

# The Power of Uncertainty

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"It feels cold." Those three words changed my life. In the summer of 2004, I went to a routine medical checkup. I was a fit 38-year old mountain biker and hiker, and there were no significant questions for the doctor or myself. As he prepared to leave, the doctor asked me if I had any other concerns. I mentioned that I had a small rash on my lip. The doctor quickly determined it would resolve with some over-the-counter cream. As he started to leave, I added one more note. "It feels cold." The doctor turned around as I explained, "It's weird; it's like I'm holding a piece of ice on it." He frowned and referred me to a neurologist for testing. I rolled my eyes and thought, "doctors love their tests; it pays the bills." While it was surely a waste of time, I decided to follow through. A couple of months later, I met with the neurologist to review my recent MRI brain scan results. By this time, the rash and cold sensation on my lip had disappeared. The neurologist said, "You look like the kind of person who would get on the Internet to figure out what things a brain MRI might turn up. Let me tell you what it's not. It's not a brain tumor, it's not ALS, and it's not a bunch of other things you don't want. But I do think it might be multiple sclerosis." With no symptoms at hand, I was skeptical. Unfortunately, subsequent testing and specialists confirmed the MS diagnosis.

Multiple sclerosis tells the body's immune system to destroy the brain and nervous system, which tends to be a bad thing. Those of us with MS really are our own worst enemy. It's unpreventable, unpredictable, often painful, and currently incurable. Medication can slow but not stop or reverse disease damage. It affects each patient differently, the impact can be a nuisance or nuclear, and there's no way to know until it happens. It's rarely fatal, but it cuts life expectancy by about 10%. Aside from disability, complications, and fall risks, people with multiple sclerosis are twice as likely to die from suicide. When I received the MS diagnosis, I didn't know any of this.

For the next four years, I attacked the disease with the best pharmaceuticals available, including an advanced medication that had a bad habit of killing people in the process of helping them. Hey, beggars can't be choosers. Sign me up.

My multiple sclerosis symptoms rapidly progressed despite the effort, and the disease partially destroyed my spinal cord. While I found ways to remain active, work, and keep a smile, by the time I was 41, the cold sensation on my lip had become an inability to walk without a cane. I also had lost most of the feeling in and use of my hands.

I went to Mayo Clinic for an evaluation and second opinion. At its completion, my supervising doctor explained I had one of the rarest types of multiple sclerosis. Medications might delay disease progression and disability, but they couldn't repair existing damage and restore function. She added, "I recommend you do the things you want to do now because, by the time you're 50, I don't believe you're going to be able to walk or travel". I don't even remember what we talked about after that. She was kind enough not to say, "it sucks to be you," but the message was clear. At 37, I was a recently married father of two, an avid mountain biker, and entrepreneur. At 38, I added a multiple sclerosis diagnosis. In just nine years, I would be homebound in a wheelchair.

As I drove home alone six hours from the clinic, there were no tears. I needed to focus if I was to ignore the instructions handed to me. I would get healthy or die trying.

From that moment, I began to create a new path. As conventional medicine increasingly failed me, I shifted to a holistic mix of controlled diet, exercise, meditation, and alternative pharmaceuticals.

I enjoyed some victories. For my 50<sup>th</sup> birthday, I took a selfie walking in Amsterdam, though more out of defiance than genuine progress. (I also took advantage of being in Amsterdam to test drive medical cannabis pain management in place of my well-worn mindful controls. May as well kill two birds with one stone, so to speak.)

While I redrew the doctors' predicted timeline, they weren't far off. Soon after my triumphant walk in Amsterdam, I began using a wheelchair. I had bouts of a nerve issue known as "the suicide pain" that left me unable to speak or eat solid food

for months. Eventually, I had to radically scale down and reshape a career and business I loved.

I recognize this may sound very depressing. Contrary to what you might think, I'm happy and thriving after 17 years with this disease. I am not technically "healthy", but I'm not dead yet. At 55, I feel I'm the healthiest and most balanced I've been in my entire life, if not physically, then spiritually. I didn't follow the path I anticipated when I was 37, but I didn't follow the map handed to me either. I feel lucky and grateful to have the right people around me and the creativity and stubbornness to find goodness I can build on. This is how I fight back. I'm a pioneer at heart, and I chose to find my own way. Like Lewis and Clark, I could reach a shining sea or end up dead on the plains. I don't have a compass. I can navigate by the stars, but who can see the stars in the raging storm I can find myself in? Sometimes, I simply go with the flow. While I haven't found the shining sea yet, I'm here to report a stunning journey. Even if I don't have a clue what's going to happen in 10 minutes, I have my intent. Navigating a chronic disease is an art, and the patients living it, the artists. And like any masterpiece, my intention to create is wrapped in a unique, organic flow.

My health voyage can feel like floating in a river. As I progress downstream, I encounter and assess new obstacles and opportunities. At times, the water is calm, and I move peacefully. There are scary moments when rocks and rapids may destroy me. The water is turbulent, and there's no solid footing. Keeping my head above water is a transient state. Staying centered requires being present and at peace. Sometimes I reach something of beauty, sometimes not. Clutching at the water, hoping to control it, is a fool's errand. With the safe shore out of reach and little chance of swimming upstream, it's wise to ride the flow and let it do the work rather than fight it. Flexibility and reflex are strength, rigidity and force can be weak. There are no guarantees, but even subtle movement can yield meaningful change.

I can't dwell on regret or the rough water behind me, just revel that I survived it. Nor can I focus on my pride or fear the uncertain water ahead. Railing against the rocks and drowning just wastes energy. There's nothing I can do about it, and there is a certain unexpected peace in embracing powerlessness and the unknown. I control what I can, strive for the best, and adapt to the rest.

At times, I am inspired by Philippe Petit, the French artist who famously high-wire walked between the two towers of the 110-story World Trade Center. With no net and nothing more than a one-inch steel wire and a balance pole to stop him from plummeting to the concrete 1,400 below him, Petit traversed the ¼ mile distance between the towers a remarkable eight times. He stopped to peer across the abyss to the ground, spectators below, and the birds who soared alongside him. In other moments, he playfully knelt, laid down, ran, and bounced on the wire, his feet often losing contact with the thin steel cable.

Unlike Petit, I did not willingly step out across the void and onto the high wire. I woke up, found myself here, and am making the best of the experience. Conventional medical treatments for my condition can be dangerous. After years of trying, I have little to show for the risks taken. Still, venturing into the wilderness of promising but unproven therapies is a calculated gamble. I appreciate his bold step off a relatively safe skyscraper roof.

Like Petit, I don't want to die. Significant research, discipline, and help enable my "walk." There may also be an element of insanity, but now that I'm here, I've found unique perspective, beauty, and grace to be had. As I look around, ahead, and down, I see what I love, what I hope to achieve, and what's at stake. I am intentional about outcomes I can reach and those that can't. I want to cross the chasm successfully. I can't do this if I am paralyzed with fear and resist the volatility and uncertainty of my journey. At times, I may walk in pain or pull myself along by my fingernails. I may walk alone, but that doesn't mean I've been abandoned. Sometimes I'm the only one who can step to something better.

Some outcomes look better than others, and I may not like my result. Still, misery, anger, and resentment will change nothing other than myself. I must respond to whatever happens as well as I can with the tools I have. And I must be okay with that. If my work doesn't turn out exactly as hoped, I can smash it or admire the beauty of its imperfection. I must accept my current state is okay, whatever it might be. It just is. Some may be good; some may be bad. If I can't make it right, how can I make it better? How can I turn negative into positive? Magnetic poles are a transient state. With the right energy, the magnet can hold things in place or propel them forward. There's no permanent negative state unless I accept it as such.

We're all playing a game where we define the rules and finish line. I choose how I respond and play, win or lose. Judgments like "should" or "should not" can trap me into a sense of false justice or injustice. MS is not the worst thing that will happen to me and is not the worst thing to ever happen to anyone. Much of my experience will happen to all of us by the time we're 70, 80, or 90. I'm living on a gift of borrowed time. I hope to do what I can to reshape and reinvent myself. Patience, acceptance, and gratitude are virtues. All things pass in time, and it will be OK if I allow it to be.

At present, I'm in the middle of my high-wire act. My DIY alternative health hacks appear to be working. The doctors are surprised and supportive. I need a wheelchair less often. My hands are numb, but my legs are slowly rebuilding. With luck, I will find solid footing, stand up, and hike out. Maybe I'll play the guitar again. Or maybe, this will all come crashing down. If so, I'll take a bow as I plummet to the rocks below. Regardless of what happens, I strive to have fun and enjoy the ride. There are things to discover if I can just "be" and appreciate the view. Be patient but keep moving. I don't know if my story will be a triumph, a comedy, or a tragedy. Hopefully, it's rewarding to follow regardless. I may have the best intentions and navigate the flow as well or better than anyone can. I can do everything right and still end up splattered on the pavement below. It's a matter of fate and timing I don't control. But when I embrace the mystery and possibility, it's a platform for joy like no other.

"You do what you can for as long as you can, and then when you finally can't, you do the next best thing. You back up, but you don't give up". – Chuck Yeager