A PIECE OF MY MIND

The Lower Seven-Eighths

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I ate only one meal in a restaurant during my five-day visit to Paris in the fall of 2011: lunch at Les Deux Magots. It took an hour. Not because I am a slow eater and not because I was in awe of the ambience but because I had tic douloureux, better known as trigeminal neuralgia. I'd take a bite, and excruciating pain would shoot up above my right eye. I thinned my sandwich by removing the top piece of bread so the bite would be smaller. I found that I could best eat by taking food to my hotel room, chewing slowly and gingerly, thinned as much as possible, while lying on my back.

After I returned home, the pain got worse. It would sometimes hit when I was interviewing medical students or lecturing to residents, and I'd have to leave the room. Sometimes blinking my right eye brought it on. Once it came on out of the blue; I had no clue why, and it lasted for what seemed like an eternal five minutes. I switched neurologists and quadrupled my medications. The pain was controlled, but the cost considerable. I once forgot the name of my grandchild. I needed naps in my office. I stopped biking because I was afraid of losing my balance. Viagra-unresponsive erectile dysfunction plagued me. I cried at the least emotional insight.

I scoured everything I could find about my condition, not in the same intellectual manner that I would for an unusual disease a patient of mine might have, but as a prisoner that must study a secret journal about maps of underground tunnels to freedom. One option for treatment of the faulty trigeminal nerve is to jab a long needle up through the face and through a hole in the skull to inject glycerol around the nerve. Another option is to radiate the nerve with gamma rays. The most invasive treatment is neurosurgery. Through a quarter-sized hole behind the ear, the surgeon delicately pulls aside a chunk of cerebellum, picks a dicey route around the seventh and eighth cranial nerves, finds the trigeminal nerve using an operating microscope, and puts a Teflon pledget between the artery (whose pulsations irritate the trigeminal nerve) and the nerve.

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I chose the surgery, "microvascular decompression," as it's called. Although surgery was riskier than the other options, it was least likely to result in anesthesia dolorosa, a very painful condition resulting from permanent damage to the trigeminal nerve for which there is no effective treatment. I remember waking in the operating room, asking if the compressing artery had been found. Reassured that it had, I fell asleep. Postoperatively, I was quickly weaned off the high doses of medicines. I have had no recurrence since the surgery.

Hemingway, a famous patron of Les Deux Magots, had an idea that has come to be known as the iceberg theory, that seven-eighths of the reality of any given event lies beneath the surface. For me, the scientific description of the cause of trigeminal neuralgia and the scholarly attempt to describe the pain was the top of the iceberg, the part that could be written down. But there was much more to the condition than pain, and that was the more sinister seven-eighths. With the surgery behind me, I remained debilitated by anxiety that the pain would return. Even now, 5 years later, if I wake at night with a twinge of discomfort in my right eye, I'll lie awake worrying that the tic has returned. I weigh in my mind what treatment option I would choose if the pain returns: another brain operation (wouldn't that be risky, going through the scars of the previous cutting?) or the "zap" (too much radiation might cause terrible facial pain that medicines couldn't stop; not enough would leave me with pain) or the needle (hope the hand that wields it is steady, doesn't hit the carotid artery). To my colleagues, I probably seem back to my usual self; they don't know I took Paxil for more than a year after the surgery.

Some good has come from all this suffering. I am now more aware of how pain dominates my patients' lives and drives their decisions. In my cardiology world, I focus much more on trying to prevent heart attacks and sudden cardiac death than managing the actual symptoms my patients live with. As a patient, pain and the anticipation of pain were more pressing concerns than the risks cited for my operation: death, stroke, a chronic leak of cerebrospinal fluid, and permanent hearing loss. With my patients, I now realize that there may be times when these concerns trump even the fear of dying. For me, what was once head knowledge is now heart knowledge.

Pain also affects autonomy. Although I had scientific training and easy access to the latest literature on trigeminal neuralgia, I had trouble weighing the risks and benefits of each treatment option. At first, I was in too much pain. Then, when the medicines dampened the pain, I was too blunted cognitively to make rational personal decisions. I sometimes thought my doctors assumed I had the scientific insight of a neurologist or that they wanted to be careful not to insult my knowledge as a colleague. They didn't seem to understand that what I wanted was a recommendation: zap, or

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needle, or cut. *Of course* I could choose what treatment I wanted, but the basis for making that decision seemed flimsy. The entire experience made me think more about how I recommend treatment to my patients. I am less swayed by what I think they know. A fellow cardiologist as a patient may require as thorough an explanation of his condition as the chef. I also empathize with a patient who says he's anxious, and I accept at face value reasons for anxiety that I once belittled.

I sometimes wonder if the etiology of trigeminal neuralgia is a metaphor for life. Tic douloureux is thought to be caused by an artery lying too close to the trigeminal nerve and hammering away for long enough that it damages the myelin sheath of that nerve. When the nerve receives the sensation of chewing or the touch of a kiss, those signals mutate into severe pain. So it is with life, perhaps. The pressures and stresses—little and big—pound away, to the point our nerves fire our brains with physical pain or mental anguish. Perhaps Hemingway had a kind of emotional trigeminal neuralgia. He took his own life, as did some people suffering from trigeminal neuralgia, before effective treatments were available.

Now and then I imagine myself sitting at an outside table at Les Deux Magots savoring a crème brulee after the main entrée, eating and drinking with gusto and with no anxiety that pain will hit suddenly. Up walks Hemingway and sits down, orders an absinthe. We talk about icebergs—the part you can see and the part you can't.

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