

The Soul of the Machine

I remember everything about that first conversation. The green fabric of the chairs, the cool fluorescent lighting on the desk, my fiancé sitting in the chair to my right; I could tell he kept glancing over at me, out of the corner of my eye. Of course, it wasn't really the first conversation. More like the tenth. But being told that it really is cancer cleaved everything into a before and an after, with that meeting as the start of my new timeline.

There are options, he said, my oncologist from Stanford. At Stanford. I guess he went there, too, according to the diploma on the wall, and what does it matter anyway?

I remember much less of the drive home. It's strange: we all know that we are going to die, but there's something different about having a more concrete sense of knowing how. Living with a sense of urgency, never knowing how much time I'd have left, was an important mantra of my early thirties, and I kept thinking that, in some way, I shouldn't be surprised. But the reality is it really didn't prepare me for looking at a timeline with probabilities written with the deaths of so many people who have heard this news themselves.

We spent the next week scheduling appointments with specialists, telling family, and crying. The first thing we did after that was go on vacation.

I had always wanted to see the light blue of the Maldives; I had felt for several years that it was a race of against time, but I had thought that race was against the rising seas, not pancreatic adenocarcinoma. It's an enormous pain to get to the Maldives even in the best of circumstances, involving almost thirty hours of travel each way. But standing in ankle-deep completely clear water on a tiny island with a horizon dotted with the big fluffy rainclouds particular to the Pacific Ocean, and I guess the Indian Ocean too, made me briefly even forget what had forced the trip.

A month later, back in California, after my second chemo session, I discovered cannabis. *Chemotherapy doesn't target your cancer, per se, Dr. Kim explained. It targets cells that are dividing frequently, which is a key attribute of cancer. But that's also why it causes hair loss.* After just two sessions, I could definitively say that it clearly targeted more than just cancer and hair. After my first chemo session, I was almost wondering whether this was worth it, given my apparent 7% chance of making it another five years. It was really everyone else telling me how strong I was that made me want to keep going; or more really, a combination of all of our fear. Weed just made the nausea much easier, and also meant I starting eating again for the first time basically since the diagnosis.

The other side though was that it brought up all of these memories; after the nausea subsided, the high transported me to places from my childhood and left me awash in stories from years and decades ago. They say that before you die your life flashes before your eyes, and that people who live through near death experiences change themselves so as not to have to face their

decisions again in the same way. Reliving all of these scenes was this reminder of everything that had gone into my life, and it made it so much harder to accept the thought of leaving it behind.

Two months later, they told us that the tumor had shrunk. *This doesn't mean we're out of the woods yet*, they said. *It's great to see this response but ultimately there's only so much we can tell from tumor size at this stage.* We both smoked a lot of weed that night.

I spent what felt like most of the new timeline of my life with doctors, but if my memory was bad before, it felt like I was only getting sporadic frames now. Kevin had started bringing a voice recorder to the appointments so we could go over them again later, but we rarely did. It wasn't that my memory had gotten worse, it was more of an attention thing. I would be looking right at the doctor and I could see their mouth moving, but sometimes all I heard was ringing.

Life fell into a new normal for us. Kevin's career had to continue. I tried to keep working, but it was too hard to be reliable, and after another couple weeks just resigned myself to becoming a full-time cancer patient. Being home alone all day was too depressing, so I ended up going for lots of walks, and if I got too tired, drove and thought. When driving all day seemed financially or ecologically irresponsible, I spent a completely unreasonable amount of time at bookstores.

My doctors ordered new imaging to see how the tumor was changing, and discovered that my cancer had spread to my lungs, liver, and kidneys. That was the news that put me in the 80% of the 20% one-year survival rate. My emotions had become this rollercoaster, some days insisting on fighting to the end and other days coming to peace with dying. The metastases sent me into a dark hole that took weeks to climb out of, and really then only because my friends wouldn't stop trying to take me places.

It was a Tuesday in August when we heard that I had been accepted to a clinical trial for a new technology being developed by some company in Boston. The idea was that they'd take some of my own blood cells and engineer them to recognize my cancer, and inject them back into me. This was supposed to help my immune system recognize what was cancer and what was me. At least this is how it was explained, something like that. Yes obviously I want to train my immune system to kill my cancer. How many things do I need to sign? Give me all of them.

It took four weeks to manufacture my new special forces immune cells. I had to stay in the hospital for the whole treatment, so I loaded a couple boxes of what most made my room my room and tried to turn the sterile hospital suite into something that felt a little more me, or at least just less of a constant reminder. I was unsuccessful; I was clearly living in a hospital.

The infusion was just like any other. A pink-red bag hanging from a cart connected to an IV in my right arm. It had come on relatively slowly, but I suddenly realized just how much strength I had lost, lying there helplessly in the hospital bed, probably looking emaciated. Things were a little foggier, but not overwhelmingly so. I briefly felt detached from my body, as if it wasn't actually me, but that was over within an hour when my reality came crashing back down over me.

I felt better immediately that evening. Maybe this new magical drug was having an immediate effect! The nurse just smiled and said *now we just have to wait*. Kevin slept in the chair in my room that night.

I awoke to a 104 degree fever and a rush of activity. Tubes and tube of blood were drawn; so many injections were given I stopped being able to feel them. The next thing I remember is - well, it's difficult to describe. I was standing in a windswept field of tall grass, looking out over a

soaked floodplain, with an enormous concrete house behind me. Then I spent a week at a complex in the desert, with couches strewn about under flapping canvas sunshade structures and a billion stars visible behind them.

Your body didn't accept the treatment, Dr. Kim told me. You had an allergic reaction to the cells that almost killed you.

Three days after the infusion I woke up, having spent the last two days drifting in and out of consciousness in the ICU.

Because I had gone through the experimental treatment, I was ineligible for further clinical trials, he said.

I remember that Kevin just looked completely destroyed. I think it was lost on me at the time what was happening. Another doctor came in to tell us about our options at hospice, so I could at least get out of this hospital.

On my last day in the hospital, we had packed all of my photos and books back into their boxes. Dr. Kim came into our room with a new doctor, Dr. Stephens. Dr. Stephens was a neurosurgeon involved in another trial I turned out to be eligible for, if I was interested in trying experimental medicine again. They were incredibly deferential, even meek, as if to apologize for what I went through before. They both said the phrase *we don't want to create any false hope* multiple times. At this point I was so far beyond hope. My terror had subsided only out of sheer exhaustion, but the fear was still there. I hadn't fully reconciled with the idea of going to hospice. I suddenly missed my old life. The wedding that was postponed, and then abandoned, unsaid. The career I used to have. Through tears I asked them *what is it?*

Your body is dying, they explained. There's nothing medicine can do to save it. But this

kind of cancer doesn't usually spread to the brain, and we don't see any evidence that it has for you. I remember that they paused then, searching for the right words, to not mess up whatever was coming next. There is new technology that could separate your brain from your body. Right now it would allow you to experience a relatively simple simulated reality, or see the real world through a camera. In the future it might even be possible to have an artificial body you can live in, but that's not certain.

Kevin's expression was just blank when we heard that. Some mixture of confusion, terror, euphoria, hope, I don't know. Of everything we had been through, all the way back from that first conversation, these were the most surprising words I think I'd ever heard. I started to try and say something but found myself speechless.

You don't need to answer now. There's more information about the procedure in these brochures. Think about it and if this is too much, we are here to care for you and do whatever you want most.

They left and we spent a full 30 minutes in silence, looking at each other, around the room, at the whole arc that had transported us - a healthy thirty-three-year-old couple - to this moment.

What do you think? he asked me. I remember just raising my eyebrows and shaking my head, like, *what?*

We paused the plans to go to hospice. My parents were in town to help with the move and, wow this feels weird to say, my funeral. I spent two days talking to them, Kevin, and just thinking it over. I made it clear this would be my decision, though I wanted help making it. My parents were dedicated Catholics, and I've never seen them so conflicted and confused as during

those two days; they could reason about my illness and potential death, but this broke their understanding of how life was supposed to work, but it was clear they also didn't want me to go. Did this even count as staying? That was the question Kevin and I tried most to understand.

What if something isn't quite right with how my brain gets connected, and everything seems fine but actually I'm living in some kind of terrible nightmare that I can't escape? What if there's some mind-bending horror on the other side of this that we can't imagine in our normal experience? Or what if it's just strangely awkwardly wrong, but then my life and experience is completely out of my hands? Would they unplug me? Who would decide?

The doctors explained that if they couldn't communicate with me after the surgery through the system, they would disconnect it and I would die, if I wasn't already brain dead by that point. I didn't have to worry about being trapped without a body, unable to communicate, but no one could say exactly what else might go wrong. They explained that the brain is capable of some crazy things, and they had never done this before. At least for the drug experiment I had been patient number 27. For this, I would be patient number one.

Eventually, there was one last question that started looping in my head. *If this is successful, when will I die?*

There was an anxious pause when I finally asked that out loud. Dr. Stephens eventually told me that *well, if it goes successfully, it's possible that it might be eventually up to you.*

Everything that I had understood about my disease - about life - was reframed in that moment, as much or more than being told I had cancer had changed my life before. Suddenly the idea of not dying seemed even more daunting than the idea of going to hospice. It was one of those instants where the world collapses around you and you realize that you have really,

seriously misunderstood reality.

The next morning I told them I wanted to do it. It took a week for them to set up everything for the surgery. When they wheeled me down to the operating room, it was transformed with all this new equipment. Apparently I was famous in the hospital, variably as either the first brain isolation patient, or as the reason everyone else was down one-third of the available operating rooms! The last time I saw Kevin with my own eyes, he was in blue and green scrubs on the other side of the plastic bubble they had put me into, to ensure I wouldn't be sick when we went into this final surgery. It's hard to say goodbye through a thick plastic barrier, but I think that moment was harder for him than it was for me, with it clearly being an ending reflected in his face, while my main emotion being apprehension about what would come next.

It isn't right to describe what happened after as waking up. It was more of a sudden realization that I was there, and might as well have always been there. I had no vision but it wasn't *dark*; I just had no vision. But I was definitely there. It also wasn't that I couldn't speak, it was that the idea of speaking suddenly was gone. *I* was gone. But I was also definitely, assuredly, very much there. I know this sounds strange but just trust me, it all kind of makes sense when you're there. After somewhere between one and two peaceful eternities, I felt structure, somewhere. It's really hard to say much more than that about what it was. I think this startup process is much faster now. Then I heard the voice. It didn't sound like anyone I knew, but it was speaking English, simultaneously coming from everywhere and nowhere, anechoic.

How are you doing in there? Can you hear me?

Yes! I can hear you! This was the scariest part: I had no voice! I wanted to make sure they didn't miss that I was there and turn me off! *I don't know how to talk to you but I'm here!* I

tried shouting, in the way that *shouting* made sense at the time. I felt panic creeping up on me as I realized I was helpless to tell them I was okay, the kind of true panic that you never want to experience.

But then! *It looks like you're doing great in there*, the voice returned. *Don't worry, we can hear you too. It's all ok.*

Suddenly I was found. I was still lost, but I was found. The whole thing was so alien I didn't know even where to begin. But at least they could hear me, and I could hear them. The structure I was feeling intensified until, I don't really know how to describe this, I could see it? It wasn't vision, but it was something almost like it, and - what, how? - there were other people here with me? I could feel them more than see them, but the distinction between those concepts was very fuzzy.

This became my world for several weeks. I could talk to them and they could talk to me. I could kind of sense my environment, in some vague abstract way. I had all of my thoughts. I began to feel like I had made a huge mistake, and this jail for my mind was worse than death, which was really driven by my fear of dying which had returned to be with me in a way it hadn't been for the last few weeks before the final surgery. I was distraught that I would be stuck here forever and yet too afraid to shut it off.

Then, they gave me my bubble. I remember Dr. Stephens coming in very excited that day, I could hear it in his voice.

We have the device to give you vision. I didn't want to say anything before because I wasn't sure when it would actually be ready, but we have approval now to give you back vision, if you want it.

Like, of course I want it. Give me!

It's different than your old vision was. It has 16 cameras and will give you much more visual information than you've ever had before. Ready to try it?

I said give it to me.

The first time they tried to start it, I was instantly hit with this enormous headache. Suddenly my universe was drowned in color and motion and it was completely overwhelming.

STOP! I communicated up in the most violent way I could. Slowly it went absent again.

Your brain doesn't know what to do with this information. It will take some time to adapt. Let's try again and start more slowly this time.

I remember pausing, having just received a lesson in the kinds of experiences my disembodied brain was capable of generating. Never forget that your brain is capable of producing some crazy things, and really take the time to understand how new forms of information are being introduced. There's nothing to be afraid of, but just make sure they've thought it through. In my experience, sometimes they hadn't in their eagerness.

But then we had to keep going. I mean, what other option was there?

It was much subtler this time. Nothing recognizable as vision, at first it was just geometry, everywhere, evolving and moving. For the next week they slowly increased it until I was starting to be able to make out objects I recognized in the motion.

And then it was like, *that's a desk, I see a desk!*

It was a long process. Now, fully adapted, I can see better than I ever could before, but even more, it's a full spherical bubble of perception. I don't know how to describe it to you. It doesn't, like warp, when I move through the room, anymore than my peripheral vision did when

I had my human body. It's just full 3D depth vision, but in all directions. I get claustrophobic just thinking about the vision I had in a human body.

Kevin and I drifted apart. I still love him, and I could feel him, but he couldn't feel me and he deserved someone he could. It was okay. We both have moved on and he is happy again now.

I was obviously heartbroken when they told me about the infection. But in some sense it was a relief. Over the last two years, I've spent a lot of time thinking about my life, and my possible death. I realized I was too afraid to make the decision for myself, but I was also increasingly afraid of outliving my parents, and my friends, and everyone else I know and love. You come to realize that finite mortality is a gift. Nothing lasts forever, but pushing this onto your own choices is an incredible burden that never goes away, especially when you're alone in it. I have experienced things that cannot be described, and I am comfortable with my place in the universe now.

I know firsthand that this is the most difficult choice of your life. Even though my time in here was short, it has felt like lifetimes, and it has been wonderful. They tell me that the problem that led to my infection has been fixed and you might expect a much longer survival. I can't tell you if that will be a blessing or a curse, and so is something you should carefully weigh. If you choose this, I'm sure you'll be able to receive things as fantastically unimaginable as the bubble was to me at first. And at the end of it, be able to look back on your own cancer as the experience that shaped your perspective of life and the purpose of its existence. Or you can choose death, and though I'm sure this doesn't make any sense to you now, know that it is okay too. Also, now that there are dozens of us, it's very different from when I was the first and alone, since we can

connect with each other in ways that we can't connect with them. All of these are paths to the same place.

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