

Holding What Has No Meaning



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John Kadlecak, Beth Mazur and me, at the Santa Fe Plaza, a couple of days before Beth died



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Almost two years ago, on the winter solstice, I was given the most terrible horror story of my life: My dear friend Beth Mazur chose to end her life while visiting me. I didn't expect to witness this, but it happened.

Beth was a [towering figure](#) in the community surrounding myalgic encephalomyelitis (also known as ME or ME/CFS). If you're in the ME or long Covid communities, her death has profoundly impacted your life, even if you didn't know her.

She spent the last two weeks of her life with me, and it was marked by ordinary moments that felt extraordinary after so much struggle for both of us. We soaked in a hot tub at a Japanese spa; went to the Santa Fe Plaza to see the Christmas lights; cuddled with my animals; spent hours with her head in my lap as I rubbed her shoulders and we talked quietly. She was in the middle of so many projects, every day on the phone with patients, advocates, and researchers. Even as she carried enormous suffering, she carried others too.

Four days after she died, on Christmas Eve, I posted a [social media thread](#) to help the community process her death, describing the sweetness of our time together and my understanding of why she chose to die. In retrospect, though, it was oversimplified. Although I was aware of her depression and anxiety, I didn't grasp the depth of her mental illness that tortured her. She was an intensely private person, and this aspect of herself she kept most hidden.

In those early days after she died, I thought a lot about why she decided to die here, with me. After years of longing to end her life, what had tipped her into doing it right then? I wondered if the very love we'd shared had somehow made it possible for her to do such an impossibly difficult act. Also, in making that decision, she saved

her partner, her family, her more fragile friends the horror of finding her body course she inflicted that on me. I certainly didn't like it, but it felt petty to argue her decision.

So after the fact, I told my friend yes. It's OK. It doesn't matter whether I agree your decision or not. You needed a place to die, and I give it to you willingly, I would have refused if you'd asked.

It's a weird sort of willingness, but it's real. It loosened any judgment or resentment placed my love for her at the center of my awareness, allowed me to feel generous toward her instead of victimized.

I've used that same strategy to deal with my illness. If God (or some such entity) come to me in 1999 and said, "Is it OK with you if I give you ME? Can I destroy your dreams for your life, give you unimaginable physical suffering, make you homeless for years at a time because you can't find a building your body can tolerate and deny you effective medical treatment and social acceptance of your condition would certainly have said no. And I would have done — indeed I did — everything I could to stop it.

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But all of those things came to be. And once it happened, my only choices were accept it willingly or not accept it willingly. Mostly, I've chosen to accept it willingly because it has eased my outrage, given me the sensation of my hands on the handle allowed me to feel generous toward the world instead of victimized.

The attitude that has helped me is believing that I'm here on earth to serve. Whether it isn't the form of service I would have chosen, I've embraced it and worked to

every bit of meaning and beauty I can from it. Sometimes, the only way I can survive by surviving and getting to the next day, apparently serving no one beyond myself. Sometimes, I have enough space that I can help another patient, or show my husband how much I love him, or occasionally even write an article. And the mere survival is essential to be able to do the acts with more obvious broader value.

In the months after Beth's death, though, the hard-won improvements in my health that I'd just barely attained broke, and my willingness — well, it didn't exactly break, but it stretched like spun sugar, growing so fine it seemed to vanish in my mouth. The worst period was after I concentrated too intently during a doctor's appointment and ended up in the ER, screaming and convulsing, feeling like my brain was being pushed out through the bottom of my skull. For two and a half weeks after that, I couldn't move, or think, or look, or listen. I tried not to ask myself if I'd improved, but that question brought up feelings, and feelings made my brain seem to swell and push against my skull. Instead, I submerged myself, squishing my existence as small as possibly could, and I waited.

When I could begin to think again, one thought pushed its way forward: "God, Beth, that was too much to take from me." And the same feeling extended to Mother. Mother had taken too much, too fucking much — far more than I was willing to give.

During that last visit, I told Beth I felt sort of pre-dead: I'd given up all my goals for life, every purpose I'd organized myself around, every expectation that used to define me. And yet I was still alive. So what was left, with all of that gone? What is it to be pre-dead?

Beth shared the feeling — though I think by then, she felt less curiosity than I do. I'm still carrying that question, as I come somewhat back to life. I've learned how much can be taken. Even my willingness. Even my ambition to serve. Sure, I'd

serve, but I can't stake my existence on that anymore. And yet, I remain. Scrap like an empty bowl.

Beth held fiercely to her sense of herself as someone full — full of ideas, play, service. She refused to use a disabled placard, even when brief walks could leave her pinned to her bed for days. Her sense of her own identity was as able-bodied, as minded, able in every way.

I also once held fiercely to my own capacities. But I can't do it anymore, even as my abilities are increasing. As eager as I am to once more fill my life with all the richness of the world, I also feel that empty bowl singing inside me, and I want to preserve what is big enough for all of it — ambition and collapse, hope and devastation, the things I want to change and the parts I can't. It doesn't filter the world down to what can be made useful or beautiful. It doesn't ask the unbearable to resolve itself.

In the earlier years of my illness, I was able to use the experience of illness to find the beauty and significance in a shitty experience. My book [*Through the Shadowlands*](#) was an expression of that meaning-making. I'm still proud of that for me, it holds up.

But in recent years, it has felt pig-headed to expect to grow personally from my illness. Being sick has felt like a job, like being a trash collector or a slaughterhouse worker, only it comes with no paycheck and no obvious productivity. I didn't choose this but it is mine.

I can't carve it into meaning, but I can hold what has none I can see. I can be that empty bowl.

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