

# REMAKING THE WORLD



Trying to exercise my way though my inevitable decline

"94...," he thinks for a moment. "94.7% chance of remission."

I chuckle. "I'm going to need two more significant figures, at least."

He laughs as well, but continues "The figure is real..."

"But you can't apply a statistic to any individual case...," I interrupt.

"Of course..."

We both have the body language of people who are explaining something to each other that both understand, looking for an exit to the next conversation point.

"I'm also happy to accept 'high,' the odds of remission are high," I say. We both smile.

I am sure this man understands my body well enough that I am willing to place it in his hands. I am going to let him cut my throat, and still, I also know that he can't understand what he's proposed doing to my life.

A few minutes after this moment my partner and I walked along the slick streets of Paris, making our way to the train station from south of the Seine. It was dark, but Paris is never dark. It is a riot of lights and colors and people and cars coexisting, but barely.

"I am scared of everything" I loud-whispered to him repeatedly. He got a little in front of me, where he gets when he thinks I might absentmindedly walk into traffic. He listened, and I explained that it wasn't just that I couldn't see my future, I couldn't even imagine it. Whatever sense I had yesterday for who I would be in six months, for who I would be for the rest of my life, it had slipped away as we had walked out of that office. All that was left was a warm, indecipherable fog.

"I am scared of everything."

I have what they call invisible disability. I'm not in a wheelchair, I have no obvious physical flaws. I turn my head to the right a lot, but it took a neurologist to notice this is not a voluntary motion, not even I had noticed. Everything else about me looks like the average small middle-aged woman.

Inside my skin is a different story. Inside, I am broken in many and fascinating ways. Not very well understood genetic problems, a lifetime of mental and physical scars, pain and blood, sometimes far too much blood, sometimes coming out of the wrong bits of me. All of this is my experience of being me. I promise, I won't get graphic. I will say this: my digestive system doesn't work right. My joints are meh. I get a lot of infections. My lungs are iffy, at best. My cycles are unusual. My mind and brain, whatever they are together, can be a slippery customer. But none of these things have made me seek out this man and his scalpel.



The bits where the vertebrae touch – that’s not supposed to be like that.

What has brought me to this office happened eleven years ago. My normal life function had declined, and then, I stopped functioning at all. Not all at once, and I fought it as hard as I could with exercise and good living, which as it turned out was not very hard at all. In the end I couldn’t move much. I had daily migraines. I was bearing unbearable pain and I didn’t know why. There were doctors, and more doctors, and tests, and big humming MRI machines. What had happened was that the vertebrae in my neck and the discs between had started pressing on my spinal cord and the nerves as they left my spine. No one knew why.

My neurologist was a straight talker. When I asked him what had caused this, he waved dismissively. “We usually ask if you’ve been in a car accident, and if you say yes, we say that did it.”

“You don’t know?”

“We don’t know,” he replied.

That was when I began to understand how clinicians see attribution and cause, and even began to agree with them. It doesn’t matter what caused something, unless knowing that helps you fix it. And it wasn’t going to help him fix me. Tell the patient it’s a car accident, and help us move on to the next step.

The thing is, I have that clinician's instinct myself. I am a fixer. So for me, the next step was figuring out how to fix this problem so I could get my old life back.

That neurologist was a wise man, so he let me go see more doctors, and get more tests, and do more research so that I would be able to hear what he had to tell me next: that there was no fixing this. I would decline inevitably. No one knew how fast or how much, but there was no way to stop this, much less reverse it. Treatments like muscle relaxants and Botox could make my life more comfortable, but this was over. This part of my life was over. I would never sit down with a good book again. I would never do a pull-up. In time, I would not be able to carry groceries home anymore. I could not safely lift a child. I would never again go backpacking. One day, I might not be able to put on a backpack. One day, I might not be able to type anymore. No one could be entirely sure how bad it would get, but it would get bad. Maybe the pain would come and go, but I would not be able to fix this.

In moments like these, you don't simply adjust a set of routines. Moments like these break who you are. They have to, and you have to let them if you're going to have any future. I thought about suicide. But in a way, suicide was redundant. The person who would have rather died than have my body already had my body. The future that I had imagined all my life was already dead. What I had now was a stranger's future, and the job of becoming that stranger. I discovered I had no malice towards this stranger, and proceeded to become her, which sounds so much simpler than it was.

I cried a lot. I spent a lot of time pretending it wasn't true. I was scared of everything. But bit by bit, over the next two years, I learned to be who I am now. I learned how to let computers read to me. I learned to love the voices of Alex and Ava on my Mac. I pushed myself too far and ended up in bed, or not far enough, and ended up frustrated. I made an

unsteady peace with this future. I learned to live again, I learned the grace within pain. I even learned to be happy, to love who I was now, even while I couldn't love how I got here.

I taught the people around me what I could and couldn't do. That is how my partner got to know me – different than the other girls he'd known. Free in some ways, but not so much in others. My daughter learned she had to help me if we were going to get certain things done, much sooner than I would have liked. I apologize a lot for this thing that I can't change.

But things always change anyway. Over the last 18 months, the bad thing got worse. I didn't understand that for a while, because I didn't want to. Each unproductive day, every headache, every clenched shoulder, they stood alone. I didn't put them together. I tried to work harder, pushing through. I spiraled into depression and pain. I went to bed, I got up and tried again. I didn't want to see it: just try harder, and it will go away. I think now that I thought if I couldn't see the future, maybe it wouldn't be here. I messed up commitments, and apologized and hated myself for it. I went to the data to fix myself, like I always do. I started keeping a daily log of how I was doing.

That's when I couldn't not see it anymore. The decline they'd promised had come. I had gotten a pretty good decade, but the future was here. I wasn't so much scared as I was angry and sad. My determination had carried me as far as it could, and it was time to shift again. I started using voice dictation. I started recalibrating everyone's expectations, including my own, of what I could really get done. I got another neurologist. I admitted that I was sick, and that I wasn't going to get better. I moved into my life again. There was more lying in big humming MRI machines, scanners, and X-rays.

Then, my new neurologist looked over the images, and referred me to a surgeon. One of the last things a specialist had said to me 11 years ago, as I was leaving his office was, "Well, maybe

they'll invent a prosthetic." I went and looked it up at the time, and they were working on one, but it wasn't finished or approved for medical use. I put the whole business out of my mind when I lost my insurance, and didn't think about it again. I had to spend my energy on learning to be me in a body I hadn't expected, and I knew counting on future medical research often leads people to disappointment and depression, waiting to live in a future that might never come.

But my neurologist referred me to a surgeon because they *had* invented a prosthetic. I went to one surgeon. We chatted, little models of spines in hand, gestures at the tiny bones, explanations. I was hesitant. My partner and I talked about it a lot. He found another surgeon, one who had worked on probably a thousand people with my particular disability. We got on a train to Paris under a gray rainy sky. We sat with him, another little model of a spine between us, and we chatted. My eyes flicked between the little delicate bones between us, and the doctor. I glanced sideways to see my partner watching me. The prosthetic is called the Mobi-C, and the doctors are pretty damn sure they can fix me.

And so, on that Monday night, as I wandered across the Seine, thousands of miles and many years from where this story began, my future died again. My identity was breaking again. "I am scared of everything." I whispered to my partner. "That man doesn't know what he's proposed to do to me," despite the fact that this man was a world expert in what he was proposing to do to me. Who was this me that might read a physical book again? That might go backpacking, do a push-up, dance again? What if I can't make myself into that person? What if I fail this new future? How could I not fail this future, when I don't even understand its shape?

Even as I write this, a date is getting set. A hospital stay is being scheduled, paperwork is getting passed around. Sometime soon I will go to Paris again, and lie down on a table. A man

will cut my throat carefully, to save me. And in doing so, he will kill me. And I will wake up, in a bed, thousands of miles and many years from where I was born, and I will not know my future, or how to live in it. They invented something, and everything will change for me, again.

---

I have a meeting today. As I write this, I'm still disabled. Coordinating my hands well enough to type is difficult. When I leave the house to go to my meeting, I will do so as a disabled person. I will carry things strapped to my hip rather than my back. I will cradle my arm so that it doesn't swing when I walk. Politically, socially, physically, and in my own mind, that's how I will move through the space between me and my meeting in a few hours.

Is this one of the last meetings I'll ever go to, as this version of me? My identity is getting ready to change, to die, my mind is trying to prepare, but I don't know who I'll be when I have all these new abilities. To move through the world without constant pain, to carry things, to be expected to work and live without the sleepless nights, the instability in my hands, the scraping sounds in my neck. I don't know how to do that, I'll have to learn. It's not what I've practiced for most of my adult life, and I'm scared I'll be bad at it.

I am often amused by the fights over what is called "identity politics." Identity is the unifying theme of my life's work, and it's what I think about every damn day. As someone who can reasonably claim some expertise in how human identity works, trust me when I say: it's all identity politics. Maybe what people mean by "identity politics" is just being plain about what makes politics, because there are no politics separate from identity. Identity shapes how you move through the world, what you expect from it, and what you expect from yourself and others. The constituents of identity are the building blocks from which we create individualism, or collectivism. It's where we

get class and race, sure, and also taste, morality, custom, and justice. When you construct yourself, you construct the world. I don't mean in a post modern we-can't-know-anything kind of way, although that can be part of it. I mean that you pay attention to your world based on the way you see yourself, and that attention, in aggregate, makes the world.



Where your troubles began.

Understanding this can help make sense of the world right now. Our identities are running into our technologies and getting broken by all these new powers we have. If you have never considered yourself someone who might one day speak to millions, you might not craft what you say on social media to cater to an audience of millions. Then, one day, maybe you do find yourself in front of an audience of millions. And if that day comes, your future as you knew it dies, much like mine has and is doing again. In truth, our futures die many times in our lives. Tiny deaths accompanied by futures we don't know how to live in. We pretend it didn't happen and push on, or when that fails, we change. Eleven years ago, I changed, losing a future and gaining the identity of a disability. Now, I am facing the loss of that disability, the loss of who I am. I'll be needing a new identity soon.

Looking around me, I see the flavor of my own anxiety everywhere. We all have access to the bulk of human knowledge now, we can find nearly anyone and speak to them. We can make things appear, and make ourselves disappear, all with an ease that we couldn't explain to our own great-grandmothers. We can spend our days alone,

locked in our houses, listening to the inner thoughts of hundreds of people thousands of miles away. Our thoughts and words make and change the physical world. No wonder we're so obsessed with wizards and superheroes these days – they describe our lives to us more accurately than our literature does.

Who are we to have these powers? We don't know what to do with them, who they should belong to. We're tourists playing at being minor deities, except we don't get to stop playing; this is our future now. Who do we have to become, now that we have all these new powers? What if we can't make ourselves into the people worthy and able to use the technologies we invented? What if we fail this future? How could we not fail this future, when we don't understand what it is?

You are reading this far from where you were born, in an unexpected world, on a device that didn't exist a decade ago, facing a future none of us know how to live in yet. You are not disabled in a way that you once were, a disability you didn't know you had is being pried away from you, and you don't know who you are becoming. We don't know where we are now, except that it's many miles from home, and we have to make the future now.

We are scared of everything.

---

*Conversations are from notes or recalled to the best of my ability. They are mostly right, but may not be exact wording.*

*My work for Emptywheel is supported by my wonderful patrons on Patreon. You can find out more, and support my work, at Patreon.*