The Pain Truth

Life can be hard when you're constantly hurting. But changing views on pain and cutting-edge treatments are finally offering hope.

By Peg Rosen

In early 1997, Allison Gollin's world seemed just about perfect. A graduate student in social work at Columbia University, she was in love with a man she planned to marry. Then one day she started feeling pain in her lower abdomen. Agonizing pain. "It felt like someone was grinding shards of glass in my belly," says Gollin, who was 23 at the time. Sitting in a chair caused her discomfort, and she couldn't sleep at night—mostly because she had to get up so often to urinate, enduring "toe-curling pain" each time. Her gynecologist treated her for a bladder infection, but the pain persisted. Desperate, Gollin saw seven other doctors over the next year—both gynecologists and urologists. No one knew what she had, and no one offered to help control the pain. "One doctor patted my leg and told me to calm down," she recalls. "Another said I looked too healthy to have anything seriously wrong."

Gollin became frustrated and anxious, wondering "how I would live the rest of my life." Then, in May 1998, she found her way to the office of New York City urologist David Kaufman, M.D., who promptly diagnosed interstitial cystitis—a chronic and painful inflammation of the bladder wall. The news was bittersweet: Dr. Kaufman told Gollin that she would probably never be cured. But she could be treated.

Gollin started taking several medications, including low-dose antidepressants, now widely prescribed for chronic pain. She did biofeedback and underwent internal pelvic massage. And, gradually, she started to feel better. Now living in Cherry Hill, New Jersey, Gollin is married and the proud mom of a six-month-old boy.

A clear gender gap

Some 75 million Americans suffer from chronic pain, according to the American Pain Foundation. And for reasons no one clearly understands, women are far
"Methadone helped me get my life back."

NAME Bonnie Wise
AGE 50
HOMETOWN Madison, Wisconsin
PERSONALS Married
PROFESSION Sales representative
DIAGNOSIS In 1987, Wise developed a degenerative condition in her spine that damaged her vertebrae and the shock-absorbing discs between them.

SYMPTOMS Pressure on her spinal cord sent excruciating pain shooting down her lower back into her legs and feet: “It felt like my ankles were wrapped in burning barbed wire.”

WHAT DIDN’T WORK Two back surgeries in two years. “One surgeon told me to pray,” says Wise.

THE TOLL Unable to work or drive for long stretches, she barely left home for five years. “I lay flat on my back. I often thought about suicide.” Her husband was supportive, “but as the pain worsened he felt helpless.”

THE TURNING POINT In 1999, word of mouth led Wise to Richard L. Brown, M.D., an associate professor of family medicine at the University of Wisconsin Medical School, in Madison, and an expert in pain management. Among other things, Dr. Brown allowed her to try different opioid narcotics.

PAY DIRT What ended up helping was methadone, commonly used to wean addicts off heroin but now prescribed for severe cases of chronic pain. “The methadone lessened the intensity of my pain, so I could start physical therapy again and return to work,” says Wise. Three years later, she continues to take the drug, has a deep massage each week, and does relaxation exercises she learned from a pain psychologist. She also works out on the treadmill, lifts weights, and stretches regularly—activities she couldn’t do for years. “I’m not pain free,” says Wise, “but Dr. Brown and the methadone helped me put my life back together.”

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Pain’s domino effect

Everyone feels pain from time to time. It’s your body’s way of alerting you to danger. Acute pain comes on suddenly, when you touch a hot pan or strain your back at the gym, for example. If an injury or illness is serious enough, pain forces you to rest your body for days or weeks so it can heal.

Sometimes, however, pain persists far longer than what is considered medically normal. It may even linger indefinitely and thereby become “chronic.” “It’s like an alarm that keeps ringing when the fire has long ago been put out,” says Edward Covington, M.D., director of the chronic pain rehabilitation program at The Cleveland Clinic Foundation. Some kinds of chronic pain, like headaches, affect a specific area, while others cause pain throughout the body.
Constant, unremitting pain has a domino effect, changing the way your body responds to pain signals. "Instead of developing a tolerance to pain over time, the nervous system becomes increasingly sensitive to it," says Christine Miaskowski, Ph.D., R.N., a professor of physiological nursing at the University of California in San Francisco. "A pinprick that was once merely uncomfortable can become exquisitely painful; just the rubbing of a bra strap against skin can be intolerable."

A woman who is hurting may also shy away from physical activity, which can cause other parts of her body to ache as her muscles shorten and tighten. She may also become clinically depressed. "If you're hurting all the time and can't do what you want, why wouldn't you be depressed?" asks Peter Staats, M.D., director of the division of pain medicine at Johns Hopkins University School of Medicine, in Baltimore. And because depression magnifies pain, "the more miserable you are, the worse your pain gets," says Dr. Staats. "It's a vicious cycle."

**Patience and persistence**

Breaking that cycle is tough. Only a tiny percentage of primary-care physicians—the first doctors many sufferers turn to—are experienced in pain management. More important, many doctors just don't want to deal with pain. "They're used to working with concrete information," says Sean Mackey, Ph.D., M.D., an assistant professor of anesthesiology and pain management at Stanford University Medical Center, in California. If a person has diabetes, for example, a doctor can monitor her blood sugar. "But there is no such thing as a pain meter, and it takes time to talk to a patient and to determine how she can be helped," adds Dr. Mackey.

That's why it's so important to find the right practitioner—and to know what to say at your first appointment (see "What Every Pain Patient Needs to Know...and Do," page 88). How to go about the search for the best doctor? Experts say a woman should find out if her local hospital has a pain-management expert on staff. If there's a support group nearby, she can ask if anyone has found a good physician to oversee her care. Help may come from doctors in a wide range of specialties, from internal medicine to rheumatology to psychiatry. What matters is that the doctor has an interest in pain and experience in treating it, according to Richard L. Brown, M.D., an associate professor of family medicine at the University of Wisconsin Medical School, in Madison.

Another source: one of the many pain centers that have cropped up across the country,

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**NAME** Linda Saluri

**AGE** 33

**HOMETOWN** Johnston, Iowa

**PERSONALS** Married, full-time mother of four kids ages two to seven

**DIAGNOSIS** Saluri had suffered from migraine and tension headaches since adolescence. Pain intensified with the birth of her second child, in 1997.

**SYMPTOMS** Extreme sensitivity to light and noise; nausea; depression

**WHAT DIDN'T WORK** For five years, she tried everything from biofeedback to narcotics: "The few treatments that did help had such horrible side effects that I had to stop them."

**THE TOLL** Her life unraveled. "I'd spend many days lying in a dark room with ice on my head, while my children were stuck watching videos. I couldn't cook dinner or clean. I'd just count the hours until my husband got home."

**TURNING POINT** She heard that Botox—which is used to erase facial lines—could ease chronic headaches. So last year she asked her doctor at Chicago's Diamond Headache Clinic about the treatment, and he let her try it. Botox isn't usually covered by insurance, so Saluri paid $1,500 out-of-pocket for an initial round of 22 injections in her face, neck, and back.

**PAY DIRT** "I felt a difference almost immediately," she says. Her second treatment was covered by insurance and is expected to help provide relief for six months. "My headaches are less severe, and I've cut back on other medications. But, no, I haven't lost any wrinkles. It would be nice, but you can't have everything."
offering a one-stop-shopping approach to managing pain (see “35 Top Pain Centers,” page 104). Some centers favor a strong medical approach, emphasizing drugs and high-tech procedures. Others focus on rehabilitative strategies such as counseling, physical therapy, and regular exercise. Alternative therapies such as hypnosis, biofeedback, and meditation—which can help a patient reduce stress and regain a sense of control over her body—may be part of the mix. Integrative clinics—which many experts believe are best—provide a little of everything.

Still, keeping the pain at bay is often an ongoing effort. When Allison Gollin, now 29, moved to New Jersey, Dr. Kaufman referred her to a leading center for interstitial cystitis, where she continues to be treated. Gollin knows that there's always the chance her symptoms will come back in full force. But she also knows something can be done if that happens.

"For a long time, my whole identity was based on being a pain patient," Gollin acknowledges. "Now that I can control my pain, I am embracing life, and looking forward to my future." ⭐

What every pain patient needs to know...and do

Keep a pain diary. Before your first doctor’s appointment, jot down what your pain feels like from day to day. "Write down what makes it worse and what makes it better," says Judith Paice, Ph.D., R.N., a research professor of medicine at Northwestern University Feinberg School of Medicine, in Chicago.

List any medications you’ve tried—and the dosage. Let the doctor know what has worked and what hasn’t. That way, you won’t duplicate a treatment. "If something helped, but you couldn’t tolerate the side effects, let the doctor know," says Paice. A similar drug may be easier for you to handle, or another dosage may be more effective.

Describe your pain objectively. "Don’t go on about how miserable the pain is making you,” says Paice. Tell what the pain feels like: Does it throb? Stab? Tingle? How long does it last? Use a scale of zero to ten to describe how it has felt lately. Then tell the doctor what the pain keeps you from doing: Working out? Sleeping? Having sex?

Think twice about surgery. If anyone recommends surgery, seek a second, third, and even a fourth opinion. "Surgeons often recommend surgery because that’s what they do, and it won’t always ease someone’s pain problem," says June Dahl, Ph.D., a professor of pharmacology at the University of Wisconsin Medical School, in Madison.