

When Chronic Pain Becomes Who You Are

For years, mysterious pain took over my life and drove me to similar people online. I soon learned my mistake.

[Isobel Whitcomb](#) June 05, 2022 7:00 PM

It was in an Instagram post that I saw myself for the first time. The black-and-white photo showed a woman sitting straight-backed in a chair, staring directly into the camera lens with a commanding expression. I'd never met her before; her image showed up in my Discover feed. In the caption, she described a run-of-the-mill sprained ankle gone awry. Instead of healing with time, it progressed to send tendrils of pain through her legs and arms to the point where she struggled to walk. The algorithm knew I'd recognize her.

I'd long kept quiet about my own pain, which began in high school with a sharp pop in my hamstring during a routine run. At the time, I was an avid track athlete; running was the core of my identity and my only distraction from loneliness and academic pressure. Days of rest turned into weeks and months, as the pain gradually crept into my back,

disappearing only to bounce to a different part of my body: my ankles, neck, arms, hands. No doctor could identify what was happening to cause the pain. I'd blush when my teammates asked why I was missing meets. I knew that if I described what I was going through, I would sound like I was making it all up. Part of me wondered whether I was.

I was in college when I discovered that my illness was classifiable, if still hard to pin down medically. And the hashtags and comments below that black-and-white photo pointed to a world of people experiencing "chronic pain," a phrase I didn't yet use to describe my experience. They called themselves "spoonies," referring to the care they had to bring to their limited "spoonfuls" of energy each day. On [Reddit](#), more than 66,000 people vent about medical treatments gone wrong, and days where they can't get out of bed. On Etsy, you can buy shirts that proclaim "I'm here, I'm queer, my joint pain is severe" and "spoons loading."

These people were like me, I thought. I began to hover at the periphery of this world. I lurked on their social media accounts and read their blog posts. I felt a vicarious fascination with their ability to not just discuss their pain, but proclaim it as part of who they are. Most of all, the existence of these communities proved that my experience was, indeed, real.

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I began to try on their language for size, but privately, the way you'd rehearse a conversation in the bathroom mirror: "spoonie," "chronic pain," "disability." It felt like a costume, but it fit. By graduate school, wearing braces on my wrists and walking with a limp, I began using the language out loud for the first time in my life: when introducing myself to others, in class discussions, as I narrated my own days in my head. It felt core to my identity, as fundamental to me as the atmosphere, or my gender. The sky is blue; I exist in a body that hurts.

Forging an identity around one's pain is a natural response to an isolating and often invisible experience. Internally, it is a way to make sense of what is happening in one's body; externally, a way to push back on the stigma of the condition, to ask for (and receive) accommodations and help. But as time passed, my own new identity began to take on a life I started to question—a new way to see myself that threatened to turn into an entire mode of existing. And as I learned more about my condition and how experts approach treatment, my nagging fears began to feel

warranted. For many people like me, it turned out, moving away from pain as an identity isn't the result of recovery—it's actually the treatment.

For decades, psychologists and pain researchers have recognized the role of thoughts and emotions in pain. Pain begins with a signal that nerves send to the brain. But what we actually experience is the brain's interpretation of that signal—and the brain can be an unreliable narrator. Pain's role is to tell us when we're in danger, said Alan Gordon, the director of the Pain Psychology Center in Los Angeles. "If you put your hand on a hot stove, the pain is letting you know you need to move your hands so you don't cause more damage," Gordon said. "But sometimes the brain can make a mistake, and interpret danger where there is none."

Acute pain—the kind that alerts you to the hot stove—is necessary to survival. Chronic pain, which lasts for [longer than three to six months](#), is less useful. In some cases, it signals a condition like cancer. But chronic pain often continues long after the danger has passed, like a smoke detector that won't shut off—a smoke detector that sets off a cascade of other smoke detectors, beeping wildly.

That's what happened to me. My pain started in my leg. Then, over the course of a decade, pain crept from my leg to my back, up to my shoulder, into my arm and wrist, and down into my feet. I dialed back the activities I loved most,

like dancing and running, and stayed home from work. I spent hours icing my ankles and wrists. When I did get up, my brain screamed danger, and my pain flared up all the [more](#).

I was stuck in a spiral: Pain told me to avoid activity, which told my brain that pain was dangerous, which ramped up the pain. It wasn't until a doctor explained to me how my [pain lived in my brain](#)—and couldn't actually hurt me—that I started to get better. He was not simply asking me to “get over it,” as many people like me can experience; this doctor examined me and set me up with resources on how to understand my pain and ease out of it. With each jog down the block, I became less afraid of the ache in my hips and ankles—and in response, the pain faded into the background.

My story wasn't unique. Numerous [case studies](#) in [medical literature](#) document patients who experienced total or near-total recovery after pain neuroscience education, or PNE. However, for most people, those improvements are modest; in some, it doesn't work at all. In one study, people who received PNE experienced a 10 percent improvement in pain levels. In another, participants saw a substantial [decrease in anxiety](#) about pain, but not pain itself.

The goal of PNE is to help pump the breaks on pain's vicious cycle, or at least soften some of the mental health effects.

Part of that process involved seeing the pain in a more neutral light. I learned to start replacing the word “pain” with neutral descriptors like “sensation” and “discomfort” when my thoughts lingered on my condition. Mindfulness exercises taught me to visualize my pain as a person or a monster, screaming for attention, whom I needed to firmly, gently reassure—not take directions from. The sensations that had ruled my life weren’t *part* of me.

Some research suggests that when pain becomes a part of one’s identity, it only accelerates the feedback loop between reactions and sensations, said Henrik Marschall, a Ph.D. student in psychology at Aarhus University in Denmark.

Marschall researches the psychology of people with endometriosis, an often-excruciating chronic condition in which cells that normally line the uterus grow in other parts of the body. His recent work delved into the “narrative identities” patients formed around the illness—that is, the way they view the arc of their life, the stuff that counts as important exposition, rising action, climax, and resolution. He and a group of colleagues recruited 120 participants and instructed them to first write the stories of their endometriosis, then complete a questionnaire that evaluated the centrality of that narrative to their sense of self.

The responses varied widely. Marschall's research, the results of which were published in 2021 in the [Journal of Research in Personality](#), showed that some people saw pain as a major part of who they were; for others, it was a minor detail. Marschall was particularly fascinated by one result: Across the board, participants who rated pain as more central to their identities also had more symptoms. Marschall and his colleagues weren't the first scientists to observe this phenomenon. Two previous studies, one on [osteoarthritis](#) and one on [chronic pain](#) with no known cause, found similar results: The extent to which people identify with pain is related to pain itself.

There are a few possible explanations for this connection between identity and pain. It's possible that more severe pain might interfere more with one's day-to-day life, making it hard *not* to incorporate into one's identity, Marschall said. But the other evidence around pain and thoughts—the fact that they can get locked together in a doom spiral—indicates it's likely more complicated than that. When I saw myself as “Isobel in Pain,” I expected myself to be in pain, which in turn helped to keep me in pain.

The connection between identity and pain extends beyond how we see ourselves; it's also enforced by our social networks. This can mean that something as simple as joining a support group might be counterproductive. A 2005

study in the [Journal of Rheumatology](#) compared 32 active members of fibromyalgia support groups with 135 people who had dropped out, primarily because of reasons unrelated to their symptoms, such as inconvenient location or lack of time. While most members felt that the support group validated their experiences and helped them feel understood, the study authors found that active members of the support group actually had more severe symptoms and recovered less over time compared with dropouts.

This might be because discussion in these support groups can trend toward the negative. "It was never a place where you felt hope," said Callie Kunz, a health coach whose fibromyalgia forced her to retire from a career as a teacher. Kunz was once an active member of several online fibromyalgia support groups, where members united around shared symptoms and grief over the loss of their old lives. "These places are not good for chronic pain patients to be," Kunz said. "They promote fear and hopelessness, which is exactly what you don't want in recovery." As she participated in these groups, pain was becoming the lens through which Kunz viewed the world.

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In some instances, people who share hopeful anecdotes or plans to start a new treatment are talked down or discouraged by other members of the online community. While conducting research on online groups for people with chronic pain, Hallie Tankha, a doctoral student researching pain psychology at Wayne State University, remembers one incident in particular: One member of a chronic pain Facebook group had left his bed for the first time in days and gone out to volunteer. When he shared how the experience had relieved some of his pain, other members of the group interpreted his anecdote as unsolicited advice and an indictment of their own inability to recover. "He got reamed," Tankha said.

This dynamic is familiar to Kunz. "People get very defensive," she said. It's a response she empathizes with. After all, people with chronic pain are constantly forced to explain their experience or try and prove that their pain is real, even in medical settings, where medical professionals frequently dismiss their experiences. (As I wrote, [my own revelation that pain lived "in my head"](#) was a very different experience: Rather than dismissing my pain, my doctor assured me that, despite its origins, my pain was very real, and helped guide me out.) To people still in the throes of

pain, other people's recovery successes can feel like criticism—that if they just tried harder, they'd feel better.

Still, these messages have the potential not only to undermine recovery efforts, but to actually set off the brain's "danger" signal, Gordon said. "Our brains are very sensitive to the tone of the messages we read," he said, "when we read something that is just kind of like someone unloading their frustration or going on this tirade, it's not going to make our brains feel safe."

Reading tirades about pain—or writing them—could end up exacerbating the pain participants feel in their own bodies. Scientists think that when we pay attention to pain, we strengthen the neural networks that process it, creating a well-worn path over time. When people with chronic pain take part in mildly painful tasks, like wearing a device that emits progressively intense pulses of heat, those who routinely pay more attention to their chronic pain experience those tasks as more painful, according to a 2013 study published in the [Annals of Behavioral Medicine](#). And multiple studies have found that patients recovering from acute injuries, like [back sprains](#) and [whiplash](#), are more likely to develop chronic pain if they record their symptoms in a daily pain diary.

What's more, participation in pain-focused networks can come at the expense of other support systems. David

Sherry, a pediatric rheumatologist and specialist in childhood pain, sees “way too many” of his patients abandoning their former social networks for online communities of other people in pain, children and adults alike. These newfound communities might validate their experiences of living in pain. But they might not celebrate days with lower pain in the same way that a parent would, or encourage kids to find new ways to participate in activities they find meaningful. Instead, Sherry said, he sees kids spend increasing amounts of time at home, bonding over one thing: pain. “Sometimes there’s an unwritten competition to see who’s worse,” Sherry said. Ultimately, support groups can “undermine people who want to get better.”

Kunz agreed. After learning about pain neuroscience, she abandoned her fibromyalgia groups.

When she was 30 years old, Elizabeth Reddell suffered a hockey injury that left pain shooting down her arm and, in turn, muscle weakness that worsened until she could no longer pick up a kitchen knife. A surgery to attempt to fix the problem only worsened it. Less than two years later, a car crash sent Reddell into emergency spine surgery—causing her pain to redouble. Reddell, who is now a graduate student at University of Arizona studying cellular and molecular medicine, came out of that second surgery

feeling like she'd spilled hydrochloric acid on her shoulder—a feeling with which she, as a student researcher who worked with chemicals, was familiar.

Reddell proceeded to be ping-ponged from doctor to doctor, becoming increasingly frustrated when medical providers, unable to find the source of her pain, told her there was nothing wrong and dismissed her as “a drug addict,” she told me. When Reddell found Reddit’s r/ChronicPain forum, she discovered others—particularly other women and people of color—who had similar experiences with the medical system. “You see it’s not just you,” Reddell said. “There’s that camaraderie. You’re not just being a wimp. You shouldn’t just deal with it.”

Though Reddell finds benefit in online community, she has learned to be choosy about these groups. She said that many can be “toxic”—especially those groups where people engage in virtual shouting matches over treatments or shun others for their recovery successes. When Reddell reads those threads, she notices her neck tense up and the burning in her shoulder intensify.

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It is possible, some experts agree, to foster camaraderie that doesn't reinforce pain as an identity or activate the brain's alarm system. Gordon has moderated online support groups where members engage in a positive way, where people cheer on one another's recovery wins. Kunz turned to Gordon's Facebook group, called "Tell Me About Your Pain." What sets it apart from the typical support group, Kunz said, is that all conversation focuses on pain neuroscience and recovery, and moderators work to keep it that way. Therapists and coaches, including Gordon himself, drop in to offer advice on specific therapy exercises, like meditations where patients focus on positive sensations or examine the fear they experience in response to pain. Moderators veto posts that include venting or contain triggering content, such as thoughts of self-harm. When she struggled or had a flare-up, Kunz would return to read recovery stories. She eventually became a moderator herself.

Gordon does worry that too much engagement even with positive networks could keep people focused on their pain in a way that's ultimately unhelpful. Not only do negative posts tell our brains "danger," but constantly paying attention to these groups keeps you preoccupied with pain. "For some people who become isolated in their symptoms,

it can be helpful, but for some people, they kind of go too far," Gordon said. "The irony was, I was running the page and I started finding I was checking it too much. I was like, I need to take a step back, because it's becoming too much of a preoccupation."

Sherry's beliefs about community around pain are more rigid: He asks his patients to stop talking about pain altogether, including in groups with one another. "We don't ask about pain. We don't want the parents to ask about pain," Sherry said. He encourages kids to leave behind their pain communities altogether. "It becomes part of your identity," Sherry said. "They need to move past that."

Sherry's approach, which also includes asking children to do hard exercise even while flooded with pain, has received [criticism](#) from members of the [chronic pain community](#). It certainly doesn't work for everyone. In a 2015 study published in the [Journal of Pediatrics](#), the mean pain score of 64 children with fibromyalgia who went through Sherry's program decreased from 66 out of 100 to 25 out of 100. But an average doesn't tell the story of every individual: Around one-quarter of patients finished the program with pain scores between 25 and 68. Roughly another quarter finished with scores higher than that. Still, a year after completing the program, nearly half of the participants had pain scores lower than 10—they were virtually pain-free.

Ignoring your pain can, surprisingly, be downright joyful. For more than 20 years, Susie Casserd, a life coach based in Washington state, lived with pain throughout her hands, feet, and back. Then in 2016, she discovered Direct Your Own Care, a pain recovery program based in mind-body principles founded by former spine surgeon David Hanscom. Casserd's first encounter with the program was a weekend-long retreat. "I was so excited," she said. "I could not wait to tell my story to people who would understand." But like Sherry's program, it took a strict approach against discussing pain. When Hanscom announced at the start of the program that there would be no mention of pain or treatments, Casserd was furious. Even so, it didn't take long for her to be won over. Hours later, she was dancing, moving, and singing that cups song from *Pitch Perfect* alongside her fellow attendees. For a moment, it was as though she was seeing herself and the world through new eyes. Though she still felt pain in that moment, she finally had some reprieve from a narrative she'd repeated to herself for decades. She didn't see her body as broken or view herself as an outsider to the rest of the world.

If you immerse yourself in the world of chronic pain for long enough, it can become hard to remove yourself. "You put on different glasses, and pretty much everything in your world is viewed through the lens of pain," said Rebecca Kilpatrick, a pain psychologist and the associate clinical director of the

pain rehabilitation program at the Medical University of South Carolina. That's where patients are when they enter the program. Kilpatrick teaches her patients what she calls the "ABC model" of pain and identity, in which Person A is the "before-pain person," Person B is the "pain person," and Person C is the "in-progress or goal person." Kilpatrick's role is to help patients move on from their identity of a "pain person" to the "progress person." Kilpatrick doesn't ask participants to stop talking about pain, but one goal of her program is to help them reduce their focus on it. Within the program, patients don't take part in open-ended support groups, which Kilpatrick says encourage rumination on pain. But they do take part in "therapy groups," based in cognitive behavioral therapy and acceptance and commitment therapy, evidence-based interventions for pain. Each session focuses on a specific topic, such as the relationship between pain and mood or mindfulness. While the program doesn't aim to control the amount participants discuss their pain outside the program, Kilpatrick does encourage some patients to keep those conversations limited to scheduled conversations with friends and family, and to make those conversations solution-oriented.

"Sometimes we encourage them to have a weekly check-in, like 'Hey, how was this week? How was your pain? How did you cope with it? What could we have done better?' "

Kilpatrick said.

The mindset shift can be a challenge even if you're no longer experiencing pain. People with chronic pain might spend years imagining a life where they're not defined by their pain, and when that moment finally arrives, it can feel surprisingly sad, Gordon said. He recently helped lead a clinical trial published in [JAMA Psychiatry](#) in which 33 patients received a psychological treatment called "pain reprocessing therapy," in which they learned about the neuroscience of pain and were encouraged to ease back into normal activity levels. Gordon described one woman who entered the trial after four decades of debilitating back pain. After four weeks, she was completely pain-free. She told Gordon how for 40 years she had imagined getting to that point. "I just thought that I'd be jumping for joy," she said. Instead, she was felled by grief, Gordon said: "She'd lost a huge part of her identity."

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When I began my pain neuroscience journey, it was difficult to accept that my pain was so manipulable. I grieved all my

experiences that were shaped by pain: my dashed dreams to run cross-country in college, the times I spent icing my ankles in bed rather than out with friends, the months I avoided writing entirely when it hurt to type or pick up a pen. That my pain was curable in such a simple way made the experience seem random, almost less real.

While pain neuroscience education hardly works for everyone, it worked for me startlingly fast—which made the transition all the more jarring. How was I supposed to explain that I was running every day, when a week earlier I had been unable to walk across Penn Station? I worried that the sudden transformation would make others believe I had faked my pain all along. When I did try to explain my recovery, I cited enough scientific studies to populate an academic review. It was hard for me to grasp that I was a rational person who had gone through a confusing and esoteric experience. I felt like a proselytizing religious convert.

In the end, I sought a new kind of social support, tuning into not just success stories from others who had recovered from chronic pain, but interviews with scientists, making recovery from pain a subject of my reporting. In that way, I have been writing a new narrative about my life, forging a new identity. It's one where pain takes a back seat: When I do experience flare-ups, I know they will pass. I'm a soccer

player, queer, writer, friend, and, oh, yeah, a person who once experienced pain.