

Pain Management: Assembling a Tool Kit, Building a Life

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The pain was becoming bolder. Not content with my hands and wrists, it invaded my elbows, annexed my back, and sent raids down my legs. It was conniving and multifaceted: dull aches, stabbing and throbbing sensations, and widespread tenderness. I fought back with medication, then physical therapy, chiropractic adjustments, stretching, elimination diets, and massage. But the pain grew stronger, while I grew weaker, anxious, and afraid. I was 20 years old (a junior in college) when the pain began, and there was no explanatory pathology. I saw several physicians, whose localized diagnoses (tendinitis, twisted pelvis) could not explain the pain's origin or why it was spreading. The relentless siege was wearing me down. I despaired for my future.

Thirteen months in, my father connected me with a chronic pain expert, and I won a victory: my pain's name was fibromyalgia. But this victory felt Pyrrhic. At 21, I had a lifelong condition and my health was terrible. Constant worry and distraction had molded my life, building habits around suffering and pain avoidance. But now that I had named my enemy, I hoped to gain some measure of control.

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My physician helped educate me and coordinate my care. Even now, I vividly remember one statement from our conversations: "I could refer you for surgery, which would cost thousands of dollars but probably wouldn't help anything. In fact, it would likely make things worse." Pain that could not be treated by advanced medical technology? This sentence shattered my understanding of pain. The best way forward, my physician continued, was to use appropriate medication for the worst symptoms while building nonpharmacological pain management tools. He directed me toward educational resources that explained the science of fibromyalgia science and evidence-based management strategies. I now had a framework to understand fibromyalgia and needed to figure out how to proceed.

Although hard to see at the time, I was fortunate in many respects. My physician had diagnosed me relatively quickly when it often takes several years.¹ I had financial support from my family to figure out management strategies. As a result, I had avoided unnecessary and invasive procedures that could have severely harmed my well-being and turned me into the pain patient that physicians least want to see: a person chasing medica-

tion and quick fixes, who appears too enculturated by passive care to take an active role in managing pain.²

Despite these advantages, building my tool kit was a slog, developed through trial and error. I was prescribed cyclobenzaprine, which helped with sleep and dulled pain but made me feel loopy and disconnected from my body. However, the relief was enough to help me start exercising. Without any options covered by insurance, I tried yoga on a friend's recommendation. I immediately took to yoga but often over-exercised and needed days to recover. It was also off-putting for my teacher to tell me that "I shouldn't take medication and that "all I needed was yoga." Right. But yoga was helpful, and I slowly gained strength and flexibility.

Between my concerns about adverse effects and increasing dependence on cyclobenzaprine for sleep, I tried medical cannabis. It helped, and I dramatically cut my use of cyclobenzaprine. My switch to cannabis brought its own challenges, beyond being federally illegal. Dosing guidelines were not—and still are not—available. Furthermore, using products in the same way for more than a couple months made me anxious and restless, necessitating that

I change varieties and administration routes to maintain useful effects.

Life moved on. I finished college and, 7 months after my diagnosis, found employment testing water filters. My symptoms were better managed, though I still suffered from daily pain without much awareness of what triggered it. I started noticing links between pain and my lifestyle. Although I had begun eating better and continued exercising, social habits (sports, drinking alcohol, video games) were harder to disentangle, for these activities were built into my friendships. I feared stigma, so I remained terse and opaque, putting on a strong face while bottling up my emotions. However, life was improving. I was managing pain well enough with my tools, and I developed an interest in public health through my job, which led to my graduate work in water quality.

This tool kit sustained me for a few years. Unfortunately, midway through graduate school, I pulled a muscle in my right thigh, initiating a lengthy symptom flare. I had terrible back pain that was exacerbated by computer and laboratory work (essential parts of doctoral research) and by a severe expectation mismatch. Had I not dealt with this already? Why weren't my tools working? I felt anxious and depressed and slept poorly, despite adding daily cyclobenzaprine back to my medication regimen. I felt trapped.

During this time, I started working with a physical therapist. She shared how tightness in connective tissue

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and fascia could contribute to rigidity in associated muscle groups, causing tension to spiral throughout the body. I felt stupid: of course everything in the body was connected! My narrow focus on painful spots ignored important surrounding tissues. Soon after, I found a massage therapist (services not covered by insurance) whose anatomical mastery complemented the physical therapy. I also obtained ergonomic funding from my university for standing desks. Despite the added utility of these tools, my suffering continued. I felt bitter and despondent.

After a challenging appointment, my physical therapist suggested that dietary sensitivities may contribute to pain. I met with a dietitian (covered by insurance), and started recording what I ate and drank, daily pain, sleep, and anxiety. My record keeping captured minor sensitivities to alcohol and sugar but identified an unexpected connection: my pain correlated strongly with anxiety.

In my search to learn more, I discovered that cognitive behavioral therapy (CBT) was effective for chronic pain control.³ My well-connected physician helped me bypass the usual lengthy bureaucracy in mental health care, and I quickly started seeing a psychologist who specialized in pain-related CBT (covered by insurance). During our sessions, my psychologist noted how I often worried and ruminated on pain and its effects. She provided new, precise language: I was catastrophizing,⁴ both in the present (this pain will never stop!) and about the future (I can't plan anything if I'm just going to be miserable!). My psychologist suggested mindfulness meditation and progressive muscle relaxation to help break these cycles.

I started conceptualizing my mind as a muscle, which I could exercise to seek peace or (as I had been) to promote anguish. This struck me as simple yet profound—a truth so self-evident that I had overlooked it. My new perspective helped unbundle my emotions, which I leveraged into being more open about fibromyalgia. I was particularly gratified by how this openness strengthened my relationships with friends and family, who gave me outstanding support in return.

This openness also brought me back to yoga. I noticed how peaceful my mind was after a particularly good practice, and decided to pursue yoga teacher training. This training strengthened my body, and followed in CBT's footsteps by uncovering thought patterns and giving me a better understanding of pain vs suffering. I began working to conceptualize daily fibromyalgia pain as background, manageable sensations—a stark contrast to suffering, which prevents me from doing things that help me find meaning.

These changes inspired me to change career paths.⁵ After finishing my PhD, I started a fellowship in chronic pain research where I continue my self-exploration through learning pain science. In this capacity, my tool kit continues to evolve. I have added new tools (acupuncture) and modulated my use of others—although not always because of ineffectiveness. For instance, I stopped taking medical cannabinoids—a hazard of working at a federally funded university.

On the research side, I have read meta-analyses of clinical trials on yoga, mindfulness, and CBT. Alarming, though known to be effective for pain management,^{6,7} these tools are typically not covered by insurance (yoga, mindfulness) or are only spottily available (CBT). Furthermore, studies typically examine single approaches rather than management programs. Although this makes for cleaner scientific studies, it is inconsistent with my lived experience. This disconnection of pain science from reality, coupled with the seemingly banal normalcy of widespread pain being viewed as multiple unconnected diagnoses, shocked me. Without a unifying framework, it is difficult to use such tools judiciously and sensibly. Like instruments in an orchestra, the synchrony they create together is more beautiful and complete than the sum of the parts.

Perhaps most poignantly, I have gained new appreciation for my incredible luck. My physician took me seriously, understood fibromyalgia, and connected me with excellent specialists. My insurance covered many important therapies, and I could afford treatments not covered by insurance. My privileged status has allowed me to channel my experiences into my career, infusing my day-to-day existence with deep purpose. Regrettably, many people with fibromyalgia—or other chronic pain conditions—don't have this experience, privilege, or access. Although institutions like the Veterans Affairs have proposed plans that support broad pain management approaches,⁸ implementation remains a distant goal for the majority of Americans.

Pain is a universal human experience—a reminder of the bonds we share regardless of where we currently stand. As a person with fibromyalgia, I'm demoralized by the state of pain medicine, not only because of poor outcomes and downstream effects (eg, the opioid crisis) but also because of what is signaled when medicine often displays such misunderstanding toward pain and inability to alleviate the resulting suffering. Yet when I consider the many tools that can help people with chronic pain live meaningful lives, I can't help but be optimistic. There are innumerable paths forward that can reunite pain medicine with compassion—a process to which I hope to contribute in my own small way.

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1. Choy E, Perrot S, Leon T, et al. A patient survey of the impact of fibromyalgia and the journey to diagnosis. *BMC Health Serv Res*. 2010;10:102. doi:10.1186/1472-6963-10-102

2. Chen JH. The patient you least want to see. *JAMA*. 2016;315(16):1701-1702. doi:10.1001/jama.2016.0221

3. Bernardy K, Klose P, Welsch P, Häuser W. Efficacy, acceptability and safety of cognitive behavioural therapies in fibromyalgia syndrome—a systematic review and meta-analysis of randomized controlled trials. *Eur J Pain*. 2018;22(2):242-260. doi:10.1002/ejp.1121

4. Sullivan M, Bishop S, Pivik J. The Pain Catastrophizing Scale: development and validation. *Psychol Assess*. 1995;7:524-532. doi:10.1037/1040-3590.7.4.524

5. Boehnke KF. When personal becomes professional. *Science*. 2017;357(6352):726. doi:10.1126/science.357.6352.726

6. Buchbinder R, van Tulder M, Öberg B, et al; Lancet Low Back Pain Series Working Group. Low back pain: a call for action. *Lancet*. 2018;391(10137):2384-2388. doi:10.1016/S0140-6736(18)30488-4

7. Hilton L, Hempel S, Ewing BA, et al. Mindfulness meditation for chronic pain: systematic review and meta-analysis. *Ann Behav Med*. 2017;51(2):199-213. doi:10.1007/s12160-016-9844-2

8. Kligler B, Bair MJ, Banerjee R, et al. Clinical policy recommendations from the VHA state-of-the-art conference on non-pharmacological approaches to chronic musculoskeletal pain. *J Gen Intern Med*. 2018;33(suppl 1):16-23. doi:10.1007/s11606-018-4323-z