When Survival Ends

We won’t always be HIV and AIDS survivors. That’s not how life works.

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The casket of my friend Jesse Peel, an elderly longtime HIV survivor who died in 2023, was crafted of gorgeous wood—oak, I think. As I stood admiring it in the alcove of the church prior to his memorial, a powerful sense of déjà vu brought suppressed emotions rushing back.

The smell of the wooden pews, freshened with lemon-scented cleanser. The sight of the ushers greeting people and handing out programs. Whispered voices gathering and tumbling over one another. The encouragement from the pulpit to celebrate Jesse’s life joyfully because “that’s what he would have wanted,” even if our broken hearts refused to play along.

The scene was so familiar, like an old, plaintive song I had not heard in years. And just underneath it, a lingering, unsettling feeling: I thought I escaped all of this.

Something in my psyche, scarred by the trauma of so many funerals in my 20s and 30s, stubbornly believed they had been left in the past. After all, after testing HIV positive in 1985, I had made it out of those plague years alive. Once effective treatment arrived in the mid-1990s, funerals in my social circle slowed and then essentially stopped decades ago.

The questions stopped too, the ones I had been forced to confront when I was terribly young and diagnosed with a death sentence: Why am I here? What happens when I die? How in the world do I prepare for it?

Those questions, like the funerals, have returned. Long-term survivors in their 60s and beyond are getting a taste of late-life mortality, the kind we once never imagined for ourselves. And that means, with increasing regularity, that our survival ends.

It makes me question my own lifelong fixation on survival. The very word survivor denies a basic human condition: We are mortal.

Maybe it’s the fact that the natural order of things—one generation ages and dies, followed by the next—was upended by AIDS. The wrong generation died. It threw us out of whack. As I enter late age, I find myself contemplating the realities of death for the second time. It just feels off. We don’t like talking about this.

Our HIV organizations, support groups and media are in the business of providing hope. It’s awkward when something runs counter to that uplifting narrative. Death is depressing. And when we’re all engaged in triumphant public messaging about thriving with HIV, acknowledging death feels like admitting failure.

The irony is that most everyone working in HIV and AIDS has experience with uncomfortable conversations. For 40 years, we have fostered public dialogue on condoms, bodily fluids, sex, gender identity, homophobia and racism. There was no time to be coy when it came to saving lives.

Silence equaled death. Now we’re silent about death.

I am convinced we are ready to talk a lot more about this renewed wave of mortality because I hear it from long-term survivors all the time. We are a stout bunch. Do not underestimate our willingness to face this topic.

Fellow survivors tell me about their growing list of ailments and physical decline and their confusing anger about growing frail when we’re supposed to be grateful for having survived at all. Or the loss of friends and family and how relieving it is to outlive our parents. They describe stepping discreetly into funerals to sign the guest book and slipping out again, so paralyzing is the posttraumatic stress when the pipe organ moans and the eulogies begin.

I may not be at death’s door, but I’m not far down the hall. It’s little things that remind me, like watching an actress play an elderly woman and realizing I saw her movie debut a half century ago. Or the grocery store clerk who asked whether I needed help getting my things to the car when I had exactly two bags containing a dozen eggs, three potatoes and a bottle of MiraLAX.

To help ground me and focus on tangible ways to prepare for the inevitable, I first spoke with my friend Ronda Goldfein, an attorney with the AIDS Law Project of Pennsylvania. Ronda is very capable and exacting—desirable traits in a lawyer—but I trust her even more because she also knows how to have fun. I once floated with her through an underground water cave in Mexico. She

loves adventure.

Ronda said she tries to dig deep when counseling a client about end-of-life wishes. When they say they want everything possible to be done to keep them alive, they might not understand what that looks like, so Ronda gently and clearly explains it to them. For example, some resuscitation methods are invasive and even violent.

Ronda strongly believes that everyone should have a few basic documents prepared, like wills and powers of attorney. “You might live somewhere with a great care provider and where you are respected,” Ronda told me. “But what if you’re traveling and end up in some horrible place that doesn’t honor your wishes or your legal marriage or partnership? These documents matter. Complete them and share copies with loved ones, with your case manager, whoever should have it.”

While Ronda’s advice was reassuring, my emotional and spiritual fears still linger. Those anxieties have been constant since the beginning of AIDS. I remember looking into the eyes of dying friends as if they might reveal something about the cosmic destination they were quickly approaching. No clues were ever surrendered, and I am not particularly proud of using their final days to try to resolve my fearful curiosities.

I assure you I live with joy and gratitude most of the time, as morbid as some of this might sound. I just know how much I will miss all of this, this life, this gorgeous chaotic world, my favorite streaming shows, all the friends and strangers reading this—even if my belief system tells me that death means it’s lights out and I will miss, well, nothing at all.

I said as much to my brother-in-law David Lanzillotti recently. We were on an afternoon walk to admire the lush forest in my neighborhood. David is a therapist, so he always listens patiently to my existential questions. “I can’t comprehend that I will be dead, that I won’t even exist, for the rest of all eternity,” I told him as we strolled along, a sunny breeze in our faces. “That kinda drives me crazy when I think about it.”

“Well,” David replied matter-of-factly, “you weren’t alive for all eternity before you were here. That doesn’t seem to have bothered you much.” I was dumbfounded. The truth of it, so maddening in its simplicity, made me want to stomp my feet.

My friend Bridgette Picou knows something about the intimacies of death and dying. She is an HIV survivor, a community liaison for The Well Project and a licensed nurse. She has seen some things.

“Loss is loss,” Bridgette told me when we discussed the topic. “But not all loss is equal. As a person living with HIV, losing a client to HIV complications has a profound effect on me. As a Black woman and mother, when I hear about Black men murdered on the street, I think of my son. That death is scary in a very different way.”

Bridgette brings real clarity to how race changes the dynamics of death. “Black men and women might die of illness like anyone else,” she explained, “but that death, from HIV or diabetes, was probably avoidable. Health care plays a role in that.”

I assumed Bridgette was talking about a lack of access to health care, but she corrected me right away. “There are inequities beyond the fact that we have less access to health care,” she contended. “My clinical care will be different from yours. I can go to the same doctor as you do and not get the same health care. Even with the same insurance.”

Bridgette’s point extends beyond doctors and patients, of course. Look at the high death rates of Black mothers during childbirth, the horrific murders of trans women, the continued drumbeat of AIDS deaths among the marginalized and you are a witness to disparity. A just death, a natural death, might be the least everyone deserves, but it isn’t promised to anyone. The impact of inequity extends to the very end of our lives.

When it comes to the actual end of life, Bridgette has this observation: “There are people who approach death more easily than others,” she told me. “They feel like they have done what they were here for. Others are more anxious because they feel like they have more to do. They don’t feel ready.”

If we’re all going anyway, I thought to myself, I hope I have confidence that I have done enough. Maybe more than enough.

And that brings us, after all the worry and advice, to a basic truth. We must hold close to the life we have and to the moments lived in the here and now, when we can set aside eternal questions about the future and enjoy the glorious sights right in front of us.

The grin on Ronda’s face as we float through a Mexican water cave. My brother-in-law David with a warm breeze in his hair as we stroll through the forest. The clarity of Bridgette’s wisdom as she speaks of death and justice. The chorus of voices singing hymns at Jesse’s funeral while the hairs on my arms stand up, as if I might believe in something after all.

Moments. Moments. Moments.

My husband, Michael, and I sat on the back porch late in the day recently, after hours of planting shrubs and creating a yard to enjoy in our rapidly approaching elder years. Then I said something that occurs to me more often these days.

“I love my life,” I told him. “And look at the yard. Isn’t it beautiful?”

“Sure,” Michael agreed, “but I do think we need a tree there, and I would like it more if we added more plants to…”

“Stop,” I gently chided him. “I mean it’s beautiful right now. Right now.”

Michael heard my point and smiled at me. “OK,” he admitted. “Everything is great. I love all of this.”

We lifted our gaze as the sky turned to night, taking in its deepening colors and unknowable mysteries.

“Yes,” I said, after a while. “Things are just right at this very moment.”

I reached for Michael’s hand, feeling released from questions and answers, as we quietly watched the gathering, infinite stars.

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Planning Ahead

Use the following documents to spell out your wishes and ensure that they’re honored. Laws regarding these documents vary by state, so do your research or work with a legal expert. Your local HIV and AIDS agency or Legal Aid Society may offer help completing these.

A will states who inherits your assets when you die. Without a will, state law decides who gets your

property. You can even handwrite your own will if you're of sound mind and 18 or older. Be sure to name an executor, name which persons or groups you want to inherit your property and sign it. It's best to have the will notarized and witnessed by two people over 18.

An advance health directive, or a living will, is a legal document stating your wishes for end-of-life medical treatment. The document allows you to choose the kinds of medical care you want—or do not want. The living will becomes effective only when there is a "triggering event" that is an end-stage medical condition. You must be of sound mind and age 18 or older when you create the document and must sign and date the written directive in the presence of two witnesses over 18.

A durable health care power of attorney, also known as a medical power of attorney, names someone to make medical decisions for you. This person is known as your "health care agent." This goes into effect as soon as it is signed. You can revoke this decision at any time.

From "AIDS Law: Your Life, Your Decisions" by the AIDS Legal Project of Pennsylvania. Go to aidslawpa.org for more information.
