descend on me. It occurred to me that just as I had let the balloons go, I could also let my son go because I would meet him again. ■

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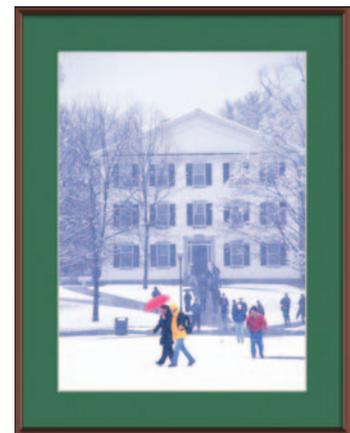
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