

What Really Matters at the End of Life by BJ Miller

Well, we all need a reason to wake up. For me, it just took 11,000 volts.

I know you're too polite to ask, so I will tell you.

One night, sophomore year of college, just back from Thanksgiving holiday, a few of my friends and I were horsing around, and we decided to climb atop a parked commuter train. It was just sitting there, with the wires that run overhead. Somehow, that seemed like a great idea at the time. We'd certainly done stupider things. I scurried up the ladder on the back, and when I stood up, the electrical current entered my arm, blew down and out my feet, and that was that. Would you believe that watch still works? Takes a licking!

My father wears it now in solidarity.

That night began my formal relationship with death -- my death -- and it also began my long run as a patient. It's a good word. It means one who suffers. So I guess we're all patients.

Now, the American health care system has more than its fair share of dysfunction -- to match its brilliance, to be sure. I'm a physician now, a hospice and palliative medicine doc, so I've seen care from both sides. And believe me: almost everyone who goes into healthcare really means well -- I mean, truly. But we who work in it are also unwitting agents for a system that too often does not serve.

Why? Well, there's actually a pretty easy answer to that question, and it explains a lot: because healthcare was designed with diseases, not people, at its center. Which is to say, of course, it was badly designed. And nowhere are the effects of bad design more heartbreaking or the opportunity for good design more compelling than at the end of life, where things are so distilled and concentrated. There are no do-overs.

My purpose today is to reach out across disciplines and invite design thinking into this big conversation. That is, to bring intention and creativity to the experience of dying. We have a monumental opportunity in front of us, before one of the few universal issues as individuals as well as a civil society: to rethink and redesign how it is we die.

So let's begin at the end. For most people, the scariest thing about death isn't being dead, it's dying, suffering. It's a key distinction. To get underneath this, it can be very helpful to tease out suffering which is necessary as it is, from suffering we can change. The former is a natural, essential part of life, part of the deal, and to this we

are called to make space, adjust, grow. It can be really good to realize forces larger than ourselves. They bring proportionality, like a cosmic right-sizing. After my limbs were gone, that loss, for example, became fact, fixed -- necessarily part of my life, and I learned that I could no more reject this fact than reject myself. It took me a while, but I learned it eventually. Now, another great thing about necessary suffering is that it is the very thing that unites caregiver and care receiver -- human beings. This, we are finally realizing, is where healing happens. Yes, compassion -- literally, as we learned yesterday -- suffering together.

Now, on the systems side, on the other hand, so much of the suffering is unnecessary, invented. It serves no good purpose. But the good news is, since this brand of suffering is made up, well, we can change it. How we die is indeed something we can affect. Making the system sensitive to this fundamental distinction between necessary and unnecessary suffering gives us our first of three design cues for the day. After all, our role as caregivers, as people who care, is to relieve suffering -- not add to the pile.

True to the tenets of palliative care, I function as something of a reflective advocate, as much as prescribing physician. Quick aside: palliative care -- a very important field but poorly understood -- while it includes, it is not limited to end of life care. It is not limited to hospice. It's simply about comfort and living well at any stage. So please know that you don't have to be dying anytime soon to benefit from palliative care.

Now, let me introduce you to Frank. Sort of makes this point. I've been seeing Frank now for years. He's living with advancing prostate cancer on top of long-standing HIV. We work on his bone pain and his fatigue, but most of the time we spend thinking out loud together about his life -- really, about our lives. In this way, Frank grieves. In this way, he keeps up with his losses as they roll in, so that he's ready to take in the next moment. Loss is one thing, but regret, quite another. Frank has always been an adventurer -- he looks like something out of a Norman Rockwell painting -- and no fan of regret. So it wasn't surprising when he came into clinic one day, saying he wanted to raft down the Colorado River. Was this a good idea? With all the risks to his safety and his health, some would say no. Many did, but he went for it, while he still could. It was a glorious, marvelous trip: freezing water, blistering dry heat, scorpions, snakes, wildlife howling off the flaming walls of the Grand Canyon -- all the glorious side of the world beyond our control. Frank's decision, while maybe dramatic, is exactly the kind so many of us would make, if we only had the support to figure out what is best for ourselves over time.

So much of what we're talking about today is a shift in perspective. After my accident, when I went back to college, I changed my major to art history. Studying visual art, I figured I'd learn something about how to see -- a really potent lesson for a kid who couldn't change so much of what he was seeing. Perspective, that kind of alchemy we humans get to play with, turning anguish into a flower.

Flash forward: now I work at an amazing place in San Francisco called the Zen Hospice Project, where we have a little ritual that helps with this shift in perspective. When one of our residents dies, the mortuary men come, and as we're wheeling the body out through the garden, heading for the gate, we pause. Anyone who wants -- fellow residents, family, nurses, volunteers, the hearse drivers too, now -- shares a story or a song or silence, as we sprinkle the body with flower petals. It takes a few minutes; it's a sweet, simple parting image to usher in grief with warmth, rather than repugnance. Contrast that with the typical experience in the hospital setting, much like this -- floodlit room lined with tubes and beeping machines and blinking lights that

don't stop even when the patient's life has. Cleaning crew swoops in, the body's whisked away, and it all feels as though that person had never really existed. Well-intended, of course, in the name of sterility, but hospitals tend to assault our senses, and the most we might hope for within those walls is numbness -- anesthetic, literally the opposite of aesthetic. I revere hospitals for what they can do; I am alive because of them. But we ask too much of our hospitals. They are places for acute trauma and treatable illness. They are no place to live and die; that's not what they were designed for.

Now mind you -- I am not giving up on the notion that our institutions can become more humane. Beauty can be found anywhere. I spent a few months in a burn unit at St. Barnabas Hospital in Livingston, New Jersey, where I got really great care at every turn, including good palliative care for my pain. And one night, it began to snow outside. I remember my nurses complaining about driving through it. And there was no window in my room, but it was great to just imagine it coming down all sticky. Next day, one of my nurses smuggled in a snowball for me. She brought it in to the unit. 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. That little snowball packed all the inspiration I needed to both try to live and be OK if I did not. In a hospital, that's a stolen moment.

In my work over the years, I've known many people who were ready to go, ready to die. Not because they had found some final peace or transcendence, but because they were so repulsed by what their lives had become -- in a word, cut off, or ugly. There are already record numbers of us living with chronic and terminal illness, and into ever older age. And we are nowhere near ready or prepared for this silver tsunami. We need an infrastructure dynamic enough to handle these seismic shifts in our population. Now is the time to create something new, something vital. I know we can because we have to. The alternative is just unacceptable. And the key ingredients are known: policy, education and training, systems, bricks and mortar. We have tons of input for designers of all stripes to work with.

We know, for example, from research what's most important to people who are closer to death: comfort; feeling unburdened and unburdening to those they love; existential peace; and a sense of wonderment and spirituality.

Over Zen Hospice's nearly 30 years, we've learned much more from our residents in subtle detail. Little things aren't so little. Take Janette. She finds it harder to breathe one day to the next due to ALS. Well, guess what? She wants to start smoking again -- and French cigarettes, if you please. Not out of some self-destructive bent, but to feel her lungs filled while she has them. Priorities change. Or Kate -- she just wants to know her dog Austin is lying at the foot of her bed, his cold muzzle against her dry skin, instead of more chemotherapy coursing through her veins -- she's done that. Sensuous, aesthetic gratification, where in a moment, in an instant, we are rewarded for just being. So much of it comes down to loving our time by way of the senses, by way of the body -- the very thing doing the living and the dying.

Probably the most poignant room in the Zen Hospice guest house is our kitchen, which is a little strange when you realize that so many of our residents can eat very little, if anything at all. But we realize we are providing sustenance on several levels: smell, a symbolic plane. Seriously, with all the heavy-duty stuff happening under our roof, one of the most tried and true interventions we know of, is to bake cookies. As long as we have

our senses -- even just one -- we have at least the possibility of accessing what makes us feel human, connected. Imagine the ripples of this notion for the millions of people living and dying with dementia. Primal sensorial delights that say the things we don't have words for, impulses that make us stay present -- no need for a past or a future.

So, if teasing unnecessary suffering out of the system was our first design cue, then tending to dignity by way of the senses, by way of the body -- the aesthetic realm -- is design cue number two. Now this gets us quickly to the third and final bit for today; namely, we need to lift our sights, to set our sights on well-being, so that life and health and healthcare can become about making life more wonderful, rather than just less horrible. Beneficence.

Here, this gets right at the distinction between a disease-centered and a patient- or human-centered model of care, and here is where caring becomes a creative, generative, even playful act. "Play" may sound like a funny word here. But it is also one of our highest forms of adaptation. Consider every major compulsory effort it takes to be human. The need for food has birthed cuisine. The need for shelter has given rise to architecture. The need for cover, fashion. And for being subjected to the clock, well, we invented music. So, since dying is a necessary part of life, what might we create with this fact? By "play" I am in no way suggesting we take a light approach to dying or that we mandate any particular way of dying. There are mountains of sorrow that cannot move, and one way or another, we will all kneel there. Rather, I am asking that we make space -- physical, psychic room, to allow life to play itself all the way out -- so that rather than just getting out of the way, aging and dying can become a process of crescendo through to the end. We can't solve for death. I know some of you are working on this.

(Laughter)

Meanwhile, we can --

(Laughter)

We can design towards it. Parts of me died early on, and that's something we can all say one way or another. 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, like that snowball lasting for a perfect moment, all the while melting away. If we love such moments ferociously, then maybe we can learn to live well -- not in spite of death, but because of it. Let death be what takes us, not lack of imagination.

Thank you.