

# The New York Times

Home

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January 3, 2017

## One Man's Quest to Change the Way We Die



B.J. Miller Credit Todd Hido for The New York Times

**How B.J. Miller, a doctor and triple amputee, used his own experience to pioneer a new model of palliative care at a small, quirky hospice in San Francisco.**

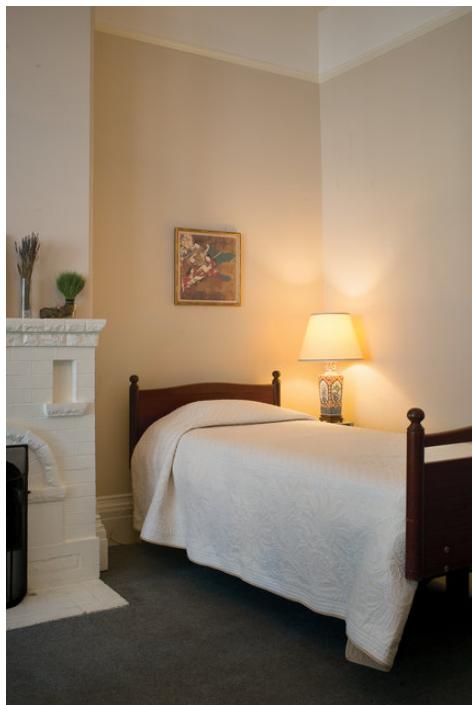
First, the back story, because, B.J. Miller has found, the back story is unavoidable when you are missing three limbs.

Miller was a sophomore at Princeton when, one Monday night in November 1990, he and two friends went out for drinks and, at around 4 a.m., found themselves ambling toward a convenience store for sandwiches. They decided to climb a commuter train parked at the adjacent rail station, for fun. Miller scaled it first. When he got to the top, electrical current arced out of a piece of equipment into the watch on his wrist. Eleven-thousand volts shot through his left arm and down his legs. When his friends reached him on the roof of the train, smoke was rising from his feet.

Miller remembers none of this. His memories don't kick in until several days later, when he woke up in the burn unit of St. Barnabas Medical Center, in Livingston, N.J. Thinking he'd resurfaced from a terrible dream, he tried to shamle across his hospital room on the charred crusts of his legs until he used up the slack of his catheter tube and the device tore out of his body. Then, all the pain hit him at once.

Doctors took each leg just below the knee, one at a time. Then they turned to his arm, which triggered in Miller an even deeper grief. ("Hands do stuff," he explains. "Your foot is just a stinky, clunky little platform.") For weeks, the hospital staff considered him close to death. But Miller, in a devastated haze, didn't know that. He only worried about who he would be when he survived.

For a long time, no visitors were allowed in his hospital room; the burn unit was a sterile environment. But on the morning Miller's arm was going to be amputated, just below the elbow, a dozen friends and family members packed into a 10-foot-long corridor between the burn unit and the elevator, just to catch a glimpse of him as he was rolled to surgery. "They all dared to show up," Miller remembers thinking. "They all dared to look at me. They were proving that I was lovable even when I couldn't see it." This reassured Miller, as did the example of his mother, Susan, a polio survivor who has used a wheelchair since Miller was a child: She had never seemed diminished. After the operation, when Miller was rolled through the hallway again, he opened his eyes as he passed her and said: "Mom, Mom. Now you and me have more in common."



A room at the Zen Hospice Guest House in San Francisco.

Todd Hido for The New York Times

It wasn't that Miller was suddenly enlightened; internally, he was in turmoil. But in retrospect, he credits himself with doing one thing right: He saw a good way to look at his situation and committed to faking that perspective, hoping that his genuine self might eventually catch up. Miller refused, for example, to let himself believe that his life was extra difficult now, only uniquely difficult, as all lives are. He resolved to think of his suffering as simply a "variation on a theme we all deal with — to be human is really hard," he says. His life had never felt easy, even as a privileged, able-bodied suburban boy with two adoring parents, but he never felt entitled to any angst; he saw unhappiness as an illegitimate intrusion into the carefree reality he was supposed to inhabit. And don't we all do that, he realized. Don't we all treat suffering as a disruption to existence, instead of an inevitable part of it? He wondered what would happen if you could "reincorporate your version of reality, of normalcy, to accommodate suffering." As a disabled person, he was getting all kinds of signals that he was different and separated from everyone else. But he worked hard to see himself as merely sitting somewhere on a continuum between the man on his deathbed and the woman who misplaced her car keys, to let his accident heighten his connectedness to others, instead of isolating him. This was the only way, he thought, to keep from hating his injuries and, by extension, himself.

Miller returned to Princeton the following year. He had three prosthetics and rode around campus in a golf cart with a rambunctious service dog named Vermont who, in truth, was too much of a misfit to perform any concrete service. Miller had wanted to work in foreign relations, in China; now he started studying art history. He found it to be a good lens through which to keep making sense of his injuries.

First, there was the discipline's implicit conviction that every work is shaped by the viewer's perspective. He remembers looking at slides of ancient sculptures in a dark lecture hall, all of them missing arms or noses or ears, and suddenly recognizing them for what they were: fellow amputees. "We were, as a class, all calling these works monumental, beautiful and important, but we'd never seen them whole," he says. Time's effect on these marble bodies — their suffering, really — was understood as part of the art. Medicine didn't think about bodies this way, Miller realized. Embedded in words like "disability" and "rehabilitation" was a less generous view: "There was an aberrant moment in your life and, with some help, you could get back to what you were, or approximate it." So, instead of regarding his injuries as something to get over, Miller tried to get into them, to see his new life as its own novel challenge, like traveling through a country whose language he didn't speak.

This positivity was still mostly aspirational. Miller spent years repulsed by the "chopped meat" where his arm ended and crushed with shame when he noticed people wince or look away. But he slowly became more confident and playful. He replaced the sock-like covering many amputees wear over their arm stumps with an actual sock: first a plain sock, then stripes and argyles. Then, one day he forgot to put on any sock and — just like that — "I was done with it. I was no longer ashamed of my arm." He became fascinated by architects like Louis Sullivan, who stripped the veneer off their buildings and let the strength of their construction shine through. And suddenly, the standard-issue foam covers he'd been wearing over his prosthetics seemed like a clunky charade — Potemkin legs. The exquisitely engineered artificial limbs they hid were actually pretty interesting, even sexy, made of the same carbon fiber used as a finish on expensive sports cars. "Why not tear that stuff off and delight in what actually is?" Miller recalled thinking. So he did.

For years Miller collected small, half-formed insights like these. Then, he entered medical school and discovered palliative care, an approach to medicine rooted in similar ideas. He now talks about his recovery as a creative act, "a transformation," and argues that all suffering offers the same opportunity, even at the end of life, which gradually became his professional focus. "Parts of me died early on," he said in a recent talk. "And that's something, one way or another, we can all say. I got to

redesign my life around this fact, and I tell you it has been a liberation to realize you can always find a shock of beauty or meaning in what life you have left.”

**One morning in** July 2015, Miller took his seat at a regular meeting of palliative-care doctors at the University of California San Francisco’s cancer center. The head of the team, Dr. Michael Rabow, started with a poem. It was a tradition, he later told me, meant to remind everyone that this was a different sort of hour in their schedule, and that, as palliative-care physicians, they were seeking different outcomes for their patients: things like comfort, beauty and meaning. The poem was called “Sinkhole,” and it seemed to offer some sneaky, syntactically muddled wisdom about letting go. When it was over, there was a beat of silence. (It was kind of a confusing poem.) Then Rabow encouraged everyone to remember any patients who had died since their last meeting. Miller was the first to speak up.

Miller, now 45, with deep brown eyes and a scruffy, silver-threaded beard, saw patients one day a week at the hospital. He was also entering his fifth year as executive director of a small, pioneering hospice in San Francisco called the Zen Hospice Project, which originated as a kind of compassionate improvisation at the height of the AIDS crisis in San Francisco, when members of the San Francisco Zen Center began taking in sick, often stigmatized young men and doing what they could to help them die comfortably. It is now an independent nonprofit group that trains volunteers for San Francisco’s Laguna Honda public hospital as well as for its own revered, small-scale residential operation. (Two of the facility’s six beds are reserved for U.C.S.F., which sends patients there; the rest are funded through sliding-scale fees and private donations.) Once an outlier, Zen Hospice has come to embody a growing nationwide effort to reclaim the end of life as a human experience instead of primarily a medical one. The goal, as Miller likes to put it, is to “de-pathologize death.”

Around the table at U.C.S.F., Miller stood out. The other doctors wore dress pants and button-downs — physician-casual — while he wore a sky blue corduroy shirt with a tear in the sleeve and a pair of rumpled khakis; he could have come straight from camping or Bonnaroo. Even just sitting there, he transmitted a strange charisma — a magnetism, people kept telling me, that was hard to explain but also *necessary* to explain, because the rapport Miller seems to instantly establish with everyone is a part of his gift as a clinician.

“It’s reasonable to say that it’s impossible to describe what it feels like to be with him,” Rabow told me. “People feel accepted. I think they feel loved.” It’s in the way Miller seems to swaddle you in his attention, the way his goofiness punctures any pretensions. (Miller, who has an unrepentant knucklehead side, habitually addresses other men as “Brother man” or “Mon” and insisted to me many times that he hasn’t finished a book in 20 years.) For people who know him, his magic has almost become an exasperating joke. When I spoke to Miller’s childhood friend Justin Burke, he told me a story about Miller running around on a beach with his dog in San Francisco years ago. A man came hobbling over and explained that he was about to have his own leg amputated and that just watching Miller run around like this, on two prosthetics, had instantaneously reassured him that he was going to be O.K. I told Burke to hang on: Someone at Zen Hospice had already told me this story, except that in her version, Miller was running on a trail in Texas. “Ask him how many times it’s happened,” Burke deadpanned.

Now Miller also seemed to be on the cusp of modest celebrity. He’d started speaking about death and dying at medical schools and conferences around the country and will soon surface in Oprah’s living room, chatting about palliative care on her “Super Soul Sunday” TV show. Several of Miller’s colleagues described him to me as exactly the kind of public ambassador their field needed. “What B.J. accomplishes is to talk about death without making it sound scary and horrible,” Rita Charon, a professor of medicine at Columbia University Medical School, says. “We know from seeing him standing in front of us that he has suffered. We know that he has been at the brink of the abyss that

he's talking about. That gives him an authority that others may not have." Vicki Jackson, the chief of palliative care at Massachusetts General Hospital, agreed. Nobody welcomes conversations about dying, she said, not even about making the experience less miserable. "But people will listen to B.J.," she said. "They want to."

Jackson pointed to the talk Miller gave to close the TED conference in 2015. Miller described languishing in a windowless, antiseptic burn unit after his amputations. He heard there was a blizzard outside but couldn't see it himself. Then a nurse smuggled him a snowball and allowed him to hold it. This was against hospital regulations, and this was Miller's point: There are parts of ourselves that the conventional health care system isn't equipped to heal or nourish, adding to our suffering. He described holding that snowball as "a stolen moment," and said, "But I cannot tell you the rapture I felt holding that in my hand, and the coldness dripping onto my burning skin, the miracle of it all, the fascination as I watched it melt and turn into water. In that moment, just being any part of this planet, in this universe, mattered more to me than whether I lived or died." Miller's talk has been watched more than five million times. And yet, Jackson told me: "If I said all that — 'Oh, I could feel the coldness of the snowball ...' — you'd be like: 'Shut. Up. Shut up!' But no one is going to question B.J."

Now, at the morning meeting, Miller began describing the case of a young man named Randy Sloan, a patient at U.C.S.F. who died of an aggressive cancer a few weeks earlier at Zen Hospice. In a way, Sloan's case was typical. It passed through all the same medical decision points and existential themes the doctors knew from working with their own terminal patients. But here, the timeline was so compressed that those themes felt distilled and heightened.

And then there was the bracing idiosyncrasy of everything Miller's staff had been able to do for Sloan at Zen Hospice. Rabow told me that all palliative-care departments and home-hospice agencies believe patients' wishes should be honored, but Zen Hospice's small size allows it to "actualize" these ideals more fully. When Miller relayed one detail about Sloan's stay at the hospice — it was either the part about the sailing trip or the wedding — one doctor across the conference table expelled what seemed to be an involuntary, admiring, "What?"

Everything Miller was saying had a way of sharpening an essential set of questions: What is a good death? How do you judge? In the end, what matters? You got the sense that looking closely at Sloan's case might even get you close to some answers or, at least, less hopelessly far away.

This is the story he told.

**'You train people not to run away from hard things, not to run away from the suffering of others.'**

**It started with** an email late one night, in April 2015. "I'm the mother of Randy Sloan," a woman named Melany Baldwin wrote to Miller. She reminded Miller how he met her son the previous year. And then: "Anyway, last week my dear son was diagnosed with mesothelioma," a rare, terminal cancer. "We are devastated. He is only 27 years old."

Miller got emails, texts and calls like this almost daily from friends, friends of friends or total strangers. And he put pressure on himself to help as much as he could. But it was also exhausting, and he put equal and opposing pressure on himself to live his own life fully — a byproduct of his extreme intimacy with mortality. "The lessons I get from my patients and their families, and from this work," Miller said, "is to enjoy this big, huge, mystical, crazy, beautiful, wacky world. And I'm too

often not doing that. That can feel distressing to me.” A few months earlier, Miller had another brush with death — a pancreatic-cancer scare that turned out to be nothing — and he told me that “it was interesting to watch myself play with that thought. Where my mind went was: ‘Cool. Now I get to quit all this work.’ ” Maybe he would just disappear, get weird, grow weed.

And so, as it happens, Miller didn’t get Baldwin’s email for several days, because he’d decided to experiment with going off the grid. He went on a weeklong, aimless road trip around the West with his mutt, Maysie, riding shotgun, and he rode his treasured motorcycle — a sleek, black, heavily customized Aprilia — up to Sonoma for a weekend with old friends. He was pulled over for speeding on the bike twice. The first cop approached a little freaked out; unable to compute a one-limbed man riding a motorcycle, he mistook Miller’s prosthetic arm for a weapon.

“I love bikes,” Miller told me. “I love gyroscopic, two-wheel action!” Mountain biking had become his way of releasing pressure in the turbulent decade after his accident. (Miller sued Princeton and New Jersey Transit, which operated the train, charging that they failed to make safety upgrades after similar accidents in the past. He won settlements totaling nearly \$6 million, but was blindsided when some in the press excoriated him as a symbol of America’s binge-drinking youth and their lack of personal responsibility.) He had returned to cycling quickly, tooling around trails with a specialized arm clipped to the handlebar and two prosthetics pedaling. It allowed him to be alone without being lonely, to remind himself that his life still allowed for adventure and risk. Soon, he was wandering into motorcycle dealerships, explaining how badly he wanted to get back on a motorcycle too, asking if anyone could build him one. But for years, none of the mechanics Miller approached would touch the idea: Engineering a machine for a triple-amputee seemed nearly impossible, the potential liability too great.

Then, in late 2013, Miller checked out Scuderia West, a boutique motorcycle shop not far from Zen Hospice, in the Mission District. Scuderia was staffed by a crew of young, wisecracking gear-heads, who, after finishing their shifts, stayed late drinking beer and rehabilitating decrepit old bikes for fun. Right away, Miller noticed a different vibe. They were excited by the challenge of retrofitting a bike for him. This was especially true of the young tech who ultimately volunteered to take the project: Melany Baldwin’s son, Randy Sloan.

Sloan grew up in Texas. He was bald, with a bushy, reddish beard and a disarming, contented smile. His social life in San Francisco revolved around Scuderia, and he was the baby of the group: not just younger, but more sensitive and trusting. “He was way too nice to work here,” his friend and co-worker Katie Putman told me. Sloan’s closest relationship may have been with his dog, a husky named Desmo, whom he rescued from a disreputable breeder. The dog was weird-looking: It had one blue eye and one eye that was half-brown and half-blue. (“He would always select the misfit,” Baldwin said.)

Sloan threw himself into overhauling a bike for Miller. For six months, he confronted a cascade of problems — like how to run all the controls to a single handlebar so Miller could accelerate and brake with one hand — while Miller made excuses to check in on his progress. “It was just an immediate man crush,” Miller told me. “The guy was helping me build this dream.”

Sloan was feeling it, too. Everyone at Scuderia was. They stalked Miller online, learning about his career at Zen Hospice. His work with the dying impressed them as fearless, just as his conviction to ride a motorcycle again did. Sloan never carried on about people or even talked that much, but he frequently referred to Miller as “a legend,” and those close to him knew what that meant. “There were not many ‘legends’ in Randy’s eyes,” Putman said.

Sloan finished Miller's motorcycle in April 2014. A crowd gathered at Scuderia to watch Miller take possession. Sloan had him climb on, then clambered around and under the bike, making final adjustments. Then he stepped back and started, quietly, to cry.

Miller was tearing up under his helmet, too. But he didn't drag things out. He started the engine, said thank you, then streaked down the alleyway at the back of the shop. Everyone hollered and applauded as they watched him disappear down Valencia Street — very fast, but with a pronounced, unsettling wobble.

Miller had been lying. He'd never ridden a motorcycle before.

**A year later**, Miller got Melany Baldwin's email. Once he was back from his road trip, he contacted Sloan's doctors at U.C.S.F. to learn more about his case.

Sloan was walking Desmo up a hill a few weeks earlier, in April, and found he couldn't catch his breath. He was rushed into surgery, to fix an apparent collapsed lung. But the surgeon discovered a raft of tumors spread across his lung, diaphragm and heart: mesothelioma. The diagnosis alone was improbable. Mesothelioma is typically seen in older people, after long-term asbestos or radiation exposure. And the way the cancer was moving through Sloan's body was shocking. A subsequent PET scan revealed it had already spread to his pancreas and brain.

His doctors at U.C.S.F. believed the tumor on his brainstem would paralyze him within weeks. And so, Sloan underwent whole-brain radiation to shrink it before attacking everything else. He didn't want to be cut off from his body — he wanted to be as much like his old self as possible. "I'm sick of being sick, and I'm sick of talking about being sick," he kept telling his mother. He insisted that she go back home to Illinois while he returned to the small apartment he shared with two roommates, waiting to start chemo.

The next two weeks were grim. Tumors crusted over Sloan's heart, hindering it from pumping blood through his body. His capillaries began seeping water into his tissues. Soon, his feet were literally leaking, and the retained water cracked his skin from the shins down, mashing him with pain. Sloan's ankles grew as wide as logs. He started walking with a cane. And because the pain in his torso kept him from lying down or even sitting comfortably, one night he fell asleep standing up and cut his head open when he collapsed.



Randy Sloan From Melany Baldwin

Putman, Sloan's friend from Scuderia, had swept in to take care of Desmo, the husky. Now she transitioned into Sloan's de facto nurse. But Sloan was a bad patient. He played down his condition and seemed to resent Putman's help, out of shame or guilt. Several times, Putman told me, she had to race to his apartment and take him to the emergency room: "I started calling it our date night." Finally, she asked Sloan if she should just sleep over. Sloan accepted her offer this way: "I think Desmo would like that."

Early in June, Sloan was readmitted to U.C.S.F., and Baldwin, his mother, returned to San Francisco to be with him. Miller saw both of them for an appointment that morning, and when he walked in, it hit him how quickly Sloan's body was failing: In roughly six weeks, Sloan had gone from a functioning, happy 27-year-old, walking his dog up a hill, to very clearly dying. His decline was relentless, by any standard. At no point had any doctor been able to give him a single bit of good news. Even now, Sloan's oncologist was reporting that after the first dose of chemotherapy, his heart was likely too frail to take more.

Still, Sloan talked to Miller about "doing battle" with the cancer and "winning this thing"; about getting back to work at Scuderia and flying to Illinois, where Baldwin would remarry later that summer. He also wanted to go to Tokyo Disneyland, he said. Miller looked at Sloan, then looked at Baldwin, trying to intuit who knew what and who might have been pretending not to know and how best to gently reconcile everyone's hopes with the merciless reality.

Good palliative-care doctors recognize there's an art to navigating clinical interactions like this, and Miller seems particularly sensitive to its subtleties. In this case, Miller realized, his job was to "disillusion" Sloan without devastating him. Hope is a tricky thing, Miller told me. Some terminal patients keep chasing hope through round after round of chemo. But it's amazing how easily others "re-proportion," or recalibrate, their expectations: how the hope of making it to a grandchild's birthday or finishing "Game of Thrones" becomes sufficiently meaningful. "The question becomes," Miller says, "how do you incorporate those hard facts into your moment-by-moment life instead of trying to run away from them?"

At an initial appointment with Sloan, two weeks earlier, Miller made the calculation not to steer Sloan toward any crushing realizations. He worried that if he pushed too hard, Sloan might feel alienated and shut down. ("I needed his allegiance," Miller later explained; it was more important, in the long term, that Sloan see him as an advocate.) At the second meeting, Miller remembered, "I felt the need to be more brutal." And, he imagined, by now Sloan would have started to suspect that the story he'd been telling himself didn't fit the reality. "I just said, 'Randy, this is not going like any of us want for you,' " and Miller began, calmly, to level with him.

Traveling was out of the question, Miller explained; best guess, Sloan had a few months to live. "You could just watch his world collapse," Miller recalled. "With each sentence, you're taking another possibility away." Sloan started crying. And yet, Baldwin also knew that her son had been waiting for his doctors to say this out loud. Sloan couldn't understand why, if he had Stage 4 of an incurable cancer, he was still taking 70 pills every day, with the doses laid out in a dizzying flowchart. And as Miller went on, he was stunned by how well Sloan seemed to be absorbing this new information, without buckling under its weight. "He was actually kind of keeping up with his grief, reconciling the facts of his life," he says. "It was a moving target, and he kept hitting it." Baldwin told me: "Randy was a simple guy. He would say to me, 'Mom, all I want is one ordinary day.'" He was sick of being sick — just like he'd been saying. He wanted to go back to living, as best he could.



Quickly the conversation turned to what was next. A standard question in palliative care is “What’s important to you now?” But Sloan didn’t muster much of a response, so Miller retooled the question. He told Sloan that nothing about his life was going the way he expected, and his body was only going to keep breaking down. “So, what’s your favorite part of yourself? What character trait do we want to make sure to protect as everything else falls apart?” Sloan had an immediate answer for this one. “I love everybody I’ve ever met,” he said.

Baldwin had heard her son say this before, with total earnestness. And he said it with such conviction now that Miller immediately believed it, too. Besides, Miller had already *felt* it to be true, a year earlier, when he drove his motorcycle away from Sloan at Scuderia. “He was an amazing person that way,” Miller told me.

Sloan got apprehensive when Miller started telling him about Zen Hospice’s residential facility, known as the Guest House; it sounded as if it was for old people. But Miller explained that it was probably the best chance he had for living the last act of his life the way he wanted. His other options were to tough it out at home with two weekly visits from a home hospice nurse or go to a nursing home. At Zen Hospice, Sloan’s friends would always be welcome, and Sloan could come and go as he pleased as long as someone went with him. He could eat what he wanted. He could step out for a cigarette. He could even walk up the street and smoke on his own stoop — the Guest House was just two blocks from Sloan’s apartment. Besides, Miller told him: “It’s where I work. I’ll be there.”

Sloan agreed but didn’t seem entirely comfortable with the idea. He told one of his friends from Scuderia: “I’m moving in with B.J.”

**Sloan arrived at** the Guest House with his mother five days later, on the morning of June 9. He insisted on walking there, trundling the two blocks from his apartment with his cane.

The Guest House is a calm, unpretentious space: a large Victorian home with six beds in five bedrooms, vaulted ceilings, slightly shabby furniture and warm, Oriental rugs. There is a large wooden Buddha in the dining room. The kitchen is light-filled and bursting with flowers. There’s always a pot of tea and often freshly baked cookies. And while Zen Hospice has a rotating, 24-hour nursing staff, the tiny nursing station is literally tucked into a kind of cabinet in the hall upstairs; the house, in other words, feels very much like a house, not a hospital.

You don’t have to spend much time there to realize that the most crucial, and distinctive, piece of the operation is its staff of volunteers. Freed of most medical duties by the nursing staff, the volunteers act almost as existential nurses. They sit with residents and chat, offering their full attention, unencumbered by the turmoil a family member might feel. The volunteers are ordinary people: retired Macy’s executives, social workers, bakers, underemployed millennials or kibitzing empty-nesters. Many are practicing Buddhists. Many are not. (Miller isn’t.) But Buddhism informs their training. There’s an emphasis on accepting suffering, on not getting tripped up by one’s own discomfort around it. “You train people not to run away from hard things, not to run away from the suffering of others,” Miller explained. This liberates residents to feel whatever they’re going to feel in their final days, even to fall apart.

At first, many volunteers experience a confused apprehension. They arrive expecting nonstop, penetrating metaphysical conversations with wise elderly people and instead just wind up plying them for recipes or knitting advice or watching “Wheel of Fortune” with them or restocking latex gloves for the Guest House nurses. But one especially well-liked volunteer, Josh Kornbluth, told me that,

after a year working at the Guest House, he understood that the value of Zen Hospice is actually “in the quotidian — the holding of someone’s hand, bringing them food that’s been beautifully arranged on the plate, all the small ways of showing respect to that person as a living person and not as ‘predeceased.’ Those are actually deep things. And I say that as the least Zen person!” In fact, Kornbluth was raised by Jewish Communists in New York City, and once, after a woman died at the Guest House and no more-senior volunteer was on hand to take charge, I watched him — adrenalized, uneasy, perspiring — fumble around on his iPhone for something to say over the body before they wheeled it away, then mangle the pronunciation of Thich Nhat Hanh.

Sloan didn’t appreciate any of this at first; the Guest House creeped him out. Shortly after he arrived, a nurse showed him to one of the smaller rooms at the top of the stairs: “Bed 5,” it was called. It had a twin bed, an ornate wooden chest and a large framed photo of a Tibetan boy in a red robe. The rest of the rooms were occupied by old ladies: one who spoke no English and kept her television tuned to blaring Russian talk shows; a retired teacher in the final throes of cervical cancer; an unflappable, perpetually crocheting 99-year-old who had recently gained back some weight and taken to playing piano and who, everyone suspected, wasn’t actually dying anymore. Sloan worried that he had exiled himself to a nursing home, and nothing he was seeing now reassured him. He told his mother he needed to “take a day off.” Then he went downstairs and walked back to his apartment. The staff of Zen Hospice, considering it part of their job to accept his trepidation, let him go.

He returned the next morning. He was ready to move in now, he said, and came trailed by a swarm of friends who’d tossed his possessions into boxes and were now hauling them up the Guest House stairs. They started hammering things into walls, mounting Sloan’s flat-screen television, wiring his stereo and gaming console, claiming unused furniture from elsewhere in the Guest House. Soon the room was filled with Sloan’s motorcycle-racing posters and helmets and a small garden gnome lying in a provocative position. Erin Singer, the house’s kitchen manager at the time, loved watching it happen. “All of a sudden, it was a late-20s-dude’s room,” she said.

Once Sloan was settled, the feeling was one of profound relief. His little collective had been caring for him as best they could. But now he had chefs eager to cook for him and nurses and volunteers to ensure that he was comfortable. His mother and his friends didn’t have to nag him about taking his pain medication anymore or try, ineptly, to clean and dress the wounds on his feet that caused him such shame. Baldwin told me, “At Zen, they talk about being unburdened and unburdening.” And that’s what happened: They could just be Sloan’s mother and friends again, and Sloan no longer had to be their patient, either.

From then on, throngs of co-workers and friends passed through the Guest House. Desmo, the dog, hung out, too. “His entourage was either one-deep or 10-deep,” Jolene Scarella, then the director of nursing, told me. They sat around playing video games and drinking Bud Light, just like they always did, or they swept Sloan around the city for dinner at his favorite restaurants. The Guest House isn’t a somber place, but still, the volunteers weren’t accustomed to this level of freewheeling autonomy or raucousness or youth. “They brought so much joy to the house,” Singer said. And yet, some volunteers also had a hard time shaking the acute tragedy of Sloan’s case. All that Buddhist, contemplative nonattachment was easier to buy into with the elderly; with Sloan, it was hard to feel as if you were helping someone transition through a cosmic crescendo at the end of a life well lived. Some of the staff, like Singer, were only slightly older than Sloan. Others had children his age. It felt cruel.

Sloan’s body, meanwhile, continued to fail faster than anyone had anticipated. Within days, breathing became more onerous and the weeping ulcerations on his feet became rawer; there was blood draining from his right foot now, and a terrible odor. On Thursday, just three days after Sloan arrived, he needed to transition from OxyContin to methadone.

The next day, he went wedding-dress shopping. Baldwin and her fiancé had scrapped their wedding plans in Illinois. But a chaplain at U.C.S.F. volunteered to perform the ceremony at the tiny park next to the Guest House instead, and Singer offered to throw together a little reception inside. For Sloan, the best man, planning the wedding with his mother became a fun distraction. He was too swollen to wear a suit, but found a purple-and-gold velour tracksuit he liked online — the tuxedo of sweatsuits, called a “Sweatsedo.” Baldwin ordered one with “Randy” embroidered on the breast.

The wedding was scheduled for the following Thursday. The Friday before, Sloan’s fourth day at the Guest House, Baldwin drove him to a David’s Bridal and helped him arrange himself on a chair. He seemed much foggier all of a sudden. As she came out of the dressing room, modeling each gown, Sloan mostly managed a thumbs up or thumbs down.

That night, Baldwin called Sloan’s sisters in Texas and his father in Tennessee and said that it didn’t seem as if Randy had months anymore, or even weeks. She told them to come right away.

**Miller hardly saw Sloan** at the Guest House. As Zen Hospice’s executive director, he was consumed by fund-raising and strategic planning or throttled by administrative work. The week Sloan arrived, Miller was courting producers from “60 Minutes,” hoping they would do a segment on the Guest House, and meeting with the Silicon Valley design firm IDEO, which he had retained to help put Zen Hospice forward as a national model for end-of-life care. IDEO, meanwhile, was calling Miller to consult on its own projects — helping entrepreneurs disrupt what some had taken to calling the “death space.”

And yet, Miller’s rising prominence made him uneasy. “If I want to keep doing this work, I have to be seeing patients,” he told me. “It’s really easy to get unhelpfully abstract.” In short, he was spending too much time in the wrong death space.

Still, it wasn’t that Miller was too busy to visit with Sloan. He stopped by his room a couple of times, early on, but eventually made a therapeutic decision to keep his distance. It was obvious to Miller that he upset the fragile sense of normalcy that Sloan and his friends were managing to create. As soon as Miller poked his head in, someone from Scuderia would start retelling the motorcycle story, saying how much Sloan loved building that bike for him, how he was “a legend.” “No one knew what to say,” Miller remembered. “Their suffering was palpable, and some of their suffering was these spastic efforts to put a smiley face on things.”

It was also easy to wonder how much of Sloan’s own composure was projected for their benefit. A friend from the shop, Steve Magri, told me that even when Sloan was healthy, “he would never let you feel uncomfortable around him.” Moreover, the whole-brain radiation had clearly changed Sloan, sent him deeper within himself. The pain medication had, too. He occasionally said things that even he seemed surprised by or that seemed ludicrously out of character. He had always been a vulnerable, childlike man, but there were moments, in his last days, when his mother couldn’t tell whether he’d achieved some higher state of openheartedness or was just disoriented. At one point, Sloan asked her to drive him to Scuderia so he could tell his boss, a friend, that he was sorry, but he probably wouldn’t be coming back to work after all. “I hate to let you guys down,” Sloan said tenderly, as if he were breaking this news for the first time.

I never met Randy Sloan. But as I heard these stories in the months after his death, it became impossible for me not to fixate on the unfathomability of his interior life, or anyone’s interior life, at the end — to wonder how well Sloan had come to terms with what was happening to him, how much agony he might have felt. Erin Singer, the kitchen manager, told me that Sloan seemed intent on keeping his distance from the Guest House. Usually, she said, he sat under a tree in the park next

door, silently smoking a cigarette. And it struck Singer as significant that Sloan “didn’t sit looking at the street or the garden. He always sat looking at the house,” as if he was wrestling with what it would mean to go inside.

The question that was unsettling me was about regret: How sure was everyone that Sloan didn’t have desires he would have liked to express or anguish he would have liked to work through — and should someone have helped him express and work through them, instead of just letting him play video games with his friends? My real question, I guess, was: Is this all there is?



B.J. Miller on the motorcycle that Randy Sloan helped make for him. From Melany Baldwin

Later, when I admitted this to Miller, he told me he understood this kind of anxiety well, but was able, with practice, to resist it. “Learning to love not knowing,” he said, “that’s a key part of this story. Obviously, I don’t know the depths of Randy’s soul, either. Was Randy enlightened or did he just not have the right vocabulary for this, if any of us do? We’ll never know. And maybe the difference between those things is unimportant. I think of it as: Randy got to play himself out.”

This is a favorite phrase of Miller’s. It means that Randy’s ability to be Randy was never unnecessarily constrained. What Sloan chose to do with that freedom at the Guest House was up to him. Miller was suggesting that I’d misunderstood the mission of Zen Hospice. Yes, it’s about wresting death from the one-size-fits-all approach of hospitals, but it’s also about puncturing a competing impulse, the one I was scuffling with now: our need for death to be a hypertranscendent experience. “Most people aren’t having these transformative deathbed moments,” Miller said. “And if you hold that out as a goal, they’re just going to feel like they’re failing.” The truth was, Zen Hospice had done something almost miraculous: It had allowed Sloan and those who loved him to live a succession of relatively ordinary, relatively satisfying present moments together, until Sloan’s share of present moments ran out.

**By Sloan's sixth** day at Zen Hospice, he'd become unsteady on his feet and was falling asleep in the middle of sentences. But when a nurse went to check on him at the start of her shift that morning, he smirked mischievously and told her, "I have cancer, so my mom wants me to go sailing."

In truth, the trip was Sloan's idea. The Scuderia gang had a tradition of Sunday trips to Angel Island, a forested state park in the middle of San Francisco Bay. And so, that morning, they met on a dock in Sausalito, motored over, dropped anchor and started barbecuing and drinking Coronas — a low-key "simulated rager," as one friend put it. Sloan barely spoke. He smiled occasionally. He pounded his pain medication. He returned to the Guest House that evening, sunburned and dehydrated and three hours later than he promised. (The nurses were upset, concerned mainly that Sloan could have been in pain all day.)

Then he went out to dinner. After days of driving, Sloan's father, Randy Senior — Big Randy, everyone called him — had reached San Francisco from Tennessee, and Sloan was adamant that the two of them get some food. They ate huge plates of eggs and hash browns at a nearby diner. Big Randy noticed that Sloan was struggling to grip his fork and that he ordered a beer but didn't touch it. Big Randy was recovering from foot surgery — he was hobbled himself. So when they were finished, he found he had to prop Sloan against a tree outside while he staggered to the curb to hail a cab. "Like Laurel and Hardy," Big Randy said. Sloan, slumped against the tree trunk, lit a cigarette and couldn't stop laughing.

He died 36 hours later, early on Tuesday morning, his eighth day at the Guest House. Baldwin hadn't yet arrived for the day and Big Randy, who spent the night with his son, had just left to take a shower. Two nurses were changing Sloan's clothes when it happened, and one of them, Derrick Guerra, who'd grown particularly close to Sloan, told me that, until the last instant, he could feel the young man's hand gripping his arm. The strength still left in his body, Guerra said, was unreal.

Sloan's family arrived. Scuderia people arrived. As Sloan's body was wheeled through the Guest House garden toward the back gate, they all placed flower petals around his head and over his chest — a ritual at Zen Hospice known as the Flower Petal Ceremony. Desmo, the husky, leapt up and licked his face.

**"It was amazing,"** Miller was now telling the doctors around the table at U.C.S.F., summing up Sloan's story. And there was a postscript, too. Two days after Sloan died, Baldwin and her fiancé woke up and decided to go ahead with the wedding they'd planned, in the park next to the Guest House. Afterward, the hospice staff invited everyone in for what can only be described as a joint wedding-reception-funeral.

One staff member later told me that the Guest House felt a little like a house on Thanksgiving that day — full and bustling, in a comforting way. Upstairs, the same women were still moving through the ends of their lives, each in her own way. But downstairs, there were tubs of beer and cheese plates and a handle of Jameson and someone playing guitar. Miller, who made a point of riding his motorcycle to work, invited Big Randy outside to see it. There were toasts to the happy couple. There were toasts to the dead young man. And there was his grieving mother in a new off-white gown.

The scene was all mixed up, upside-down and unexpectedly joyful, Miller told the doctors: If you'd walked in off the street, it would have been impossible to explain. "It makes you happy for a place like the Guest House where such things can happen," he said, "a roof where these things can coexist."

“Have you had many weddings?” one of the doctors asked.

“Not a ton,” Miller joked. “We haven’t put it in the brochure yet.”

It was a Wednesday, the day Miller had his cancer clinic at the hospital, and he excused himself from the meeting to dash to another floor. His first patient, heavily medicated but still tearing up from pain in his spine and legs, fumbled through his symptoms and worries, still wondering how this had happened to him. Miller mostly listened and said things like: “There’s nothing you could have done to cause this, pal. That’s important for you to know.” A lot of his patients were like this, he later told me. He couldn’t do much for them, medically. “But I’m letting them know I see their suffering,” he said. “That message helps somehow, some way, a little.”

It did help, all morning. It was an astonishing thing to witness. Over the previous weeks, I noticed Miller struggling with his administrative role at Zen Hospice, looking depleted after a long lunch with a donor or while being talked at about options for optimizing the Guest House’s automated phone directory. Now, he seemed in his element: the bedside was his natural habitat. When his next patient, a hunched older woman arrived, Miller started by asking her not just about her pain, sleep and meds but also about how she was doing since her dog died. “It’s a big hole to fill in the heart,” Miller told her. She whimpered, “The space is just so big.” She seemed relieved just to admit that.

Not long after that, Miller decided to step down as Zen Hospice’s executive director. He spent months trying to create the right part-time role for himself — something less administrative and managerial that would get him back at people’s bedsides again — but finally resigned. He continued to see patients at U.C.S.F., began co-writing a kind of field guide to dying and started raising seed money for a dream of his, something he’s calling the Center for Dying and Living: a combination “skunk works and design lab,” as he puts it, to dig into more imaginative possibilities for palliative care. He also ramped up his public speaking, and as he traveled around the world, he usually did so wearing Randy Sloan’s favorite, beat up belt, a gift from Sloan’s mother. Only Miller, with his mischievously counterintuitive style of insight, his deep appreciation of one, maybe trite-sounding truth — that the dying are still very much alive and we all are dying — could have thought about Sloan’s life, even the last phase of it, and decided, without hesitation, to wear that belt “for good luck.”

He was still hopelessly busy, still chastened by the volume of good work he saw in front of him but couldn’t do. But it felt right. Miller hadn’t unburdened himself, exactly, but rearranged and rebalanced the weight. He was committing to the parts of himself that felt most meaningful and trying to shake free of all the other, unhelpful expectations. “It’s the same thing I would counsel a patient,” Miller told me. It’s what he had counseled Randy Sloan.

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Jon Mooallem is a writer at large for the magazine and the author of “Wild Ones.” He last wrote about the [death of Pedals](#), a New Jersey bear who walked on two legs.

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A version of this article appears in print on January 8, 2017, on Page MM39 of the Sunday Magazine with the headline: The House at the End of the World. [Today's Paper](#) | [Subscribe](#)