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If I get really sick again, will I do it differently?

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Not long ago some friends and I were talking. One of them referred to the time “when Sean had AIDS.” The phrase sounded so strange to me, yet perfectly appropriate to everyone else at the table. Did I used to have AIDS? Am I still a PWA? It’s not only the semantics that are tricky. Externally, my appearance has more or less returned to what I looked like before I became very ill, albeit older and with less hair. Most days, I no longer think AIDS will kill me, having replaced that expectation with a sense of immense relief. And more. At times it all seems too good to be true; at times it all seems too goodto last. People treat me, to their immense relief, as though I’ve been “cured.” Often it seems to me that they think the Sean they’re speaking to is the one who existed before I got very sick, but I’m no longer that person. I can’t respond the way I once did. Sometimes I want to scream at people and remind them how very close I came to death; other times I want to move someplace far away where no one but me knows of my disease-encumbered past.

Beneath the renewed health and vigor, I’m uneasy. Part of it’s physical: Lingering side effects of treatments and symptoms of disease, such as night sweats and neuropathy. I’m terrified of the long-term effects of the anti-HIV medications. I worry that as I get healthier, adhering to my regimen gets harder.

Like thousands of other survivors, I live in a continuous state of limbo, waking every day to wonder if this will be the day my treatment stops working. But more bothersome is this: The guilt I feel over the fact that I have done so well on new therapies while others have not. Many I loved died before these drugs were available; others have not benefited or had access to the new treatments.

Survivor guilt whips me between, on the one hand, the selfish desire to abandon the epidemic and set out on a new AIDS-free life and, on the other, the obligation I feel to push deeper into the epidemic and the bottomless pit of injustice that let it happen. Most of all, this guilt drives me to make sure my friends, my generation of PWAs, are not cast onto the ash heap of history and forgotten.

If I get really sick again, will I do it differently? I tell myself that I learned so much about life when I was seriously ill that there ought to be lessons I can apply to my future. But I don’t know how to articulate those lessons, except in clichés: Live in the moment. Keep hope alive. Sow love in all relationships. Tend to mind and body.

Yet sometimes I desperately want to ignore all those lessons. I get fed up fulfilling a survival destiny that’s expected of all those who have come through serious illness. What bothers me is the cruel and unfair difference between what’s expected of the survivor and what’s expected of the sick.

I learned, the hard way, that well and unwell, ill and healthy, are often euphemisms for those who matter and those who don’t. Those with a future and those without. Those whose opinions, ideas and dreams are taken seriously and those whose opinions, ideas and dreams are dismissed. As I became sicker, I could feel my own image, words and feelings fading in the minds of many around me. Evaporating into the mist of impending death. This was especially evident to me when my health improved: Suddenly so did the attentions of the world. It gave me a new rage to accompany my new health.

I didn’t much like it. I didn’t like getting sympathy when I was sick and I don’t like being congratulated because I am healthier. Either way, I’m just me—sick or well, young or old, with a full head of hair or balding.

Maybe that’s the ultimate lesson: Just to try to see everyone, each of us, in our personhood, finally free of demographic, label and status—positive or not.