The perils of being your own doctor

When an experienced physician became convinced he had ALS, none of the specialists he consulted could persuade him he was perfectly healthy

by

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In the summer of my 44th year, when everyone did the ice bucket challenge for ALS, when friends and strangers and celebrities soaked themselves with iced water to "raise awareness" on my Facebook feed, I did not participate. I took note of these social media affirmations with some interest, but I was never tagged by my friends to participate in the awareness raising. I thought about doing the ice bucket challenge on my own, but I got caught up in the specific detail of whether a middle-aged man should have his shirt on or off during an internet display of virtue. And so nothing happened.

Some time after that, in the autumn, I began to notice a certain hitch in my left leg when I walked or stood for too long. The knee would give out periodically, as if I had forgotten to attend to the basic task of keeping it straight. My leg was otherwise normal, it was strong, it didn't hurt. I'm a doctor and so I looked at it. It looked fine. At the time my toddler son demanded to be carried up the stairs and everywhere, and I was riding my bike to work every day. Maybe, I thought, I was extending myself too far. Maybe I had reached my fabled turning point. A month or so after that, I started to have some numbness and an ache in my left arm and a feeling of clumsiness in that hand. Probably a pinched nerve, I thought, and did what most doctors do for medical problems, which is to take some ibuprofen. Soon after that, while I was giving a lecture to medical students one morning, the microphone slipped from my hand and fell to the ground. Medically speaking, dropping things is a big deal. I realised that something was happening, something troubling that I couldn't ignore any more.

You never plan for a serious medical problem in your life, it intrudes, testing the boundaries of your constructed reality. Things had been going well enough for me. I was married with two young children and I liked the work I was doing. If I was stressed and sleepless and maybe a bit overwhelmed by new fatherhood, it was still a very happy time. I was working in an academic emergency department and teaching a course to medical students about the soft skills of being a doctor: how to talk to patients, how to understand their experience, how to make sick people feel better. It had occurred to me that to be a healthy person teaching students about illness might be a provocation of fate.

I ended up in a neurologist's office the next week sitting on an examination table in a hospital gown. Dr K came in and introduced herself. She had been recommended by a mutual colleague as someone who was clinically sound but also "just gets it". This much was immediately clear; she was warm and attentive and present. I felt self-conscious and exposed in the gown, powerless, vulnerable, all those things I teach medical students, but at least I was taking mental notes for my

course. It is hard to be a patient, I had told them, yet this fact is famously hidden from the daily experience of the medical professional. When the tables are turned, you discover how unequal the relationship is, how completely dependent you are on another individual's goodwill. Check. But being a doctor-patient involves making a preliminary choice: should you reveal that you're a doctor? I typically do not, at least not at first. I want to get a measure of my physician when they're not on their best behaviour. I also know from practising medicine that anything that makes the doctor self-conscious or trips up their routine can affect their judgment and decision-making. The physician might, in their awkwardness or self-regard, take a shortcut or over-think the problem at hand.

That said, sitting across from her I realised that I was worried. Suddenly I clung to whatever advantage I could: "I'm a doctor!" I blurted. As I told her my symptoms, the numbness and weakness that I had, the clumsiness and dropped microphone, I watched her expression carefully. She nodded and said it could be a disc, just as I had suspected. "But as you know," she said, "any space-occupying lesion in the spine or brain can also cause these symptoms." This was a way of saying "tumour" without using the word. I nodded, mentally picturing a tumour in my spine. "And we also have to consider things like MS. Or A said, and then she looked away for a moment before glancing back to register my reaction, which was a welling sense of foreboding, of tumbling, of skidding down an embankment. "OK, yes," I said pleasantly, "I hadn't thought about that one." Her office scheduled an MRI for me later in the week.

The abstraction - the intellectual understanding of disease - is a position of relative safety. The very real concern for one's own existential continuity is a different situation entirely; it is real, it is physical and, in my case, felt in the throat and chest.

Our occupational disability as doctors is the awareness of the unlimited ways in which things can go wrong in the body and how lives can be ruined in a moment. We study disease in medical school and manage most of the time to keep the knowledge at a distance. But when it's our turn to be ill, our medical training can be a kind of inconvenient asset. Combined with a proclivity to connect the dots, the resulting suspicions can keep you up at night. It's common for medical students to experience spasms of hypochondria during their training. This hypochondria is a kind of paranoia, a tendency to see patterns when they don't exist. But I had never been a hypochondriac. And here was an experienced neurologist, a certifiable objective opinion telling me that there was something here.

The next few weeks were hard. I waited nervously for my MRI and more than once invoked my doctor's privilege: to skip the waiting list and get my results right away, to get a copy of the studies burned on a disk before I left the radiology suite, to text my neurologist on her personal cellphone for the final readings. I was working in the emergency department the evening after my MRI, seeing patients with the desperate complicity of a dying man tending to other dying men. Intermittently I would look up the dismal survival statistics of various spinal and intracranial tumours and then go back to my sad work.

When Dr K's personal cell number flashed on my phone, I excused myself from patient care mid-sentence and walked out to the waiting room where I could get better reception. She had looked over the studies and spoken with the radiologist. Everything was normal. I did a fist pump as patients in the waiting room looked on. It was the elation of the near-death experience, of return to life! I came back to the ER with good cheer, full of hope for my patients as well, and that night I

went to dinner with friends and slapped everyone on the back like I had won the lottery. When I saw my neurologist in her office the next week for the victory lap celebration she said, “Well, I guess we should get that EMG now.” Oh right. The MRI had only ruled out a tumour. I had forgotten about ALS.

An EMG or electromyogram is a specialised test used to diagnose motor neurone diseases such as ALS. But why did she suggest it the way she did? Was the initial concern about tumours just a feint where ALS had been her real concern all along? What was she really thinking? The full force of my analytic mind was employed in the service of generating worry, but not for want of evidence.

ALS - amyotrophic lateral sclerosis, more commonly known in the UK as motor neurone disease - has been thrown into the spotlight because of the highly successful ice bucket challenge, but for many years it was known in the US as Lou Gehrig’s disease in memory of the New York Yankee first baseman whose career was marked by record-breaking endurance. He played over 2,000 games in a row without a day off until the middle of the 1938 season when he began to tire and lose his coordination, no longer hitting with any power, sometimes falling down when circling the bases. He was diagnosed at the Mayo Clinic at the age of 36 and he died less than two years later. Charles Mingus also died of ALS, as did Dmitri Shostakovich. A few years ago the historian Tony Judt died after a brave and stoic fight. I had wondered to myself at the time if I could be as brave as Judt. Probably not, I had concluded. But was it courage? Or some particular relationship to life, of being so enmeshed in it and caring so much about it that each remaining moment was a gift? Judt had his writing to finish. And I? Nothing quite so grand, but I had my family and two kids to raise. Suddenly I became aware my lack of any grand plan, my aimless floating through life.

In time, ALS destroys the neurons controlling muscle movement, leading to complete loss of strength and the ability to control one’s limbs and trunk and face, and finally the muscles of breathing. The cause is unknown, there no cure, there is no decent treatment and it is fatal within a few years - often much sooner. Perhaps most awful is that, in many cases, as victims are progressively disabled, unable to speak or swallow or move, their cognition is maintained. They must endure the burden of progressive disability and then the dying process as mute witnesses, without the grace of dementia that marks most other deaths. The affliction forces an existential confrontation for which nobody can be prepared. In any hierarchy of terrible diseases, ALS ranks near the very top.

Dr K referred me to see Dr M, an ALS specialist at Beth Israel hospital who would do the needle EMG, which, as it turns out, is an uncomfortable test. But first Olga, the Russian technician, did a nerve conduction study. She put electrodes on my skin near major nerves to test the speed at which they conveyed impulses. My muscles twitched rhythmically without my consent and I glanced at the computer screen that was running something like a seismograph. I had no idea whether what it showed was good or bad. Olga chattered good-humouredly about her husband and grandchildren in Brighton Beach as I fidgeted in pain. When she was done, she left and told me to wait there for the doctor.

I didn’t even bother to sit up. I lay on the table and stared at the ceiling until the smiling Dr M entered. An Irishman with a strong brogue and a warm and disarming manner, he put his hand on my shoulder and made a comment about my choice of underwear before cutting to the medical interview. Not exactly textbook, but I liked him. I explained my worries about ALS and told him why Dr K had sent me and he seemed unimpressed. “You’re not that interesting,” he said to me.

His dismissiveness was reassuring, but then I imagined this was part of his routine to put me at ease. As my brain careened between extremes of fate, Dr M and I talked politics and he started to put small needles into my leg.

He drew blood but did the examination without gloves, a gesture that in my shaky state I found vaguely consoling. I suppose that with my mortality nakedly exposed, this small intimacy felt like a comfort, an encounter without barriers. Later I would see him from the waiting room giving a long hug to a patient. He must have done this many times, breaking the news to someone about their fate. He finished the procedure and with a deep breath, absent-mindedly swabbed the small areas of bleeding on my skin and told me to meet him in his office. He stood abruptly and left. I found some plasters in the drawer and put them on the puncture points that were still oozing blood. I felt that everything in my life up to now had led to this point. I got dressed slowly.

In his office, I scanned the diplomas and photos on the walls while he typed, looking at his kids and smiling wife and wondering how much of his work permeated his home life. He was frowning at something on his computer. Then he looked up said, “There’s nothing wrong with you. The test was completely normal.” I smiled inadvertently and felt warm inside. Waters rushed into a parched riverbed. Eagles soared over valleys. Are you sure, I asked? Yeah, he said, brusquely. Do you have any more questions? I didn’t. I thanked him, this magnificent man, and stood up and walked out of his office and out of the building and on to the street of the wonderful living city. I called my wife to tell her the good news and on the way home I splurged on an expensive woven wool hat and smiled at all the New Yorkers in the subway.

In the week that followed, I woke up early and happily performed all the mundane tasks of my life. I went cheerfully to work. But physically, I didn’t feel back to normal. My symptoms hadn’t improved, I just felt better about them. In time, I returned to the internet in an effort to understand what might be happening. I knew that people make mistakes in medicine, and wondered if he could have missed something.

You can find whatever opinion you want on the internet, and I did. A woman on a discussion board related the story of her husband, who was convinced something was wrong: he was feeling weaker and weaker, but his EMG was normal. Six months later he had another EMG and their suspicions were finally confirmed - he had ALS. Of course, the EMG, like any test, is operator-dependent and potentially fallible. The medical literature supports EMG sensitivities of only 60-70% for motor neurone disease. Dr M hadn’t mentioned this possibility, that one EMG might not be enough. But then he was experienced with these things and he was only telling me what I needed to know. If I had a normal EMG but I might go on to develop ALS, then why tell me that now? What would be gained by subjecting me to six months or more of worry. Better that I enjoy my last few healthy months. And if I were smart, I wouldn’t ask too many questions myself. A diagnosis is a curse. And so I decided I would live with the ambiguity in a kind of modified denial. I would not seek out more tests or opinions but rather wait for the disease to reveal itself - or hopefully not. At least this way, there was a chance I didn’t have ALS. Throughout that dark winter, I lived aboard that tiny raft of hope.

By the middle of February, I had started to get muscle twitches, another of the cardinal features of ALS. They started in my hand. A muscle would begin twitching for a few minutes and then stop. And then it might start somewhere else. Sometimes two muscles would be twitching at once. They would start without warning, tic tic tic, like someone tapping me on the shoulder to remind

me I was going to die. Then would come a wave of fear, drawing back a curtain to reveal the mortal reality that I had successfully hidden from myself. I hid the fasciculations from my wife, but she figured something was wrong and I finally had to tell her. She thought I was being ridiculous, and I had to convince her to be worried. I showed her the twitches and then she did become worried. Then I had to convince her not to worry. I comforted her. I joked about it. But I felt lousy and weaker as the winter wore on.

Meanwhile, my life was a gif loop of diapers and sleepless nights. My daughter, who was less than a year old, would wake up at three and start yelling. An astonishing man-like sound issued from her throat and grew in intensity until I got up and came to her crib and put my hand on her back for eight minutes. She would fall back asleep but then I would be wide awake, sitting in hallway in the dark, blinking in the glare of my phone as I read about ALS at three in the morning.

Nothing had prepared me to confront my death. Despite having taught medical students about it and worked with dying patients, despite having read about it and done meditation and silent retreats, I quickly realised that I was lost. I was inadequate to the experience. I had not done any of the kind of spiritual work that would be required to forestall the panic and dread of facing my mortality. I didn't even know what that kind of work would look like. Leaving my children without a father was the worst of it. In my dreams they wandered through empty streets calling for me. I thought of Michael Keaton in My Life, making home movies to leave something behind for his newborn. I thought I should do this too, with my iPhone. But what to say to a four year old? Or to a 14-year-old? And how might I devise a system to deliver the content at set intervals?

By the end of winter, I became accustomed to a novel feeling: living without hope. It was a physical sensation, a heaviness that presented itself shortly after waking in the morning and interwove itself into my daily activities. I went to work with my cloudy disposition but had no appetite for much else. The only thing that gave me some pleasure was buying electronic things on Amazon. The house was littered with motion operated LED lights, Bluetooth speakers, USB battery chargers, and other electronic detritus. In the medical school, I was tasked with writing the death and dying curriculum for first-year students. It was a cruel coincidence, as ALS is the exemplary case typically used in medical schools to teach issues around death and dying. My research on the topic required reading cases of patients grappling with weighty decisions as they died slowly of the disease, their spouses wringing their hands. I wasn't sure I could trust myself to calibrate the mood and hit the right note in the lecture; the trick was to include just enough grey realism for their level of development, tempered with some uplifting words to buoy them and give them purpose in their introduction to clinical mortality. It was work that had to be done but it gave me no pleasure.

At the same time, I was testing first-year students on the physical examination. I sat in a cold room watching them examine each other, each one reassuring the other after every step as we had taught them: "great, your lungs sound fine", "your heart is totally normal!" Strung one after the other for hours, the performance seemed a celebration of their youthful immunity from harm and disease, their separation from the world of real patients and actual sickness. How absurd it all was, what a charade. And what a disservice to their real education. I imagined an exercise where students would be told they have cancer and left for a semester to pick up the pieces of their lives. It was only with my patients that I could escape from my predicament for a little bit. It felt good to care about them and try to put them at ease. My own proximity to death made me more present in their suffering. And whenever I came home to my two-year-old son running to hug me

and tell me about whatever charming trifles had made an impression on him that day, I tried to be cheerful for his sake.

One week, on two separate occasions at the hospital cafeteria, I bought a drink and something from the salad bar and the total came to $6.66. The cashier looked at me warily and my rational mind decided to take a break. I started doing everything in sevens as I had read that seven is a lucky number. Seven brushes of the teeth, seven chews of the burger. At the same time, I couldn't help but wonder whether I had brought this illness on myself. Whether I had eaten too many microwavable burritos, or taken the wrong vitamins, if somewhere I had made a mistake, had become a person I was not supposed to be, whether I was paying some existential price for shirking my responsibility to some other life that I didn't pursue. I looked for meaning in my symptoms. I tried to read my disease as a sign. And all the while, I was bargaining with fate.

One night after a few drinks, I donated $777.77 to the ALS foundation. I kicked myself for having forgotten to do the ice bucket challenge and promised to attend to that as soon as the weather got better. I promised I would have more fun, I would take a larger perspective, I wouldn't get enraged at how people drive in Brooklyn. I promised to live more bravely. To whom was I promising these things? At a friend's festive dinner, I was seated across from a woman from Shanghai. We talked about superstition and my fixation on the number seven—it was part of my way of opening a door, if only she were to ask one more question then I could tell her about the ALS which I desperately wanted to do. Instead, she laughed and said seven is very unlucky number in Chinese mythology, a number associated with death. I felt like throwing up. I couldn't even manage a smile.

By the spring I had lost 5kg. My left arm and leg felt like jelly most of the time and fasciculations travelled over my body throughout the day. Sensory symptoms are not common in ALS, but can be found early in the disease. I still wasn't certain that I had the disease, but in my mind I was just waiting for it to get worse before I completely gave up hope. The inconceivable, irreducible, bewildering fact of my mortality was like some grotesque object that looked different from every angle, a concept that resisted incorporation into my understanding. It kept occurring to me how surreal it is that this is how it all turns out: this the resolution to the to the varied plot lines of my life. This is the punchline. I was not fun to be around. My wife was supportive and she was patient, but also gently pointed out the possibility that this whole thing could be all in my mind. Was there any objective evidence that I had the disease? Did I have any objective weakness? The answer was no and no. I carried my kids up the stairs, I could do 50 push-ups. Had the studies all been normal? Yes, they had. She convinced me to get out of my psychic echo chamber, to stop being my own doctor, as it were, and to go back to the neurologist.

A week later, I sat in the examining room again, dressed in the insubstantial paper gown waiting for Dr K to walk in. I had decided to apply for life insurance and planned to ask as a favour that she minimise her concerns about ALS in the medical record. When she entered the room and asked how I was, I became overcome with emotion. I kept my composure with some effort and said that I didn't like the direction things were going and I was afraid I would have to make some serious choices soon. She looked at me quizzically and then when she got the point of what I was saying, she told me that I should see a psychiatrist. "That's all right," I said, taking a deep breath. "I'm coping all right. I'm certainly not going to take any antidepressant. I've been… "

She held up a hand to stop me. It was her opinion, she said, that my symptoms were not an organic illness. They were an expression of some inner psychic distress. It was all in my head, in other words. I blinked. This was welcome news, yes it was. In my own clinical practice, I often believe this of patients, and on rare occasions I've suggested this sort of thing directly to them, but it's a tricky business. Many patients would take it as an insult. I, on the other hand, was delighted by the possibility. Certainly, the thought had occurred to me as well, but to hear her say it was better. But the solution felt too facile. Psychosomatic disorder should have been the diagnosis of exclusion, after having ruled out more serious things. I had never had psychosomatic symptoms before. In fact, while medical students are thought to be prone to hypochondria, practising doctors tend not to be. They are often notoriously dismissive of their symptoms, either because of fatalism or awareness of the limitations of medicine.

"Are you sure?" I asked. She examined me and pointed out I had no muscle wasting. My reflexes were normal and my strength was fine. She couldn't elicit any fasciculations and she reminded me that all my studies had been normal. The lab tests and MRIs and EMG had shown nothing. I really don't think you have ALS, she said. Two neurologists have told you this now, and still you're not convinced. Maybe you need to change some things about your life. "Yeah I'm sure I do," I said, "but could it be early ALS?"

She paused. "I don't think so," she managed. But it was clear that she couldn't give me a definitive no and I was going to be miserable until I knew for sure. We both agreed that it could be time that I see the ALS specialist. And this is how I was referred to Dr HM at Columbia.

I was familiar with Dr HM because I had searched online for ALS specialists in New York. I had read his scientific articles on PubMed and looked at his photos on Google Images and had developed a deep admiration and gratitude for him based solely on projection. He was a distinguished-looking Japanese man whose image conveyed competence. I was eager to meet him for a third opinion because in one of his papers he had detailed a list of agents that may possibly slow the disease down. At the very least, I thought, he could tell me how to buy some more time.

What I was hoping for most of all was a diagnosis of benign fasciculation disorder, a poorly understood phenomenon of muscle twitching that appears to be more common in medical students and physicians. One author had coined the term Fasic - Fasciculation and Anxiety Syndrome in Clinicians. In his paper, he presented a case series of 20 consecutive doctors who presented with fasciculations over the course of a few years. Being doctors, and being familiar with ALS, they sought medical attention. A third of them were practicing neurologists. The majority of them left with a diagnosis of benign fasciculation syndrome. In other words, it was a thing: doctors who think they have ALS, but who actually have Fasic. But I kept getting stuck on doctor number 20 described in the paper, a neurologist who developed ALS and died.

On a gusty and drizzly day, I sat in Dr HM's waiting room scanning the other patients for signs of motor neurone disease. A small neatly dressed Japanese man appeared in the doorway, looked at me and said my name. Dr HM emanated a benign and kindly paternal presence and immediately commanded my trust. I followed him into his large, not particularly modern, not particularly neat office and sat across from him. He took out a single sheet of paper and a pen and asked me to tell him my story. As I talked, he politely interjected questions and urged me to continue, all the while writing on that single white sheet of paper. When I was done, he looked up with raised eyebrows and said, "Is that all?" I felt embarrassed and had the urge to make something up. But if

he was unimpressed, certainly this was a good sign. Then he led me to the table and did an exceedingly thorough examination. Everything about him was careful and measured and calming and I took note for my own practice - should I survive this ordeal.

After the examination, I sat across from him as he slowly scribbled notes in his deliberate way. He looked up and took off his glasses and said, “You’ve been to two doctors now who told you that you don’t have ALS. So it will be hard for me to convince you that you don’t have it, but I will tell you that I have seen many patients with isolated fasciculations without any muscle weakness or objective signs and none of them have developed ALS.” He paused. “This is over many years. None of them.” I nodded. “In fact,” he continued, “I myself have had fasciculations for 20 years. I’ve thought I had ALS many times, but I have never developed it either,” he said grinning. This self-disclosure was an unexpected gift. I nodded, involuntarily and continuously and let the generosity of this great and learned man fill me up like oxygen.

“So I don’t have ALS?” I asked. “I really don’t think so,” he managed. I stopped nodding. And as if reading my mind, he suggested that if I had any further doubts, that I should get one more EMG, and that if that were normal, then I should forget about ALS.

I did get that second EMG from Dr M and it was normal. He confirmed a diagnosis of benign fasciculation disorder, mostly because we couldn’t think of whatever else this could be. I told Dr M that I had developed a profound respect and admiration for the people who were working to find a cure for ALS. I had thought so many times of the families who loyally took care of their loved ones and the patients who bravely faced the unfaceable. I had donated money to the organisation, I had liked it on my Facebook page, I had considered going to some of their events. He shook his head and said that I should just forget about ALS. “Erase it from your memory and from your life,” he said. His view was that the more I dwelled on this diagnosis, the more claim it had over me and the more I would keep manifesting symptoms.

My symptoms are essentially gone now, though occasionally I feel something in my leg that will remind me of that dark time. In my memory, I was circled by a shark that ultimately lost interest and swam away. In the spring I decided to change jobs after 15 years at the same place. I took a long break. I started to lift weights. Some turning point occurred that I still don’t have the perspective to understand. I was initiated, as people my age often are, into an awareness of the fragility of our being. I realise too that my adventure was a rehearsal for something else, the reality behind the curtain of youth that older people politely keep to themselves. Yet I have no interest in dwelling in the shadow of death’s certainty. As the psychiatrist Irvin Yalom has written, living in proximity to death is like looking directly at the sun. In the absence of strong faith, it takes a special kind of spiritual evolution to face it with equanimity. I don’t have that so I continue to live as before, with the adolescent’s illusion of eternal life. This is not to say that nothing has changed. I have seen that life is dear and it is on loan to us. And so everything just feels more precious.

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. This article was amended on 4 and 5 August to clarify that ALS stands for amyotrophic lateral sclerosis, that the condition is better known in the UK as motor neurone disease, and that cognition is not maintained in all people with ALS/MND: about 50% of people with the condition experience changes in thinking and behaviour.

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