

For Some Chronic Pain Patients, ‘Without Opioids, Life Would Be Torture’

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APSTOCK

As the nation begins responding to the epidemic of [overdoses and deaths](#) caused by opioids, some people with chronic pain who have relied on these powerful painkillers for years are finding them harder to get. A survey conducted by the Boston Globe and [Inspire](#), a health care social network of 200 online support groups with 800,000 members, found that [nearly two-thirds of respondents](#) reported that getting prescribed opioid medication had become more difficult in the past year.

STAT asked three Inspire members with [Ehlers-Danlos syndrome](#) — a painful condition that affects the connective tissues that support the skin, bones, blood vessels, and other organs and tissues — to talk about their experiences with opioids.

[Dianne Bourque](#): Pain control is a problem in rural areas

[Michael Bihovsky](#): Opioids give me quality of life

[Alison Moore](#): People who responsibly use opioids for chronic pain aren't addicts

Dianne Bourque: I lived with chronic pain for years. I was able to

make it through the day because my work as a surgical nurse kept me distracted. When not truly busy, though, the pain was impossible to ignore. By the time I got home to my family, I was spent. Nights were hard, as sleep was challenging. A colleague finally convinced me to see a pain management specialist. That visit changed my life. I don't think I would still be working — or maybe even alive — if I hadn't met Dr. Shah.

He has worked with me to find various ways to keep my pain under control. I have had spinal cord surgery, employ mind-body approaches, and use opioids. I take the absolute smallest dose of pain medication possible. I am very cautious with my meds because I don't want my judgement to be impaired. Opioids have that potential, but so does pain.

In my work surveying rural health clinics for accreditation, I have seen how difficult it is for people living away from big cities to control their chronic pain. Some rural health clinics are staffed by [nurse practitioners](#) and physician assistants. They provide safe, quality health care and are often the only health care providers available to entire communities. Depending on their state's regulations, some nonphysician providers may encounter obstacles in their ability to effectively treat patients with complex conditions. Although rare, some providers admit they don't feel comfortable treating chronic pain. I've actually seen signs in clinics stating "This clinic does not prescribe opioids" or "We don't treat chronic pain."

If you are [elderly](#) and have crippling arthritis pain, or have a chronic pain condition like Ehlers-Danlos syndrome, as I do, what happens when you don't have access to humane health care? Although I appreciate the need to [tighten up](#) the prescribing of opioids, I worry that medical legislation could make life more difficult for people living with chronic pain, especially rural Americans.

Some experts have proposed that only pain management specialists be allowed to prescribe opioids for chronic pain. Although inconvenient, this isn't a hardship for me because I live in a major metropolitan area. But for rural Americans, the closest pain specialist may be many miles away. Since doctors can now prescribe only a 30-day supply of opioids, that means making the trip once a month. Many specialists also require mandatory urine testing, which only adds to the financial hardship of treatment.

The addiction crisis is terrifying, and many people don't comprehend appropriate opioid use. When I first started taking pain medication, I remember a family member saying, "Dianne, you're going to become an addict!"

We need to help people understand that taking pain medicine to maximize one's ability to be productive and to sustain enriching relationships is very different than the disease of [addiction](#), which limits one's ability to contribute to society and maintain healthy habits.

Getting different people with different perspectives to the table is the first step in solving this crisis. At least one of the seats should be occupied by someone promoting the conversation about rural health care.

Dianne Bourque, RN, is a health care surveyor for The Compliance Team.

Michael Bihovsky: I've begun to worry about changes in the way opioid painkillers are prescribed.

I have Ehlers-Danlos syndrome, a connective tissue disorder. It leads to frequent joint dislocations, ligament and tendon tears, and muscle

spasms that cause intense acute and chronic pain. My daily pain from it is compounded by whiplash injuries I got not long ago from being rear-ended by an SUV.

Since my symptoms began 13 years ago, I've tried every form of pain management I could access — NSAIDS, nonopioid analgesics, neurologic medications, [acupuncture](#), laser therapy, physical therapy, prolotherapy, massage, and trigger-point injections. Most of these have been unhelpful; others provide temporary relief, often at great expense. At the end of the day, when my body is fully depleted of its resources and in the most pain, a single dose of Percocet is the only tool that silences the pain enough for me to fall asleep.

I honestly don't know what I'd do if Percocet became unavailable to me, and the very thought scares me. I've been taking it for five years. To avoid any chance of addiction, I only take it at night and have stayed on a consistently low dose. My doctors, who are not cavalier with prescriptions, give me this medication because I have earned their trust. And yet, with mounting government and public pressure, my doctors' hands are becoming increasingly tied. They apologetically explain to me why they are required to make the medication even harder for me to get, against their own medical judgment. If the day ever comes when they aren't allowed to prescribe Percocet to me at all, it may well be the end of the minimal quality of life I fight so hard to achieve.

We have a genuine and devastating epidemic of opiate abuse in this country, and it is of critical importance that this problem be addressed. But we must do so in a way that doesn't cut off an effective (and often the only) treatment for the chronically ill, many of whom are able to function in this world at all only because of the small respite that responsible opiate use provides.

Michael Bihovsky (@MichaelBihovsky) is an actor, composer, playwright, and activist for often-invisible chronic diseases.

Alison Moore: I've been living with pain since I was a child. It has increased and has been completely debilitating since 2012. When I was younger, I had severe leg pain in both legs. Doctors shrugged it off as "growing pains." They were wrong. I've since been diagnosed with Ehlers-Danlos syndrome, fibromyalgia, and other issues that affect my health. I worked as a nurse for 19 years until pain and numbness in my legs made it impossible to safely care for patients.

I relied on ibuprofen for a long time. Unfortunately, it stopped working and also led to worsening gastrointestinal difficulties. I currently take Lortab, which is a combination of acetaminophen and hydrocodone. I'd rather not take this medication, or any medication for that matter, but it is the only one that controls my pain adequately enough to allow me to function on a daily basis. I take care of my 78-year-old mother, who has dementia, and my 13-year-old daughter. I take the smallest dose possible to enable me to remain as clear-headed as possible to do what I need to do each day.

Government agencies are trying to get doctors to cut back on prescribing opioids. I understand that they need to do something about the epidemic of overdoses. However, labeling everyone as addicts, including those who [responsibly take opioids](#) for chronic pain, is not the answer. If the proposed changes take effect, they would force physicians to neglect their patients. Moreover, legitimate pain patients, like myself, would be left in agony on a daily basis.

The government needs, instead, to allow doctors to assess patients' pain individually. Lawmakers and "overseers" need to let doctors sift out legitimate pain patients who maintain their appointments and comply with care and prescribing instructions from those who do not,

as well as those who obtain opioids illegally.

I'm not sure what I would do if my doctor felt he had to stop prescribing opioids, or moved away. If the new physician decided I didn't "qualify" for an opioid, I would not be able to get out of bed, much less attend to anyone or anything else. I imagine I would be forced to do whatever it takes to lessen my pain in order to function. Even with the minimal opioids I take, I still have pain *all the time, 24 hours a day*; without opioids, life would be torture.

When you have chronic pain, your mind, your body, your everything is fixated on the pain, even though you don't want it to be. You can't sleep, shower, fix food, or walk across a room. I have to be able to do all of those things and more to care for myself and for the two people who depend on me every day.

Alison Moore, RN, lives in Spring Grove, Pennsylvania.