

Most of the time you can't spot chronic pain sufferers from a distance — there are no casts or crutches or other external indicators to show how much pain they're enduring.

There's also no way to accurately measure the intensity of a person's pain.

Why pain is such a puzzle to quantify, what it's like to live with constant pain — and a look at some groundbreaking new treatments

SHIFRA ERNEST



For Amanda Greene, it started with spontaneous bruising. Then her skin began breaking out in hives when exposed to the sun (an almost everyday occurrence in her home state of California). She found herself chronically fatigued, unable to maintain her rigorous schedule as a member of her high school's student council and drill team.

Her doctor was baffled by her symptoms. Although Amanda tested negative for mononucleosis, the test was repeated every four to six months as the extreme tiredness, clumsiness, and odd skin reactions continued to plague her. Eventually, it was decided that she was anxious and depressed. Amanda was placed in group therapy.

It was only due to preoperative blood work before a nose job (which never came to be) that Amanda learned she had a clotting issue. This led to another barrage of medical tests. After a year

of dealing with lab results and follow-up appointments, Amanda's doctors finally figured out what was triggering her symptoms: lupus, an inflammatory disease caused when the immune system attacks its own tissues.

Following her diagnosis, Amanda's body was pumped with cortisones. It was only once they wore off that the pain began: throbbing, intense, and unyielding.

It's been 36 years since then. And Amanda still feels that pain today. Every day. Although she's tried an array of treatments and therapies, nothing has managed to relieve her pain in a significant way.

"There is no measurement that can tell you how much it hurts," says Amanda. "My body feels like a rubber band that stretches and contracts with the weather. It hurts so badly that there are no words to explain it."

With a staggering one in three adults having suffered chronic pain, according to a study conducted by Peter D. Hart Research Associates, Amanda is far from alone. She's also not alone in her inability

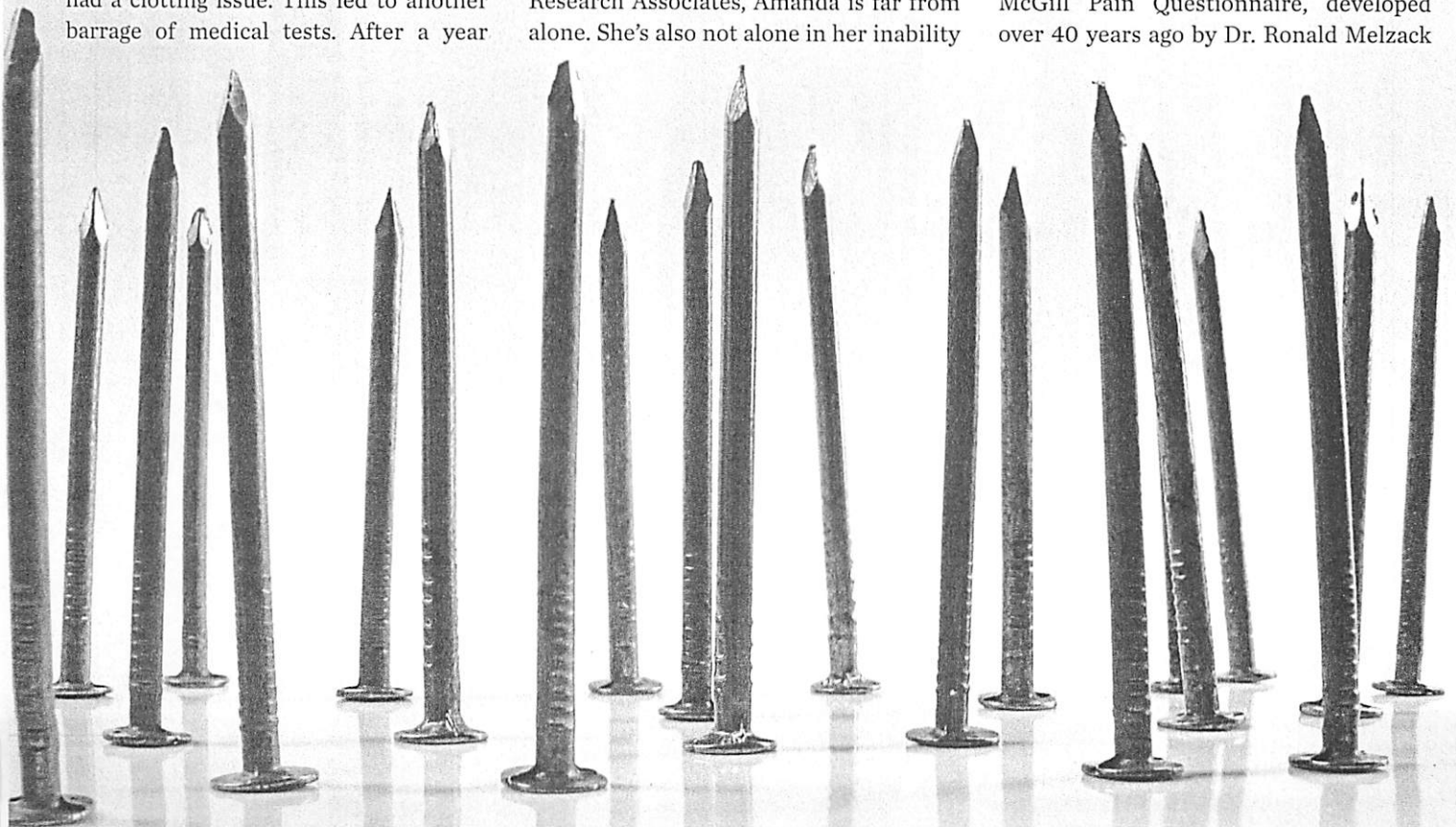
to describe what she feels. And that's part of the problem for chronic pain sufferers. How do you manage something that can't be quantified?

CAN YOU RATE THAT PAIN?

When a patient complains of pain, they are typically asked to assess their discomfort on a scale from 1 to 10, where 1 would be trivial, and 10 would be sheer agony. (Amanda says she's answered that question with a 12.)

This method is far from perfect. A woman might rate childbirth as the most intense pain she's felt — a 10 on the scale — while a man might give that same rating to a wisdom tooth extraction. Both might feel as though the pain is intolerable — and there's no arguing with that — but are both cases comparable? No one can answer that. A person's perception of pain is based on his or her individual experiences; a 4 on one person's scale may be equivalent to a 10 on another's.

A more accurate assessment is the McGill Pain Questionnaire, developed over 40 years ago by Dr. Ronald Melzack



and Dr. Warren Torgerson, whose groundbreaking research in the area of pain perception is still referenced today.

The McGill Questionnaire is based on Dr. Melzack's classification of pain into three not-so-distinctive areas: sensory (heat or pressure, for example), affective (tension and fear), and evaluative (overall pain intensity). It also contains an intensity scale and other determiners of pain. But when patients are asked to describe their pain, they're confined to the simple McGill terminology, which includes words like "hooting," "tender," and "aching." And that's rarely enough to convey what a patient is really feeling.

Indeed, when 12 people with chronic pain were asked to describe their symptoms on the website The Mighty, they needed far more than just adjectives. One person replied, "Your body feels like concrete — heavy and impossible to move. You know

the type of flu... where the sheets hurt your toenails and your pillow feels like rocks under your throbbing head? The kind when you can't stop writhing in pain because it hurts so bad, but it also hurts to move?"

Another offered, "Imagine someone with a rubber mallet keeps dropping it on your bare foot repeatedly, over and over, for an hour. Now imagine that in every joint." And then there was this: "I'm 37 years old and at a healthy weight, and my body feels like I'm 90 years old. It hurts to move, washing my hair hurts.... It's a good day if I can lift my arms."

If pain is so difficult to describe and rate, why put so much emphasis on it? Is it really that important to be able to quantify pain?

"Yes," says Dr. Paul J. Christo, MD, an associate professor of pain medicine at Johns Hopkins University and the author of *Aches and Gains: A Comprehensive Guide to Overcoming Your Pain*. "The

reason we need a precise measuring system is so patients can accurately communicate their pain. That's essential to deliver targeted relief management, allowing us to determine, for example, whether to prescribe opioids or anti-inflammatories."

There's also a link between validation of a person's pain and the management of it, a physical-emotional connection that's exacerbated when pain is minimized or unnoticed.

"Pain is invisible, which makes chronic pain sufferers feel very misunderstood," says Dr. Aviva Gaskill, PhD, a clinical psychologist who specializes in co-occurring health and psychological concerns, and deals with chronic pain patients. "People usually have difficulty communicating their symptoms with their doctors. But even when they can communicate them well, they often still

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have difficulty getting diagnosed.”

The best way to understand pain “is by understanding what area of the brain is related to it, and there are inroads being made in that direction,” says Dr. Christo. “Functional MRI imaging can highlight certain areas of the brain. Perhaps we can eventually tap into that to determine the intensity of an individual’s pain.”

ROUTES TO RELIEF

Kaye Nutman believes her chronic back pain may have started after a fall down a short flight of steps years ago. That pain gradually evolved into a host of other issues, including intense knee pain. She underwent a surgery known as ACDF (anterior cervical discectomy with fusion) after an osteophyte (bone spur) impinged on her spinal cord. Kaye tried just about every therapy she could find to combat her pain, with little success. Finally, at the Pain Clinic in Clayton, Australia, a treatment called neuromodulation was mentioned “almost as an aside,” says Kaye. Neuromodulation, otherwise known as spinal cord stimulation, uses electricity to interrupt pain signals and trigger endorphin release.

After researching the effectiveness of this pain therapy, Kaye began the procedure with a trial op, during which temporary wires were inserted in her spine with a battery remaining outside her body. Six months ago, a permanent stimulator was implanted. In addition to the small, thin wires attached to her spine, a battery was inserted under her skin. She was given a battery charger and a remote control that allows her to control the bursts of electricity when she feels pain.

“My pain is cut by 50 percent,” she says today, “sometimes more when I’m busy and don’t think about it, sometimes less when I’m on my feet all day. Fifty percent makes a huge difference to how I can live my life, and my feelings about the future.”

Peripheral nerve stimulation, another pain therapy, is similar to spinal cord

stimulation. It too uses small currents of electricity administered through flexible, thin wires placed next to the injured nerves. Dr. Christo chose this option for a patient suffering from chronic post-stroke shoulder pain. “It has made a huge difference,” he says.

As the medical world moves forward with research and development, manufacturers continue to create smaller and shorter wires that can reach more specific areas of pain. Dr. Christo is currently involved in studies on neuromodulation for abdominal pain, an area of the body that currently has no targeted method of relief other than nerve blocks or medication.

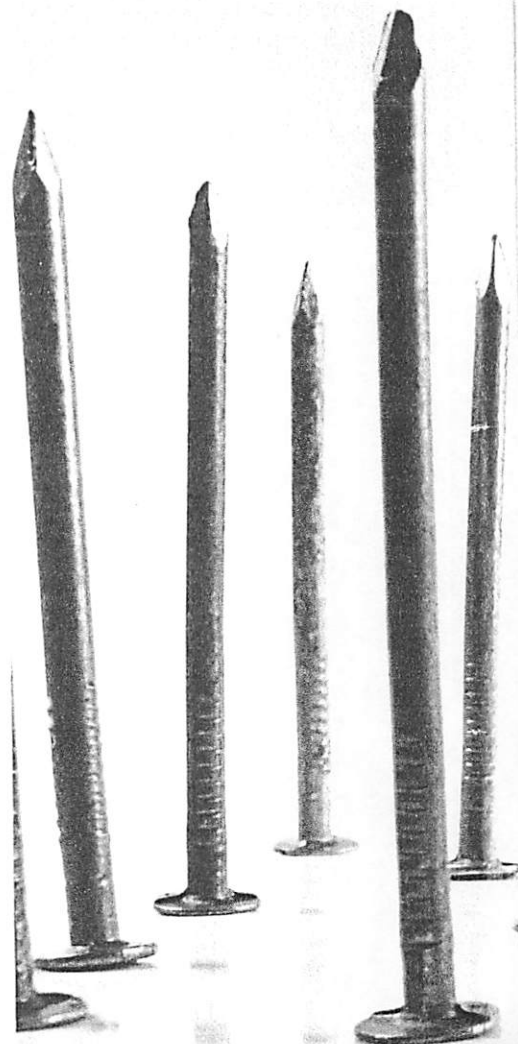
One treatment Kaye tried before neuromodulation was radio frequency intervention in her lower back. Although it wasn’t successful for her, Dr. Christo says that it was life-changing for a patient of his with severe knee pain. “That patient is now able to go the mall, wash dishes — things she couldn’t do before.”

Dr. Christo himself suffers from recurring migraine headaches, which can be debilitating. One form of chronic migraine therapy involves a series of Botox injections — an increasingly popular treatment for pain relief — in the face muscles, scalp, and upper back administered every three months. “They can be quite effective,” he says.

Opioids such as Oxycodone are usually considered a last resort. “We hear about a lot of deaths associated with addiction,” Dr. Christo explains. “I believe that only patients who have tried other treatments that have failed, whose lives are disrupted by their pain, should be considered candidates.” Amanda falls into this category: She has used prescription opioids to get through particularly rough pain spells in the past, although she tries to be on as few prescriptions as possible.

As for alternative non-invasive treatments, Kaye has tried meditation, massage, and gentle exercise to reduce stress and gain flexibility. She found

“Pain impacts me in everything I do. Dropping off a gift would be a ten-minute trip for anyone else. For me, it’s a huge effort”



What's the Source?

There are three common causes of chronic pain:

Lower back pain A lot of back pain is due to our body mechanics, Dr. Christo says. There are degenerative changes that happen to our spines as we age that are hard to combat. Incorrect posture is also a big contributor to back pain; we tend to lose track of body positioning, particularly when we spend large swaths of time leaning over a desk — which causes neck pain as well.

Arthritis Osteoarthritis, the most common form of arthritis, is caused by normal wear and tear of the cartilage cushioning the joints. Injury or infection can speed up this deterioration.

Headaches Dr. Christo credits the prevalence of chronic headaches to stress — emotional, societal, or work-related — although there can be a genetic cause as well.

hydrotherapy — which uses water to ease pain, among other things — somewhat helpful. She also tried the Feldenkrais method, a mindfulness approach.

There's no end to the list of possible treatment and management options. "We're hearing a lot about platelet plasma and stem cell therapies," says Dr. Christo. "They're on the horizon and are being used for musculoskeletal issues. We're in the early stages with those."

Dr. Christo says inroads are being made in determining mechanisms of pain and targeting drug therapies to reduce them. "We have drug therapies that we use to target chronic pain, but they are broad acting. We have to learn to target a specific pathological mechanism — for example, what exactly causes migraine headaches? — in a way that eliminates it. We have anti-inflammatories, but they're not specific enough. With more science, we'll be able to develop specialized therapies."

LIVING WITH PAIN

Amanda is now 50. In addition to lupus, she has developed osteoarthritis and fibromyalgia — "Autoimmune diseases don't come alone," she says wryly. The constant presence of something so hard to describe has taken its toll on Amanda's life in many ways. She attempted to go to

college, but after just three weeks realized that it wasn't a realistic option for someone in constant pain. She also can't hold down a full-time job. At times, Amanda has been in bed for several days in a row — days that disappeared in a haze of pain, with no cognizance of their passing.

"Pain impacts me in everything I do," Amanda says. Tiny tasks require a huge amount of time and planning, and leave her exhausted. "Dropping off a gift would be a ten-minute trip for anyone else. For me, it's a huge effort."

Nights can be as hard as the days. "I have 'painsomnia,'" Amanda says. "If I'm asleep, the pain wakes me up. Sometimes it feels like burning. I have nerve pain and joint pain. There are no distractions."

Kaye says she goes by the Spoon Theory, a metaphor used to describe the limited energy reserves of people with chronic illness or disability. "You have only so many 'spoons' to use in a day, and if you run out of spoons, then you'll experience more pain and exhaustion," she explains. "To combat this, I've learned to pace myself. What I did before on auto pilot is now done at a slower pace and with more thought, and I may need to rest and even take a nap to complete the tasks."

Socially, Kaye likes to have just one thing to do in a day — say coffee at 10:30

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Invisible Illness

a.m., or a hospital appointment at noon. What's her social life like? "I hardly ever go out late in the evening," she says. "If I'm invited somewhere, I often skip it — partly because sitting down for several hours can get uncomfortable if the seating isn't right, partly because I'll be yawning, partly because I'll be thinking how comfortable I could be back home."

There's also the issue of being misunderstood by others. "Pain can leave you feeling lonely even when you're with other people," says Kaye. "My physical reality is different from that of other people who just do things without pain. They can't understand where I'm coming from when I try to explain that fibromyalgia intensifies pain tenfold, or causes sudden exhaustion after just taking a bath. I read an article where someone said it was like being Alice going down the rabbit hole into a whole different world. Sometimes a life with chronic pain just seems surreal."

When Amanda is invited out, she accepts tentatively, with a disclaimer that she doesn't yet know how she'll feel that night. If she has to be in a crowded enclosed space, she wears a surgical mask over her face — something she says doesn't help improve her social situation.

Amanda calls chronic pain her "invisible illness." Dr. Gaskill says that's part of the problem. "It makes chronic

pain sufferers feel very misunderstood," she says. "While I have some clients who use a wheelchair, walker, or cane, many people I work with appear 'normal' but are suffering tremendously inside.

"There can be a ton of ramifications from pain, such as loss of relationships," Dr. Gaskill continues. "I see people give up on relationships with friends and family because of their pain. Sometimes this occurs because the patient feels that he or she is a burden. Sometimes it happens because the friend or family member becomes frustrated dealing with someone who refuses to leave home often or is otherwise restricted because of their pain and they start avoiding the pain-sufferer."

Job loss is also fairly common. "I often talk with patients about doing small jobs or volunteering," says Dr. Gaskill, "but many chronic pain sufferers are fearful of making even these type of commitments because what if their pain gets really bad?"

Kaye volunteers at a Day Oncology Wig Room. The rest of the time, she works at home as a freelance writer. "My volunteer job helps me to see that there are those worse off than me," Kaye admits, "and keeping busy writing at home helps take my mind off the pain, though I need to move every half hour to avoid extreme stiffness."

Amanda uses her experience with pain as a channel to advocate for others: She is a regular on Capitol Hill, where she shares the need for research, improved care, and access to the right kind of care by chronic pain sufferers. She is also a unique source of support for fellow sufferers. "Those of us in pain have a kind of shorthand," she says. "My neighbor's daughter was just diagnosed with an illness and now has to deal with the impact of that diagnosis — living at home instead of going off to college, the constant trips to the doctor, dealing with the moods and emotions. I'm able to give her support and empathy as someone who understands."

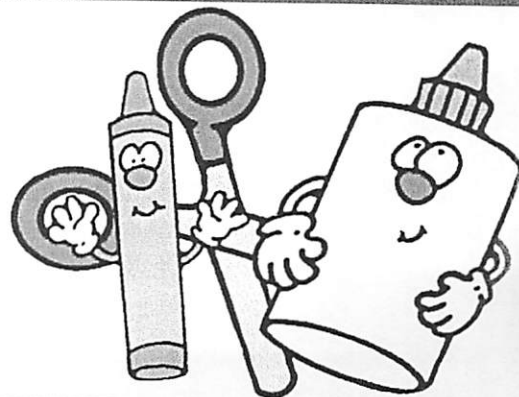
Despite living with chronic pain, Kaye says she tries to remain as upbeat

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The Right Reaction

"The worst response I get from other people is, 'But you look fine!' " says Amanda. "They'll typically follow that up with, 'Have you heard of Munchausen?' Do they want me to walk around with a backpack of my diagnoses? The truth is that people don't really want to know how you're doing. When they ask, 'How are you?' I feel like I just have to reply, 'Fine.' " What Amanda wishes people would say instead is, "What can I do to help you?" — as long as the offer is genuine.

"Don't forget about us," she stresses. "Call and say 'I was thinking of you.' "

Kaye says she'd like to meet friends without having to answer the inevitable, "How are you feeling?" or "How's your back?" She explains, "I feel like they expect me to one day say, 'Oh, it's all gone.' It's not that I don't appreciate being asked, but I tend to reply with a bright smile and say 'I'm fine' even when I'm not. I sometimes wonder if they see me as weak for having chronic pain.

"Colleagues will say, 'Here, let me lift that,' which is great if something is heavy or awkward. But it can make me feel a bit useless if it's something lightweight that I should be able to manage. I like to be treated normally."

Steer clear of unsolicited advice. "Sometimes, people tell me things like, 'I get tired and get back pain too; you should do this, then it will go away,'" says Kaye. "I interpret these kind of statements as, 'You're not trying hard enough, because if my pain went away, then so should yours.' Believe me, if a remedy or treatment is out there for my condition, I've researched it!"

as possible. But maintaining a cheerful disposition can be difficult. Mood levels are impacted by lack of sleep, which is common among chronic pain sufferers like Amanda and Kaye.

Pain also generates negative thoughts, which make it even harder to maintain equilibrium. "Depression, anxiety, and anger are huge factors for people dealing with the psychological effects of their pain," says Dr. Gaskill. "Someone with chronic pain might say to themselves when the pain is really difficult to deal with, 'I'll never feel better. I'll be in pain like this forever.' " She trains her patients to counter these thoughts with positive messages such as, "I will feel better. I will enjoy life again sometimes. Some days will be better and some days will be worse, but I will not feel like this forever."

Dr. Gaskill points out that the role of psychology in understanding pain has been well researched for many years.

"While we feel worse emotionally when we're in physical pain, we also rate ourselves as having elevated pain when we feel more down and depressed. So, if we can improve people's moods, we can begin to help manage patients' pain."

Before the neuromodulator implant, Kaye used to think, *Is this my life now? Is this how I'm going to be until I die?* But she has a more overall positive approach now. "While I know a cure is unlikely in the next few years, I'm adapting to life with chronic pain and believe there will be a cure eventually. There are days when I have a fibromyalgia flare where I wonder if the pain will stay at that intensity forever, but I know that painkillers and pacing will help, as will a positive attitude.

"My mom used to say about any adversity in life, 'This too shall pass,' " continues Kaye, "and even though I know the pain won't fully go away, that has become my motto now." ☺

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