

GRAVELY ILL

It began at a work function dinner. I had just peeled the crispy skin off my chicken breast and slid it onto my husband Mic's plate. I could feel a change in my heartbeat as the elderly woman across from me admonished me for this misguided act of kindness. It felt like my heart skipped a beat every few seconds. It eventually settled into a beat-beat-stop, beat-beat stop rhythm. I visited my doctor the following day. She felt my pulse for a few seconds, and said there were a couple palpitations, which she described as a premature beats. She said this was quite normal for a woman in her 40's. This was a plausible answer, yet I felt uneasy at her hurried manner, and prompt dismissal. My former doctor was thorough, and would have spent more time with me. However, my insurance company had ended its association with him some time ago. I verified on the internet that this rhythm (called bigeminy) was "generally benign". It came and went for some time, was annoying and unsettling, and eventually seemed to be present more than not. I could still function normally, including regular workouts, so I learned to live with it. The rhythm seemed to even out when I exercised. Still, there was an overall feeling that something strange was happening to me.

A few months later my husband and I were caught in a sudden thunderstorm heading up a river in our fishing boat. We took shelter under a bridge to dodge the microburst. It was difficult to hold our position next to the tugboat moored there, and the sky was now endlessly ominous, so we sped toward the boat landing. We could hardly see beyond the driving rain, and a rush of adrenaline came over me as lightning crashed nearby. We quickly secured the boat onto its trailer, and I bolted up the hill to get to the truck. I could not catch my breath as I jumped in. This had never happened before, so I attributed it to the anxiety/adrenalin rush of being caught in the storm.

Later that season Mic and I embarked on a road trip. I reluctantly agreed to abandon my tendency to over plan vacations, and went along with my husband's method. This involved loading suitcases into the car, turning on the GPS, and choosing a direction. A day later we found ourselves in Kentucky. My rock hound eyes grew wide as we passed a sign for Mammoth Cave. I implored Mic to stop for this noted international treasure-the longest cave in the world. We chose the more advanced tour that descended

deeply and rapidly into the cavern. The guide warned about the 500 stairs and significant ascent back to the surface. He further noted this was not the tour for anyone with health problems, or knee issues. Having been in good health and religious about working out, I dismissed this admonishment. Besides, there were individuals quite a bit older, as well as children, in line with us.

We started down the metal stairs single file, midway through a long line of participants. A welcome blast of cool air wafted upward to ease the intense heat and humidity of a southern, summer afternoon. After a brief period, my legs began to feel like quivering rubber. I had to hold the railing tightly to support my weight, as they felt like they were going to give out altogether. I began to worry I would hold everyone up, and wondered what was wrong with me. Was I getting the flu? All the muscles in my arms were straining to keep me from diving onto those in front of me. When we completed the descent I seemed to be fine. My background in psychology caused me to quickly dismiss the episode. It was likely a visceral reaction to the close proximity of the cold, wet walls, sweaty hikers and steep descent into darkness. Could I be developing claustrophobia? Perhaps the number of stairs were challenging to my middle aged knees. Any concern melded into fascination with the glistening rock formations, ghostly stalactites and stalagmites. Then we started our ascent.

I began to have a hard time catching my breath. The longer we climbed, the more I struggled. It was well beyond winded, as though no air was entering my body. Instinctively I began to breathe rapidly, but it was non-productive. I began to panic. Could this be a first panic attack? I became afraid I would pass out if I kept trying to keep up, and reached forward to grab Mic's arm. When he turned around, his usual playful demeanor was instantly replaced with alarm at my distress, and apparent straining to get a breath. He notified the guide. We were led to an easy outlet (exit-for-wimps, I told myself). I was disappointed that I missed the best part of the cave, and worried that I was developing some psychiatric issues, perhaps anxiety. On the drive home my heart had a few brief episodes of rapid beating in a light, fluttering way, like someone was tapping me softly on my throat.

I resumed all regular activity after our trip, including workouts. These went well, but I still had wobbly, rubber-like legs while going down stairs. I used to dash up the stairs at work numerous times

throughout the day, but now I was quite winded after doing so. I had to catch my breath before I could speak, or answer the phone. My heart was constantly in bigeminy and now I also had trigeminy (feels like beat- beat –beat- skip). It never seemed to beat regularly. I made another appointment with my doctor, vowing to be more assertive. She listened to my heart, and was concerned enough to refer me to a cardiologist. Meanwhile, one of my staff gingerly asked if I noticed I had a hand tremor. I now became concerned that something was seriously wrong with me, such as Parkinson’s disease, and began searching for my symptoms on the internet. I was afraid to confide my concerns to Mic, being newly remarried, with so many plans for our future. While I felt quite secure in his love for me, I knew he had not signed up for a devastating illness. Several individuals who knew me well had asked if I was nervous. One even said I looked like a “deer in the headlights.” This caused me to take inventory of the perceived changes, and yes, I did have to admit I felt strangely anxious, or on edge, most of the time now. Yet I had always been the “go to” person for crisis management, as the director of a program for individuals with severe and persistent mental illness. I had been dubbed the “queen of calm” by my staff. Why would my demeanor suddenly change?

Sometimes it felt as though my leg muscles were disconnected from my brain. I had a hard time initiating certain moves, like stepping from the dock to the boat. On a visit to a client’s home I knelt on the floor to retrieve a fallen object, and felt I could not get up. It took great effort to pull myself up with my arms on a nearby table. I felt overwhelmingly weak at times, but better after a brief rest in a chair.

The cardiologist seemed kindly, thorough and reassuring. He noted the arrhythmia and recommended a treadmill stress test. I told him how I was used to exercising, but became winded on hills. The treadmill was at a steep incline, and he placed an O2 sensor on my finger. He noted it did not register correctly, nor did a second. He tried it on his finger and it worked well. He did not find anything wrong with my heart after completing a number of tests. He was concerned that there was something wrong with my lungs. He asked if I had ever smoked, had been exposed to second hand smoke, had asthma, or any family history of lung issues. He seemed surprised when I answered no to all of these. He conferred with a lung doctor, and set up an appointment.

Then I began to lose weight. I started eating larger amounts, but kept losing about 2 pounds per week. I worried about cancer, as it does run in my family. Subsequently I noted a significant increase in bowel movements. Soon this turned into severe constipation, as though my muscles could not complete the basic function of having a bowel movement. My once normal menstrual periods became alarmingly heavy. My skin was itchy and my soft, fine hair became brittle, and began to thin. I remembered hearing once that itchy skin could be a sign of hypothyroidism (lack of thyroid hormones), but when I looked this up, I learned the symptoms included weight gain and fatigue. Yet I was losing weight and having trouble sleeping. I could hear my heartbeat pounding in my ears at night when I lay on my side. I began to have throbbing headaches in my temples. I never made a list of these odd symptoms as I was so involved in a busy career, working over forty hours a week and on-call in addition. My biggest concerns were my heart and my lungs, and I was seeing specialists for these.

I told the lung specialist that I felt “trembly” all over, and described the difficulty I had with inclines. He told me my heart sounded like Morse code, and scheduled a series of pulmonary tests. A test called a ventilation perfusion scan came back perfectly normal, as did the chest x-ray, hemoglobin and a number of other tests. Blood clots in my lungs were ruled out via more tests. I did insist we continue to investigate, even though a part of me felt these symptoms could be in my head. Perhaps the doctor thought so as well.

A cardiopulmonary stress test was then ordered, to assess breathing on inclines. I noted that morning that my heart rate was no longer like Morse code, but was now steady and fast, about 120 beats per minute. Prior to the test, the nurse said my blood pressure was high on the top, and low on the bottom. She noted my resting pulse was 127 - all strange, but she attributed this to all the wires and gadgets attached to me. I told her I never had blood pressure issues before. As the test began, the doctor raised the treadmill to an 8% incline. He stopped at 5 minutes, looked puzzled, and told me the results were indeed abnormal. He said I had “reached my anaerobic threshold quite early” indicating a problem with my lungs. This sent a paralyzing jolt of concern through me. He scheduled a high resolution CT scan to look for tiny blood

clots. If nothing was found, this would be followed by a CT pulmonary angiogram (lung biopsy) to look for “interstitial lung disease”. I felt shaken and scared as I dressed to go back to work.

Unable to concentrate I searched for interstitial lung disease on my computer, and learned it is a disease that results in a hardening of the lungs. The phrase “treatment involves a lung transplant” jumped off the page, and now I felt weak with fear. I stood up, and walked over to shut my office door. Sitting at my desk in disbelief, I suddenly had a sensation that my heart jumped high in my chest while quivering rapidly. I waited a few minutes to see if it would go away, then asked one of my staff members to drive me to the emergency room.

I was given multiple aspirin and told my heart was going from “sinus tachycardia to atrial fibrillation, to super ventricular tachycardia (SVT), over and over”. An IV medicine called adenosine was administered, followed by another one called diltiazem. The doctor was surprised that this did “absolutely nothing”. He consulted with an electrophysiologist (specialist in heart rhythm problems) via phone. This specialist recommended shocking my heart (cardioversion) while it was in SVT. ***Shock my heart?*** I asked them to wait until my husband arrived. It eventually settled into a fast, steady rhythm, called sinus tachycardia. The ER doctor scheduled an appointment with the electrophysiologist, and said I could go home. The nurse expressed concern, as my blood pressure was again quite high on the top number, and oddly low on the bottom number. I explained that my blood pressure had always been fine before all this. In fact, I had always been in good health. I felt uneasy and worn down as we left with no diagnosis. I prayed the irregular heart rhythms would not return before the next specialist appointment.

As feared, I had several bouts of tachycardia in the days before my appointment. My husband and I lay awake each time it happened at night, and wondered if we should return to the ER. At work, I would shut my office door when my heart had an episode of rapid pounding. Several times I readied myself to go to the ER, but it would cease before leaving. Therefore I was relieved to arrive at the electrophysiologist’s office. I related my story of specialists, numerous tests, and the lung biopsy I was facing. He began to describe a heart ablation procedure to correct the rhythm problem, when a shocked look came over his face. He paused for a while, stared back at my records, and told me I would not need an ablation as the

problem was not originating from my heart. He asked me if I was told my blood work was abnormal almost a year ago. I told him that I received a call (recording) after my physical saying all the blood work was fine. In fact, I had gone back a couple times to complain of symptoms. He looked disturbed and uneasy, and told me my TSH, a lab measure of thyroid hormones, was non-existent. He explained this meant I was in hyperthyroidism. My thyroid was out of control, and producing too much of the hormones. Because a number of conditions cause hyperthyroidism, another battery of tests would be required. He said to call my primary care doctor to obtain a referral to an endocrinologist.

I went back to work and closed my door, flooded with overwhelming relief, and gratitude. This seemed like something treatable. I looked up the symptoms of hyperthyroidism and the entire last year was represented on the screen in front of me. Anxiety was among the many symptoms I had been experiencing. At the end of the long list was “shortness of breath with exertion” and I remembered I was scheduled for a lung biopsy. I quickly called my pulmonary specialist and left a detailed message. He returned my call immediately after he conferred with the other specialists. He was upset that the results of the basic thyroid lab, done so long ago, went unnoticed. He indicated he phoned my doctor and communicated his concern regarding all the unnecessary tests and radiation. He said there was never a need for referrals to the specialists- all who had assumed the basics had been covered. I told him I was greatly relieved at this diagnosis, as it seemed treatable with medication. He responded that it may not be so simple at this point, and that my breathing difficulty was due to atrophy of my diaphragm, from excess thyroid hormones. It would take a long time for this to get better. He also instructed me to get a referral to an endocrinologist, as soon as possible, to determine the cause and treatment of this hyperthyroidism. Cancer of the thyroid would have to be ruled out.

After being put on hold, my doctor’s nurse said she would no longer see me, and would not make a referral to an endocrinologist. Angered welled up, and I wondered if she was worried about liability, or if my lung doctor’s admonishment had put her on the defensive. I had no intention of suing, but needed a referral. I tried calling TSH myself, but could not get in for months. This was unacceptable, as my symptoms were becoming more acute. I read about “thyroid storm”, a life threatening condition

associated with severe hyperthyroidism that can result in congestive heart failure and pulmonary edema. Furthermore, it was getting harder and harder to function in a job I could rarely afford to take time off from.

My husband and I then remembered our insurance through his work had changed again, and found that I would be able to see my former primary care physician. Dr. Richard Greene had that invaluable combination of communication skills, knowledge, and thoroughness. However, I was disheartened to learn via a phone call he no longer accepted new clients. My equally distressed husband very determinedly called back and asked for his nurse, Arlene. He explained the situation, and stressed I was a patient some time ago. He simply begged her to let him see me. We received a call back shortly thereafter, asking if I could come in early the next day.

I learned I had an autoimmune disorder called Grave's Disease, which was confirmed with a few more tests. My doctor explained this disorder affects 2-3% of the population, and is seen in far more women than men. He assured me it was treatable with a number of options, including radioactive iodine therapy, or surgery to remove the thyroid. Had it been caught earlier, there would have been the possibility of using anti-thyroid medications. He immediately put me on a mega dose of a beta-blocker medication, which helped to control the heart issues. I opted for radioactive iodine to knock down, or destroy my thyroid.

My symptoms gradually improved. I now require daily thyroid replacement medication, to treat the resulting hypothyroidism. However, I have been leading a full life, with a number of manageable symptoms that include dry, somewhat protruding eyes, occasional moodiness, and a sluggish metabolism. Regular exercise, a healthy diet, a positive attitude, and a multi- room humidifier (prevents eyes from sticking shut at night) have become my greatest allies. Mostly I am grateful that my illness did not progress to significant permanent damage, and that it is a condition that does not necessarily shorten or diminish one's life.

My story is not unusual. There have been many similar cases of undetected or incorrectly diagnosed thyroid conditions, including Graves' Disease that one can read about. In addition, similar

stories have been told to me by friends and acquaintances. A co-worker's father nearly died from misdiagnosis of his hyperthyroid condition. Sadly, many other thyroid patients' concerns are written off as psychiatric symptoms. Yet it is easily detected with an inexpensive blood test. I am now more assertive with doctors, and no longer see myself as a recipient of healthcare, but rather a partner in my health care. When feeling dismissed, it is vital to press a doctor to address your concerns. If not satisfied, find another doctor. Always obtain a copy of your lab results. Be vigilant. You can find more information, and support on Graves' disease through the Graves' Disease and Thyroid Foundation website at www.gdatf.org.

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