

# The Story's Story

## How much suffering is too much?

AUGUST 16, 2023 By Jake Seliger in PERSONAL Tags: PERSONAL 6 COMMENTS

*This is by my wife, Bess.*

For the second time in a two weeks, Jake tells me he's ready to die. The first time he says it, he's frustrated: red-faced and retching, trying to hack out a thick glob of the mucus of the sort that's incessantly collecting in the back of his throat. Jake has [squamous cell carcinoma of the tongue \(https://jakeseliger.com/2023/07/22/i-am-dying-of-squamous-cell-carcinoma-and-the-treatments-that-might-save-me-are-just-out-of-reach/#comments\)](https://jakeseliger.com/2023/07/22/i-am-dying-of-squamous-cell-carcinoma-and-the-treatments-that-might-save-me-are-just-out-of-reach/#comments), and each new attempt to burn, poison or cut out the cancer has added to a list of losses that aren't adequately balanced by gaining time on this planet.

The first surgery used a CO2 laser to cut out a cancerous portion of the left side of Jake's tongue, and as soon as Jake recovered adequately from the surgery he got hit with radiation, which scorched away mucous membranes and skin. Radiation caused dry mouth and thick, ropy secretions—but the surgery and radiation didn't prevent the cancer from recurring. As bad as the original treatments were, the new surgery entailed a “total glossectomy” and “partial laryngectomy,” which is medical terminology for “his whole tongue and part of his larynx were removed and replaced by a flap of tissue from his thigh.” The new treatments cost Jake the ability to speak and swallow normally, or to feel saliva pooling in the back of his throat and clear it. The thick secretions and abnormal swallow mean he's constantly battling to expel phlegm, only to have it immediately return. The “goo,” as he calls it, is relentless. He is constantly spitting, hacking and choking.

“It never fucking stops!” he wheezes between attempts to hack that mucus up and out. He gets some out, but it's obvious that he's not getting all of it.

The blue, v-shaped vein in his forehead is popping. He's clutching the edge of the sink, trying to expel a thick glob that I can hear rattling as he tries to speak through it. His fingers are turning white. He attempts a sip of water—a skill he has just recently started to re-learn—which gets caught in the mucous, so he aspirates some in his lungs. He gasps stridulously but no air is moving into his lungs. For thirty terrifying seconds he's not getting air. The muscles around his ribs retract, straining. I'm an ER doctor, but a Heimlich maneuver for a small amount of water isn't going to do much. Anyway, in this moment I'm not thinking like an ER doctor, I'm a panicked wife. I *need* him to breathe again. I need this spasm to pass before he passes out. I'm hopelessly planning out how to get a man nine inches taller than me to the ground safely, when he turns red and gasps. Finally, he spits out a huge lump of goo. It's quickly followed by another. He strikes the counter with his hand.

“Enough!” he says. “All day, every day. It’s disgusting. I’m disgusting. I try to sleep and there’s goo, I wake up and there’s goo. I spit it out and there’s more goo. I’m ready for this to just be over. The only way it’s ever going to stop is when I finally fucking die.”

I stop reaching towards him and keep my mouth shut. I just squint at him like I’m staring directly into the truth. He’s right. I don’t want him to be right.

How does a person decide how much suffering is too much? I’ve spent nearly every day of my career faced with that question. Each emergency room shift brings patients with their tenth bowel obstruction after their fifth surgery for recurrent colon cancer, patients on their second transplant (with more organs failing) coming in twice a week to have fluid drained from their abdomens, their lungs, from around their hearts. Autoimmune patients and diabetics losing limbs piecemeal. All these people, trying to stay alive in a state of perpetual falling apart. Entropy is so clearly winning. I can see why they’d want to say “enough,” and let go of the gift.

**Before we knew for sure** that Jake’s cancer had returned, we were walking hand-in-hand around downtown Phoenix after grabbing tacos for dinner (back when we could just grab something, put it in our mouths, chew, and swallow, like it was nothing at all). We knew Jake’s PET scan was abnormal, and that the CT scan was too. But Jake had just completed radiation, which frequently causes inflammation, leading to false-positive early PET scans. There was a good chance the abnormal CT showed destruction of the hyoid bone in his neck—a potential side effect of radiation—which, while not optimal, isn’t a tumor and thus wouldn’t kill him.

We’d met with his ENT surgeon, a Dr. Michael Hinni, earlier in the day, and we’d scheduled a biopsy to settle the “is it cancer?” debate. That night, we had the luxury of speculation. It was Schrodinger’s tumor: both present and not present, with us heavily leaning on the side of “not present” as a comfort. Dr. Hinni had told us that a recurrence meant “salvage surgery”, which would cost Jake half his tongue and part of his larynx, and could leave him unable to eat, swallow or speak. Dr. Hinni and the surgery team would have to replace half of his tongue with a flap of tissue harvested from his thigh. The other option was immunotherapy, which was estimated to have a 30% cure rate—a number which we now know is so overly optimistic as to be laughable.

“If it’s cancer, I’d rather not have surgery and take the 30% chance at a normal life,” Jake says as we walk. I grip his hand as if he were a balloon about to float away. “I know that isn’t what you want to hear.”

I nodded. It wasn’t. But I could be magnanimous. It was still a thought experiment at this point. So I say, “I understand,” because I do. But also because I could still say, “I just hope that isn’t a decision you have to make.”

It was cancer. When faced with the certainty of a diagnosis, Jake moved forward with the surgery. “It’s surgery or death,” he said, and he wanted to have a shot at living. For me, he said. He’d still get the immunotherapy, to increase the odds of a long-term cure. I felt as much relief in his decision as I did fear about what that meant for the rest of the life he might or might not get.

The second, “salvage” surgery occurred on May 25 and lasted twelve hours. Around hour ten, I started to wonder if Jake wasn’t ever getting off the table. When Dr. Hinni finally called me in to tell me they were able to remove all the cancer, I was elated. He got what surgeons call “clean margins.” Then Dr. Hinni explained that, because the cancer had grown in the short time between the April scans and May surgery, he’d to remove Jake’s entire tongue, not just half—and with it, Jake’s ability to speak, to swallow, to taste—and the relief was replaced by horror. I blacked out for a moment. Jake wouldn’t want this. I walked into the hot night air and hyperventilated in the parking lot. We hadn’t even considered the possibility that Jake might lose his entire tongue. I wondered what I would have done if Dr. Hinni had called me with an update and asked me if they should move forward with the removal? I threw up in the parking lot and felt sick relief that they hadn’t.

In a panic, I called the one person I could think of: our speech pathologist, a woman named Jessica Gregor. She reassured me that, if the surgery hadn't removed Jake's entire voice box, he'd likely be able to speak after a fashion again. And swallow some liquids. She told me not to give up hope, and that the road would be long, but that not everything I feared and expected would come to pass. The surgical margins were free of disease. The cancer was gone. I needed to focus on that.

I spent the first night in the hospital sitting awake at Jake's bedside (<https://jakeseliger.com/2023/08/09/are-you-taking-care-of-yourself/>), certain that he'd decide to die after learning the news. He didn't want to live like this. It seemed entirely possible to me that he would just decide not to.

It's amazing what people learn to live with: Paralysis, dialysis, blindness, deafness, pain, the loss of a limb, impotence, incontinence, the loss of a tongue. For some patients, the losses accrue by degrees. I'll see them dwindling across years of emergency room visits. Their suffering slowly compounds, each gradual change requiring a small adjustment, yet adding up to tremendous deficits. But for others, like Jake, the door to the person they were before shuts so suddenly and so loudly that it shakes the whole foundation of the building. There's no getting used to the idea of a new life, slowly. There is just a new life. I'm not sure one way is better.

But there's a lot we think we can't live with that, once faced with having to live with it, we do. I'm constantly amazed by patients, like Jake, who are incredibly resilient, finding reasons to live in a landscape they expect to be desolate of motivation. Maybe we don't even need the motivation. Maybe it's just what we're programmed to do. Survive.

Still, I try to give Jake something to live for.

The big things: love, affection, and (hopefully) a kid if he can make it that long and science is on our side. And I try to remind him of the things he loves to do that he has always lived for: writing, thinking, learning. Me.

But there's also the unexpected gift of rediscovery. Eventually, Jake gets his tracheostomy breathing tube capped, and we can speak to each other. It takes time for me to get used to his new speaking patterns, but I now understand him without great difficulty, although I need to clarify what he's saying to people who aren't around him frequently. Incredibly, just a week ago, he swallowed water for the first time, with the support and instruction of Jessica Gregor.

The ability to swallow escalated quickly—what time was there to lose?—and he discovered that when he swallows, he can taste, probably using the taste buds left in his esophagus and on his hard palate. So now I'm blending brownies and cookies and melted ice cream as many times a day as I can, stuffing him with sugar like a foie gras goose, hoping it'll be pleasurable, but also in the hope that it's one more thing—and no small thing—to live for. A way to feel reconnected to himself. Victories that distract him from ruminating on the question: how much suffering is too much? How much mucus and hacking and struggles breathing can a man tolerate? How much pain? How many things taken away? Without the victories, I'm scared that the more Jake thinks about the questions, the more he'll settle on an answer that is: less than the suffering he's experiencing now.

**Just two months after the horrific surgery that was supposed to buy us years together**, the cancer has reappeared in four new places along the margins of his tongue flap, neck, floor of the mouth, and larynx. It's metastasized to the lungs. Suffering, it seems, just begets more suffering. It's hard to see the person you love suffer. But even when Jake suffers, I'm glad he's here. Here to lie next to me at night, to edit this essay when I'm done with a draft, here to just exist in the same piece of spacetime. I'm glad he's here, because he's still trying so hard to be. But I think I'll probably also be glad he's here when he no longer wants to be. I won't be able to help myself. I

want him to stay through the pain, the mucus, the feelings of drowning. And I wonder if that makes me a monster. I'm so greedy for him—for time with him for his body next to mine—that I wonder, if it hasn't yet, will it turn me into one eventually?

I've seen it happen. Finally faced with the actual end, families have begged me for medical violence in the ER. As if only more technology, procedures or sheer force will solve the problem of every human's inevitable decline. "[How Doctors Die \(https://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/\)](https://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/)" describes the way doctors understand that medical violence at the end of life isn't a good answer, and that compassion often means declining the last possible bits of care, which resemble torture more than medicine. I've felt the ribs of a desiccated 95 year old break under my hands while doing CPR. I've seen a heart failure patient's family refuse comfort care in the hopes that more meds and devices will convince the heart to squeeze harder. I've heard the words "do everything," so much that my relationship to futility has changed.

It would be easy to say that families' desires for more medicine, more effort, is a product of medical ignorance—too many TV shows convincing people that CPR has more than a 10% survival rate. But that's not the whole story. I realize now how easy it is to forget that something doesn't work when you want it to work so badly. Sometimes, we justify these requests by hoping for a miracle. We ask ourselves: can I live with myself if we won't try *everything*?

So I have been trying to ask myself: can I live with myself if we do?

**I ask our friend Fiona**, who was Jake's charge nurse when he first had cancer in 2005, and who lost her own husband after caring for him through a prolonged illness just five years ago: "What if Jake is going through surgery and chemotherapy and suffering just to stay with me because he knows how badly I don't want to lose him?"

"What if he is?" she says "If that's the gift he wants to give you, let him. If he wants to stay for you, he *wants* to stay. Let him."

"I've told him he doesn't have to," I add, hoping for absolution.

"He'll tell you when he's had enough."

**The second time Jake tells me he wants to die was just a few hours ago. We're sitting** in the chemo cubby, as I've come to call it: the semi-private, three-sided cubicles in the Mayo infusion center, where you can hear the other cancer patients—the coughs, the chatter, the pumps beeping—but not see them until you get up to find a bathroom. We're walled off by windows on one side, and while it's bright and a little hot, the light is nice. From here, we can see the 101 freeway, which we agree is admittedly less exciting than watching First Avenue from our folding dining room table back in our old Manhattan apartment. Both of us would love to go back and visit our old life, to walk down 14<sup>th</sup> Street together, hand in hand. But cancer makes your world small, so much smaller than your old life, and the prospect of a transcontinental flight for a pleasure trip in the face of so much exhaustion feels impossible. The place I most want to be these days, is just wherever Jake is. Even if it's the hospital. We're adjusting our expectations.

The nurse comes into the infusion cubicle with the pre-treatment medications. She pushes six different meds, including Ativan and Benadryl, which cause sudden psychomotor slowing. It's like watching the batteries running down on a wind-up toy. Jake fights the wave of somnolence, and he starts to mutter. He asks the nurse about the coordinate tattoo on her arm. He closes his eyes and says he sees visions, patterns, but can't clarify more. Are they psychedelic or dream like? Both? He's not sure. He's making some sense but is clearly affected by the meds. Suddenly, he opens his eyes, looks out the window, and says, "at least I have a good view from here."

Then he starts to cry.

We've been doing a lot of crying. But the suddenness of it, the way it feels like the reality of the situation is spreading through his veins along with the sedative, breaks my heart. There's not a moment when we aren't aware of the sand running so rapidly out of his hourglass, but there are moments when we feel time slipping away more acutely. Did he cry during the first infusion? I think so. I could go back into my journal and look, tell myself that this is a medication reaction and not a sign of worsening despair (of course it is, his, and mine, as I'm crying along with him now), but I'm almost positive it is despair—how could it not be?

Chemo is so brutal, and for squamous cell carcinoma patients it is only “palliative,” in that it may extend his life but won't extinguish the cancer. He'll have more time to say goodbye but will trade the suffering from chemo for some months more. I hold Jake's hand and kiss his face and look at his color in the bright daylight—which is sallow, but brighter than it's been the last few days. He just stares out the window, glassy-eyed, and weeps. I squeeze my body against his to hold him firmly in the chair beside me. His Dad, who is visiting during the infusion gets up to hold his other hand, which is limp.

“You can give me a squeeze back,” his Dad says, because he needs reassurance, too. I'm not the only one. Jake squeezes. His Dad seems relieved, but not reassured. For a few moments, we both cling to Jake, as if we could grip hard enough to keep him here as long as we need him. When his Dad sits back down, Jake drops my hand and picks up his phone, holding it so only I can see. He can't really speak any more, but he types:

“I'm ready to die, but not wanting to. Key difference.”

I don't know if he'll remember telling me after the Benadryl and Ativan wear off. That this declaration came after being disinhibited from the drugs, though, makes it likely that this is what he really feels. Strangely, it feels like a terrible, heartbreaking reassurance. Not yet, he's telling me. But one day. Once again, I say nothing, but this time I do reach for him, and I hold him.

I think gently about all the people who have asked me to try futile, frustrating things to try to save the person they love; doctors may “know enough about modern medicine to know its limits,” but most people want to burst past those limits, though they can't. I think about the way people look at me when I explain that there's nothing more I can do to help, and anything I do will only to make a bad situation worse. I think about their anger and their fear. And for the first time, I think about the relief they must feel when I, not they, am the one who tells them that enough is enough. No more. They don't have to be the ones to decide.

It doesn't make them monsters to want to cling to hope past the point of sense, it just makes them human. It makes me human, too.

I'm both not ready for him to die, and I don't want him to. But I don't get to decide, either. All I can do is try to tip the balance in favor of the life he has, until Jake, or his disease, decides that it's too much. Because the only moment when you can answer the question of how much suffering is enough, is the moment that it stops.

*If you've gotten this far, [consider the Go Fund Me \(https://www.gofundme.com/f/help-the-fight-against-cancer-with-jake-s\)](https://www.gofundme.com/f/help-the-fight-against-cancer-with-jake-s) that's funding ongoing care.*



(<https://jseliger.files.wordpress.com/2023/08/how-much-suffering-is-too-much.jpg>)

## 6 responses

ALISON CLAY says:

August 17, 2023 at 5:12 am

So sorry for your suffering, and for Jake's. You describe well the questioning we often have of patients with your own. I remember when I had a trach and PEG (and I'm an intensivist), thinking about all the cancer patients who came to the ICU with hypotension on IL-1 infusions and wondering how and why they said "yes"—then I remember dreaming about the trach and wanting to scream, "it isn't about a trach yes or no, its about this miserable disease with a trach or without, neither are awesome decisions."

As a profession, we have more to learn about empathy.

Thank you for writing bravely and beautifully about this tough tough road

JAKE SELIGER says:

August 17, 2023 at 8:44 am

I talked to an oncologist who told a story about his mentor, who got cancer himself after thirty plus years in the business. The mentor said: "I've been around this for all these decades and I still had no idea how bad it really is."

RACHEL KILPATRICK says:

August 17, 2023 at 9:10 pm

What an incredible story. Thank you for sharing his story and yours. This is a good reminder of our fragile human condition. I hope you guys are able to find peace through this together.

JENNIFER says:

August 18, 2023 at 4:39 pm

My thoughts and prayers go out to you. Beautiful writing. I am 52 years old. I lost my first husband at 33 from Hodgkin's Disease. He had remissions from age 13 on. 2 bone marrow transplants. He got Aspergillus and was ready to pass. I was in bed with him, holding him. My second husband developed ALS. Terrible. A blessing to be gone. I am with number 3 for 8 years. 👍 God has his plans, and we just ride along. I feel and pray for you and your husband. I am in FL but can always talk. I found you n the physician group. I am FP. 🙏🙏🙏

JAKE SELIGER says:

August 18, 2023 at 5:12 pm

Jennifer—that is an incredible run of luck. And yet it's heartening to know that you found love again; I've told Bess that that's important, and that she needs to do it, when it's time.

DEBORAH BUTZBACH says:

August 18, 2023 at 7:41 pm

I am a radiation oncologist – my nonsmoking urologist husband developed a vocal cord cancer 4 month after our son was killed in a car accident. He got RT at my work site and recurred only 6 weeks after treatment – like you, laryngectomy, trach, peg. Life isn't fair. I'm sorry for you and Bess. Happy to chat if she wants.

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