SPECIAL REPORT

the chronic pain puzzle

Millions of Americans suffer, but finding relief can often seem impossible. Here, we piece together what you need to know. BY RITA RUBIN

Cindy Steinberg's life changed forever when she opened a file cabinet drawer one day in 1995. She didn't realize that workmen who were dismantling cubicles in her office had stacked partitions behind the tall cabinet. When she pulled the drawer open, everything toppled onto her.

"I didn't have any cuts, but once the initial shock subsided, I felt a stabbing pain in my back," says Cindy, who at the time was in her late 30s and the mother of an almost-2-year-old daughter.

It turned out that she had torn ligaments and damaged nerves in her back. "I went through two months of physical therapy and took medication, which helped ease my discomfort in the beginning, but I haven't had a day without pain in 16 years," says Cindy. At first, the pain was so bad that she couldn't even pick up her daughter. *(Please turn to 98)*

CHRONIC PAIN CONT'D

As horrific as it sounds, Cindy's situation isn't so unusual. In a 2006 special report by the Centers for Disease Control and Prevention on pain in America—the most comprehensive government report on the subject to date—1 in 4 U.S. adults said they'd experienced pain lasting longer than 24 hours in the previous month, and of those, 42 percent said it had lasted for at least a year. Pain hurts our wallets, too: It costs Americans more than $60 billion a year in lost productivity.

"It's a public health crisis," says internist and psychiatrist Scott Fishman, MD, chief of the division of pain medicine at the University of California, Davis and president of the American Pain Foundation, a nonprofit patient advocacy group. "Chronic pain is a disease just like diabetes or heart disease. Our bodies are wired to alert us via pain when something is wrong, but when that system becomes diseased, people may feel pain even when there's no obvious reason."

For some people, like Cindy, the discomfort is the legacy of an accident. For others, it accompanies a condition like arthritis or fibromyalgia. And sometimes the cause is a mystery. The worst part is that finding relief can be a huge challenge.

> Pain is hard to prove, says Dr. Fishman. "It's subjective. Doctors have to accept that pain is what the patient says it is."

"BUT YOU DON'T LOOK SICK"

As any chronic pain sufferer will tell you, a big barrier to getting doctors—not to mention friends and family—to take the pain seriously is that in many cases, there aren't any solid diagnostic tests to prove what you're feeling. "Pain is subjective," says Dr. Fishman. "Doctors have to accept that pain is what the patient says it is." Stereotypes about women being more sensitive also get in the way, and these only add emotional pain to the physical suffering, say patients.

"More than anything, people with pain want validation," says Penney Cowan, founder of the American Chronic Pain Association, an international support and advocacy organization. "Living in pain is devastating, and not having others believe you makes you feel even more isolated."

Cindy, who lives in a Boston suburb and worked in corporate training, spent five years searching for relief. "Many times I was dismissed and demeaned because there was no objective evidence of my pain," she says. Some doctors gave her nerve blocks and steroid injections, which didn't help much. But others said things like, "'I don't see why you should have pain—this injury should have healed a long time ago,'" says Cindy. "It's like they think you're making it up."

Finally, she found an osteopathic doctor who convinced her to try Lortab (also sold under the brand name Vicodin), which is a combination of acetaminophen (the active ingredient in Tylenol) and hydrocodone, a narcotic. It helped, but not as much as low doses of the antidepressant amitriptyline, which she still takes along with a muscle relaxant to prevent back spasms. (Antidepressants may alleviate pain by acting on similar pathways in the brain.) She also participates in water-based physical therapy.

Penney, who now lives in Sacramento, California, also had a hard time getting treatment—in her case, for fibromyalgia. *(Please turn to 102)*

getting your doctor to listen

Whether you see your primary care doctor or a specialist such as a neurologist or physiatrist, clearly explaining your symptoms is the best way to get the right help. The American Pain Foundation recommends that you keep a journal to record when, how often and how intensely you feel pain. (Use it to guide conversations with your doctor.) Some other tips:

FOCUS ON HOW PAIN HAS CHANGED YOUR LIFE Explain what you were able to do before that you can't now. Are you sleeping in a chair because lying in bed is too uncomfortable? Are you skipping church because sitting in a pew is excruciating?

RATE IT Describe how it feels compared with other pain you've experienced. Is it similar to having overdone it at the gym, or is it more akin to twisting your ankle or burning your hand on the stove? On a scale of 1 to 10 (with 10 being the worst pain imaginable and 1 being mild discomfort), how would you rank it?

NOTE WHAT, IF ANYTHING, MAKES THE PAIN GO AWAY Whether it's soaking in a warm bath, getting a massage or going from sitting to standing (or vice versa), mention what eases your discomfort. Or is the pain always equally bad?

CHRONIC PAIN CONT'D

When she started having muscle pain throughout her body, extreme fatigue and trouble sleeping, no one could explain why. She tried physical therapy, several medications, even counseling. At one point she got so out of shape that she couldn't hold a cup of coffee.

But still doctors dismissed her, telling her "'you're just going to have to live with it,'" she says. Six years went by before she finally got a diagnosis and the help she desperately sought when she enrolled in an inpatient program at the Cleveland Clinic. Penney declines to discuss whether she now takes medication, because she doesn't want to influence others' choices. But she does say that relaxation and stretching exercises help, as does trying not to overdo it on "good" days.

(UNDER)EDUCATION OF DOCTORS

It's not surprising that Cindy and Penney searched so long for help. On average, U.S. medical schools devote just seven hours (out of roughly 3,000 instruction hours) to pain treatment, says Beth Murinson, MD, a Johns Hopkins University neurologist and author of *Take Back Your Back*.

Medical schools focus on the diagnosis and treatment of specific diseases and conditions, she explains. Because chronic pain is considered a symptom that can be caused by a variety of conditions, it doesn't quite fit in with that focus. Thanks to Dr. Murinson's efforts, Johns Hopkins is now one of four U.S. medical schools that require students to take an 18-hour pain course. (The others are at Stony Brook, University of Pittsburgh and University of Chicago.)

Another problem is that the American Board of Medical Specialties—an organization that plays a key role in the development of standards for board certification in different fields—considers pain medicine a subspecialty of neurology, anesthesiolgy or physiatry (physical medicine and rehabilitation), not an independent specialty in its own right. Some say that discourages doctors from pursuing it. The American Board of Pain Medicine, an association "committed to the certification of qualified physicians in the field of pain medicine," does offer its own certificate exam, but only 2,200 doctors in the U.S. have passed it since 1992.

The pharmacist said, "We don't usually fill these kinds of prescriptions at this time of night." It was 9 P.M.

Due to the lack of highly trained experts, only 5 percent of chronic pain patients ever see a pain specialist, according to research conducted by neurologist Russell Portenoy, MD, chair of the department of pain medicine and palliative care at Beth Israel Medical Center in New York City.

THE RELUCTANCE TO PRESCRIBE—AND TAKE—NARCOTICS

Because most doctors aren't well versed in pain treatment, patients typically bounce around to different providers and experiment with a variety of treatments before finding a solution that works for them—if they ever do. Many of those who find relief say that taking narcotics (opioids) is what ultimately provides the best remedy. However, narcotics such as hydrocodone (Vicodin), oxycodone (OxyContin) or hydromorphone (Dilaudid) can be addictive for some people, and this has created a stigma.

Mary Vargas, 38, an Emmitsburg, Maryland, attorney and mother of three, wears a patch containing fentanyl (a narcotic) to help relieve neck pain from an injury she suffered when a distracted driver crashed into her car in 1996. But the patch is not easy for her to get, despite having a valid prescription.

"There are so many hoops that you have to jump through," says Mary, who says pharmacists are wary of these drugs and their association with abuse. Once, after a long day at work, she stopped at a major chain drugstore. The pharmacist looked at her prescription and said, "We don't usually fill these kinds of prescriptions at this time of night." It was 9 P.M. After a few similar incidents, she switched to a mail-order pharmacy.

Many doctors are hesitant to prescribe these drugs, too. Not only are they undereducated about treating pain, they're also afraid of getting into legal trouble. In most states, either a medical board or state health agency monitors who's prescribing these drugs and how often, and they, along with the U.S. Drug Enforcement Agency (DEA), have the power to sanction doctors who they think are acting inappropriately. In reality, it's rare that a doctor would face charges or sanctions for prescribing a narcotic: A study in the journal *Pain Medicine* found that only 725 U.S. doctors—or about 1 out of every 1,000 practicing physicians—were charged between 1998 and 2006 with criminal and/or administrative offenses related to prescribing narcotics.

Nevertheless, the fear of facing charges or losing a medical license looms large. Twenty-nine percent of primary care doctors and 16 percent of pain doctors said they prescribed narcotics less often due to such concerns, according to a 2010 study led by Dr. Portenoy.

Sometimes, it's the patient who isn't comfortable *(Please turn to 104)*

CHRONIC PAIN CONT'D

taking a narcotic. Atlanta resident Larondra Terry, 44, developed fibromyalgia symptoms shortly after the difficult delivery of her son, Dyson, in November 2006. She tried out several different medications, but none of them worked well. The only drug that's really helped is OxyContin, says Larondra, who, with her husband, recording artist Tony Terry, has become a spokesperson for the National Fibromyalgia Association.

"I'm not happy about having to take OxyContin and am trying to wean off it," she says. "It dulls the pain enough for me to function, but it makes me dizzy and nauseated, and I don't like taking a drug that has a stigma attached to it."

DEPENDENCE VS. ADDICTION

While the negative associations can make life difficult for those with legitimate pain problems, they aren't entirely off-base. The abuse of prescription drugs is a growing health problem, with about 5.3 million Americans currently abusing prescription pain relievers, according to the National Institute on Drug Abuse (NIDA). Some of them, of course, started off by filling a legitimate prescription. But that hardly means that everyone who takes narcotics for pain relief will become addicted to them.

Narcotics can alter the brain's activity, causing physical dependence and sometimes addiction. But many people don't understand the difference.

Dependence happens when your brain and your nerves become so accustomed to a drug that if you stop taking it, you may experience withdrawal symptoms, including restlessness, muscle pain, insomnia, diarrhea, vomiting, involuntary leg movements and goose bumps (hence the term "cold turkey").

Addiction, on the other hand, has a powerful psychological component. NIDA defines addiction as a condition "characterized by compulsive drug-seeking and use despite harmful consequences." In other words, addicts will go to great lengths to obtain a drug, even if it's illegal, even if it costs them their jobs and relationships.

When given to the right patient, however, narcotics can be lifesavers, which is why the American Pain Foundation considers them useful tools. "Every treatment option has risks, but so does inadequate treatment," says Dr. Portenoy. "These drugs are appropriate for carefully selected patients."

So who is a good candidate for a narcotic? In a nutshell, someone who doesn't have risk factors for becoming addicted. These include a personal or family history of substance abuse and/or mental illness such as depression, obsessive-compulsive disorder, bipolar disorder or schizophrenia. But anyone who takes a narcotic should be on the lookout for signs of addiction, such as taking more than the prescribed dose or feeling like you wouldn't be able to stop if you had to.

Of course, narcotics aren't the only option. Other treatments include anti-inflammatories, medications that target the nervous system, and antidepressants that affect brain chemicals. But if you don't have risk factors for addiction and your doctor is unwilling to even consider *(Please turn to 108)*

+ Many people worry that they'll become addicted to a narcotic—or that people will assume they're an addict.

where to find help

PAIN SPECIALISTS

+ The American Board of Pain Medicine lists doctors who've passed their certification exam at abpm.org.
+ The American Academy of Pain Medicine gives a directory of its members (including internists, neurologists and occupational therapists) at painmed.org.

ACUPUNCTURISTS

+ Locate a licensed acupuncturist at nccaom.org.
+ For a directory of medical doctors who also practice acupuncture, go to medicalacupuncture.org.

SUPPORT AND EDUCATION

+ The American Chronic Pain Association has a variety of resources to help cope with pain (like links to support groups) at theacpa.org.
+ The American Pain Foundation has info on treatments, a physician search tool and more at painfoundation.org.

INTENSIVE HELP

Inpatient pain treatment programs are offered by:

+ Cleveland Clinic (clevelandclinic.org; search for "pain rehabilitation")
+ Johns Hopkins Hospital (hopkinsmedicine.org; search for "pain treatment program")
+ NYU Medical Center (med.nyu.edu; search for "inpatient pain rehabilitation")

CHRONIC PAIN CONT'D

narcotics—especially if other drugs have failed you—it's time to consult a specialist.

LIVING WITH PAIN

Because of this reluctance by prescribers and patients—and a lack of adequate training and research in the medical community—many patients continue to struggle, with pain permeating every aspect of their lives. Although her employer was understanding, Cindy Steinberg ultimately had to quit her high-paying job in favor of Social Security payments. Going out and socializing can be hard, too. Crowded movie theaters are out of the question. Instead, Cindy will attend a matinee at an art house, where there's room to spread out. She'll sit as long as she can, and then roll out an inflatable mat at the front of the theater and lie on it. "I've gotten used to checking in with theater managers before buying tickets," she says.

Still, Cindy has chosen to use her pain as a motivation for good. She leads the American Chronic Pain Association's Boston-area chapter meetings, serves on the board of the American Pain Foundation and chairs the Massachusetts Pain Initiative's legislative council. She also works with officials in the state health department and professional licensing boards on regulatory matters affecting pain.

Patient advocates like Cindy, as well as pioneering doctors, are working to eventually change the way that pain is viewed and treated. For now, most of them simply wish for a greater understanding.

"Chronic pain is an illness in its own right," says Dr. Portenoy. "Patients seeking care for pain should be given the same respect as those with any other ailment." ■

Medical reporter RITA RUBIN often writes about drug safety and women's health.

alternative treatments

More often than not, patients must cobble together a variety of treatments, and increasingly those include some type of complementary and alternative medicine (CAM) remedy such as yoga or acupuncture. One recent study found that 44 percent of chronic pain patients on narcotics (opioids) had used a CAM remedy in the previous year. They may seek these out because conventional treatments have failed, or because they mistakenly believe that CAM therapies have no side effects.

Because of such misconceptions, the National Center for Complementary and Alternative Medicine (NCCAM) urges patients not to replace scientifically proven treatments with unproven CAM therapies. It's also important to discuss with your healthcare provider any CAM treatments you're considering; that's especially key if you're planning to take any supplements, as many can interact with prescription or even nonprescription drugs.

That said, the evidence showing that some CAM therapies are beneficial continues to mount. "There's a strong mind/body component to managing chronic pain that some CAM treatments address—which drugs don't," says Dr. Portenoy. "It's about learning how to use all of your resources to function better." Here's a quick guide to some of the CAM therapies that may be worth pursuing.

+ **ACUPUNCTURE** A popular option (nearly 60 percent of chronic pain patients try it), this traditional Chinese medicine method entails the insertion of fine needles into the skin at specific sites to disperse negative *qi,* or energy. In recent studies, patients with lower-back pain felt better after undergoing an average of 10 treatment sessions.

+ **MASSAGE** Since tense muscles often contribute to pain, it's no wonder that massage, which works to relax the muscles, can also be effective at easing lower-back pain. According to a 2001 study published in the *Archives of Internal Medicine,* patients who had 10 massages (one per week) reported better pain relief than those who had acupuncture or followed pain-relieving techniques described in books or videos.

+ **SPINAL MANIPULATION** The jury is still out on the efficacy of this technique, in which a chiropractor, physical therapist or osteopathic physician applies controlled force to a joint of the spine, but there's some indication that it may minimize lower-back pain and chronic headaches. NCCAM is currently funding research to determine how often and how many treatments work best.

+ **YOGA** It's one of the most popular CAM therapies, and for good reason. One large study found that taking yoga classes twice a week for 24 weeks helped relieve lower-back pain. Other studies have indicated that it may help relieve arthritis symptoms.

+ **TAI CHI** A study published in *The New England Journal of Medicine* found that fibromyalgia patients who participated in this Chinese martial art for 60 minutes twice a week for 12 weeks fared better than those who spent that time on general wellness education and stretching.

+ **ACETYL-L-CARNITINE** This dietary supplement appears to be promising in treating diabetes-related nerve pain. A review article published in *The Annals of Pharmacotherapy* found that patients who took at least 2 grams daily fared best.