

Health Affairs

At the Intersection of Health, Health Care and Policy

Cite this article as:
Janice Lynch Schuster
Down The Rabbit Hole: A Chronic Pain Sufferer Navigates The Maze Of Opioid Use
Health Affairs, 33, no.7 (2014):1294-1297

doi: 10.1377/hlthaff.2013.1013

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NARRATIVE MATTERS



DOI: 10.1377/HLTHAFF.2013.1013

Down The Rabbit Hole: A Chronic Pain Sufferer Navigates The Maze Of Opioid Use

A woman living with chronic pain tries to manage her condition while maneuvering through the maze of opioid medications.

BY JANICE LYNCH SCHUSTER

I have never been one to visit my primary care physician regularly. For many years I kept healthy, with periodic visits to local urgent care facilities for my minor health care woes. By fifty, though, I had accumulated my share of problems and had found my way to specialists who could help me along: an orthopedist for my arthritic knees; an ear,

nose, and throat doctor for my poor hearing; and a dermatologist for occasional instances of squamous cell cancer. Even so, I considered myself to be among the mostly well.

But in the winter of 2013 I began to experience a terrible and persistent pain in my tongue. It alternately throbbed and burned, and it often hurt to eat or speak. The flesh looked red and irritat-

ed, and no amount of Orajel or Sensodyne relieved it. I paid a rare visit to my doctor, who suggested I see my dentist, who, in turn, referred me to an oral surgeon. He thought the problem was a result of my being “tongue-tied,” a typically harmless condition in which the little piece of tissue under the tongue, called the frenulum, is too short, limiting the tongue’s range of motion. It seems I have always had this, but had never noticed because it hadn’t affected my ability to eat or speak. Now things had changed. The doctor recommended I undergo a frenectomy, a procedure to remove the frenulum and relieve tension on the tongue.

“Just a snip,” he promised.

It sounded trivial, and I was eager to be done with it. Although I make a living writing about health care, I didn’t even bother to Google the procedure. It never occurred to me that “a snip” might entail some risks. I trusted the oral surgeon. His medical and dental degrees gave me confidence in his skills and knowledge.

And so in March 2013, a day before I was due to travel to Chicago for a week-long business conference, I went in for the frenectomy. I sat back in the dental chair and, as I have always done, closed my eyes lest I catch sight of what I imagined must be an exceedingly long novocaine needle.

My calming thoughts ended abruptly with the first novocaine shot, dead center in the floor of my mouth. I nearly fainted with pain. By the second shot, I was in tears, grasping the surgical aide’s hand in distress.

The procedure began and although my mouth was numb, the slicing sounds of the cut made me anxious. It felt as if the oral surgeon was, in fact, slicing my entire tongue away. When I thought the ordeal was surely over, it proved to be only halfway there, as he still had to sew up the wound—a task that required several stitches to the underside of the tongue itself. The oral surgeon and I were both surprised at how painful the process had been for me. Even when he was done, I continued to cry.

He prescribed routine follow-up care:

salt water rinses and an antibiotic. And Percocet, a fairly common painkiller, for when the numbness wore off.

Down The Rabbit Hole

I had optimistically expected to be back to normal in time for my flight to Chicago the next morning. But that evening, when the novocaine wore off, the intense pain returned. I took the Percocet. When that didn't help, I added aspirin and then dutifully swished with warm salt water, all to no avail. I called the oral surgeon to explain that my mouth was killing me. He prescribed Norco, a slightly stronger medication than Percocet, and I picked it up from the pharmacy. Norco was a bad match. It left me itching from head to toe. On my way to the airport the next day, I stopped at the CVS to get yet another prescription painkiller, but this one made me vomit. I boarded my flight anyway, certain that I'd feel better at any moment.

But over the next few days, the pain worsened. It was a combination of sensations, alternating between the feeling that I had scalded my tongue, bitten down on it hard, or pierced it with something sharp. No matter what I did, it hurt. In the ensuing days, my oral surgeon called in a variety of medications, none of which helped. I managed to get through my talk at the conference by sucking on ice chips.

Later the following week, still in terrible pain, I went back to the oral surgeon, whose colleague suspected that an undissolved stitch was triggering my pain, and removed it. That didn't help, either.

The Root Of The Problem: Nerve Damage

Though I did not know it then, my misery had just begun. In the ensuing months I would become one of the estimated 100 million American adults who live with chronic pain. In my case, the pain was eventually characterized as neuropathy: pain caused by nerve damage. Although the course of neuropathic pain varies by source and mechanism, and treatments range from sophisticated surgical interventions to massage, the outcome is often the same: The chronic pain itself becomes an affliction to be treated, in addition to whatever



injury or condition caused it in the first place.

Invisible pain is hard for others to understand. If I'd broken my leg, for instance, I could have propped up my foot or limped around on crutches. Neuropathic pain is far less evident. As far as oral pain goes, there is little to be done. And little, really, can be done, to let others know you suffer from mouth pain. Yet such pain is constant: You cannot simply put your tongue up or not use it for a while.

Severe chronic pain can make life itself a test of endurance and will. People who suffer from chronic pain—and who turn to physicians to heal it—often discover that some clinicians view us with skepticism or disbelief. At times we are reduced to begging for help. Even then, many of us are dismissed as drug-seeking addicts.

For several weeks after my return from Chicago, I was in nearly daily contact with the oral surgeon, who said again and again that he had not heard of a patient experiencing such pain as a consequence of a lingual frenectomy. And yet when I began to Google relevant terms—tongue damage, tongue pain, frenectomy, and so on—I found repeated references to the kinds of damage that can occur. Eventually, I joined a closed group on Facebook, where I met a few hundred other people who were suffering from mouth pain, triggered for the most part by routine oral surgeries.

I had now entered the maze of pain management, where getting effective medication that I could tolerate, and an adequate supply, itself became a con-

stant struggle.

At one point, when my oral surgeon was away for a week, his assistant refused to call in a refill of pain medication. This was in 2013, before newer regulations were enacted that would have prohibited such a prescription from being called in. According to the surgeon's electronic records, I already had been prescribed a veritable pharmacy of pain meds and had received more than 100 pills over the course of the month. The electronic record did not include my bad reactions to several of these, nor that I could not take them as prescribed.

The surgeon's assistant finally agreed to order a refill once I had returned any unused medications to the office or to the pharmacy. Unfortunately, it turned out that the office could not accept my unused pills, nor could CVS, which had no collection mechanism in place. The pharmacist did, finally, call the doctor to verify that I had at least tried to return the pills. Finally, the new prescription was filled.

More than a month after my surgery, the pain had become even worse. Some days I could hardly get out of bed; I was so incapacitated by pain and its companion, despair. The oral surgeon called on his colleagues and, eventually, I wound up at the University of Maryland School of Dentistry, seen by an oral surgeon who specializes in oral and maxillofacial surgery.

He injected two points in my jaw with novocaine. The relentless pain subsided almost immediately—an indication that, in fact, the pain was originating somewhere in the tongue itself, and not in my brain.

The surgeon told me he suspected that an errant stitch had wrapped around a nerve in my tongue. Although exploratory surgery was possible, he said, it was unwise, as the nerves were so small and the process so likely to cause more damage. Left on their own, he continued, the nerves might heal in twelve or eighteen months. He suggested I find a neurologist to explore appropriate treatments.

Eventually, I found one who could actually see me, but I was dismayed when she handed me a few samples of antidepressants and antiseizure drugs, both indicated for the treatment of neuropathic pain but both likely to cause troublesome side effects. It was up to me to

Policy Checklist

The issue: Chronic pain and its management are a major public health problem, exacting an enormous physical, emotional, and financial toll on patients. Complicating the matter is the widespread opioid abuse epidemic, which challenges law enforcement and threatens patient access. Policies that alleviate the stigma on patients with chronic pain, and strategies for understanding the mechanisms of pain and how to manage it, are essential.

Resources:

American Academy of Pain Management, <http://www.aapainmanage.org/>

American Society of Anesthesiologists, <https://www.asahq.org/>

Pain and Policy Studies Group, <http://www.painpolicy.wisc.edu/>

Related reading:

Federation of State Medical Boards. "Model Policy on the Use of Opioid Analgesics in the Treatment of Chronic Pain." Washington (DC): Federation of State Medical Boards; 2013 Jul [cited 2014 20 May]. Available from: http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/FSMB_pain_policy_july2013.pdf

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select which I'd prefer—a choice that worried me, since neither seemed a good solution. I saw another neurologist, who suggested a trial of Cymbalta, an antidepressant that might lift my mood and relieve my pain. It could take six weeks to kick in.

And so, week after week, I continued to see my own oral surgeon, who would dutifully examine my tongue and lament my ongoing need for painkillers. I had told him about my lifelong problems with depression and my ongoing treatment for it, and he was concerned that I might be predisposed to addiction. I assured him that the opioids had no salutary effect on me—I certainly didn't feel euphoric, as some apparently do—other than to take the edge off the pain long enough for me to get through each day.

Risks And Benefits Of Opioids

Like most US clinicians, my oral surgeon and other health care providers have reason to be concerned about the safety of long-term use of opioid analgesics, such as Percocet and OxyContin.

First touted as a godsend for the management of severe and chronic pain when the Food and Drug Administration (FDA) approved it in 1995, OxyContin has since become a widely abused medication. Contrary to claims by leading advocates for better pain management, OxyContin can, in fact, lead to addiction. It undoubtedly leads to physical dependence, and those who take it routinely cannot simply quit.

In the mid-1990s Russell Portenoy emerged as a champion of opioids for use in managing moderate-to-severe pain for a range of medical conditions. Until then, they had been used almost exclusively for advanced cancer. Portenoy pointed to research that, he claimed, indicated that patients would not abuse opioids but would limit their use to managing pain. Today's opioid epidemic tells a different story.

Since the introduction of these drugs, there is no denying that millions of suffering Americans now have more effective options for pain management. But the cost of this improvement has been the emergence of a widespread public

health crisis of addiction and fatal overdoses. Figures from the Centers for Disease Control and Prevention (CDC) indicate that in 2010 some twelve million Americans were using prescription painkillers without a prescription. The CDC reported that in 2008 painkillers played a role in as many as 15,000 overdose deaths—more than heroin and cocaine combined. In addition, as regulations have been tightened to control OxyContin and other prescription painkillers, more and more people have resorted to heroin and other illicit drugs.

In the fall of 2013 the FDA took back-to-back actions that reflect our confused national response to opioids. On October 24, 2013, the director of the FDA's Center for Drug Evaluation and Research announced that the agency would recommend tightening regulations that govern how hydrocodone is prescribed, making it harder for people to acquire it. The very next day the FDA approved a new extended-release opioid, Zohydro ER—despite recommendations by its own technical advisory committee that the drug presented such significant risk of abuse that it should not be approved.

In the realm of chronic pain, such competing and conflicting aims are the norm. Pain patients like me often feel trapped between the clinical need to treat and manage pain and the social imperative to restrict access to such drugs and promote public safety.

Widespread access to opioids for every single ache and pain is clearly not the answer. In a 2011 report the Institute of Medicine (IOM) calls pain management a "national challenge" that will require "cultural transformation" in terms of researching pain to understand its scope, particularly in terms of its underdiagnosis and undertreatment. Among the IOM's recommendations are that providers and patients alike receive more education on the ways in which biology and psychosocial factors affect the experience of pain. For me, understanding and accepting those factors has not done much to alleviate the day-to-day experience of pain.

The IOM also recommends that providers "tailor care to each person's experience" and promote self-management of pain, which could include strategies such as keeping a pain journal; monitoring pain triggers; and learning coping

strategies, such as meditation and yoga. Experts also recommend that primary care doctors coordinate care and treatment with pain specialists. When my primary care doctor dismissed my symptoms, I wound up trying to organize and coordinate my care as I journeyed among my oral surgeon, neurologists, pain experts, primary care, and psychiatry. It was more complicated than I could manage. During a two-week period last summer, I wound up in the emergency department four or five times because of adverse reactions to several medications.

One of these visits occurred early in the course of my ordeal, after I had a severe reaction to Cymbalta. I had not been warned that it could make me photosensitive, and, as a fair-skinned person, I was at even greater risk for this. When I erupted in giant welts, I called my dermatologist, perplexed by what was happening. As I sat in her examining room, I fainted, and she called 911.

It was terrifying to leave the dermatologist's office on a gurney. I remember the cool rain that fell and how the EMTs shielded my face from it. I remember their urgency and their calm as they got an IV going and tried to get my vital signs back to normal.

At the hospital, the ED doctor stood near my head, patting my arm as he looked at my chart, then saying, "I see that you are in chronic pain."

"I am," I said, crying.

"And are you depressed?" he asked. "Because I have never met a pain patient

Pain sufferers like me swim against two tides: the pain itself and the experience of seeking treatment for the pain.

who was not."

To be sure, the complex interplay of mind and body affects how one experiences pain, as well as how it is treated. No doubt, clinical depression simply makes one feel worse and makes it even more difficult to try alternative and complementary pain treatments. In my case, I had little energy for anything.

Waiting For Better Days

I have since explored alternative therapies: herbal remedies, guided meditation, journaling, exercise. These lift my spirits but do not reduce the near-constant presence of pain.

There is still a chance that my pain will vanish—for instance, if the nerves do heal in the next few months. If they don't, then I have a lifetime ahead of me to adjust to this situation.

I do my best not to let pain run my life. Some days are better than others. I try to keep a sense of humor. Some days, though, are hard to endure, and I chide myself to be grateful that I am still standing.

Had I spent a moment or two researching the risks of the frenectomy, would I

have avoided this experience? Perhaps. But now I have few choices but to live through it.

I am weary of this experience. When I am not overwhelmed by pain, or depressed by it, I am furious at the attitudes I encounter, especially among physicians and pharmacists. It has been stigmatizing and humiliating. The cost to my productivity has been steep, and the toll on my family has been high. I have spent countless hours in doctor's offices, and even more hours in bed. Some people find meaning in suffering, but I find none.

I read science news closely, hoping that some new non-narcotic pain treatment will yield better and more effective treatments that do not include the risk of abuse and addiction. In the meantime, though, pain sufferers like me swim against two tides: the pain itself and the experience of seeking treatment for the pain. Pain represents a complex nexus of mind and matter. Surely, for all our yearning to understand both, we can find better ways to ease the suffering and devise treatments and strategies that do more good than harm and that do not shame and stigmatize those who suffer. ■

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