

# The Prepared Patient®



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## When Pain Doesn't End

### Living Beyond Pain

**F**or people with severe chronic pain like Kelly Young and Teresa Shaffer—both of whom have become patient advocates—coping with agony is a fact of life. Young suffers from rheumatoid arthritis while Shaffer's pain is linked primarily to another degenerative bone disease.

Chronic pain is one of the most difficult—and common—medical conditions. Estimated to affect 76 million Americans—more than diabetes, cancer and heart disease combined—it accompanies illnesses and injuries ranging from cancer to various forms of arthritis, multiple sclerosis and physical trauma.

Pain is defined as chronic when it persists after an injury or illness has otherwise healed, or when it lasts three months or longer. The experience of pain can vary dramatically, depending in part on whether it is affecting bones, muscles, nerves, joints or skin. Untreated pain can itself become a disease when the brain wrongly signals agony when there is no new injury or discernable other cause. Fibromyalgia—a disease in which pain in joints, muscles and other soft tissues is the primary symptom—is believed to be linked to incorrect signaling in the brain's pain regions.

### Finding a Doctor

The first step to deal with chronic pain is to find a physician or medical team who can accurately diagnose your condition and work with you to lessen pain.

"It's not easy," says Shaffer. "You have to find someone [with whom you can] build a relationship of trust and open communication."

### Acute or Chronic Pain

**Acute pain** is pain from an injury or illness, typically lasting only hours or days—and definitely not continuing once the original cause has cleared up. By contrast, chronic pain lasts months or years and continues even when the initial problem has been resolved. **Chronic pain** is itself considered a disease because it reflects pathology in the brain and nervous system — which transmits pain—that persists and affects all aspects of life functioning.

Dr. Russell Portenoy, chairman of pain medicine and palliative care at Beth Israel Medical Center, agrees. "You need to identify someone with a high level of knowledge and competence, good communication skills and a network of professionals with whom they work, someone who has compassion," he says.

Dr. Paul Christo, director of the multidisciplinary pain fellowship program at Johns Hopkins School of Medicine, also suggests looking for someone who has completed at least a year-long certification in pain management. This information can usually be obtained on the doctor's website or by asking about his or her qualifications.

### Comprehensive Treatment

Experts agree that comprehensive care—which can involve medications, exercise, psychological therapy, massage, physical therapy, injections and complementary treatments, depending on the patient and condition—is essential.

"The reason we now call chronic pain an illness is that we recognize that it is more than just a sensation in the body," Portenoy says. "It affects your ability to function as a human being, your relationships, your ability to be productive, to think straight."

Unfortunately, because they have so often been dismissed as having a problem that's "all in your head," many people with chronic pain resist considering talk therapy as a part of treatment.

"A lot of people have the misconception that what I'm telling them [when recommending therapy] is that their pain is a figment of their imagination," Christo says. "That's not what we mean. Pain has such an emotional component and psychotherapy is extremely useful in terms of helping patients reorganize and rethink how they interpret it and how it affects their lives."

Says Shaffer, "Pain encompasses the entire person. It's not just in your leg or back. It encompasses the entire being of who you are and what you can do and don't do. So physically, mentally psychologically: you have to take care of all of those things."

## The Opioid Question

Although drugs like aspirin, ibuprofen and even some antidepressants can help relieve pain, the most effective medications for most severe pain remain the opioids, like Oxycontin and morphine. Both doctors and patients tend to fear these drugs because of concerns about addiction and overdose.

However, of patients without a prior history of addiction, less than 3 percent of patients who take opioids regularly for pain will become addicted to the drugs, according to a Cochrane review of studies. Opioids are currently under a cloud because of a sharp rise in overdose death and addiction, mostly resulting from misuse by people who aren't pain patients. The majority of overdoses occur in people who abuse the drugs along with alcohol and depressants like benzodiazepines (for example, Xanax).

Virtually everyone who takes opioids on a daily basis will become physically dependent, however: They will suffer withdrawal if the drugs are not slowly tapered. But that is not the same as addiction, which is defined by craving, negative consequences, reduced ability to function and compulsive drug-related behavior.

Kelly Young avoided opioids for years, relying on high doses of ibuprofen (Advil) and similar drugs. But when the pain became excruciating, her doctor suggested she try an opioid. "I was afraid of side effects," she says. "One night it was really bad so I took it." At first, she felt severe dizziness. "But in 30 minutes, the pain started going away and I thought, 'This is amazing, this is the first time in 4-5 years that I've been without pain,'" she says.

## Pain Management Resources

**American Pain Society** is a "multidisciplinary community that brings together a diverse group of scientists, clinicians and other professionals to increase the knowledge of pain and transform public policy and clinical practice to reduce pain-related suffering," their website says.

<http://www.ampainsoc.org/>

**American Academy of Pain Medicine** This is a directory of physicians whose practice is primarily devoted to pain and offers its member continuing medical education in pain. The site's Patient's Center page provides general information and helps patients locate pain specialists in their area.

<http://www.association-office.com/aapm/etools/publicdir/search.cfm>

To reduce the dizziness, she cut the dose, starting with a liquid usually given to children so that she could find a level that allowed her to be most comfortable. Neither Young nor Shaffer, who also manages her pain with opioids, has ever developed addiction.

## Two-Way Trust

Because doctors can lose their licenses or go to prison if they don't detect addicts who fake pain, patients find themselves in a difficult position when they want to discuss opioid medications. Asking for a drug by name, for example, which might be fine with other conditions, is seen as a "red flag."

"When you initially go to an appointment, you don't want to go in there saying I need medication; that's the worst thing you can do," Shaffer says. "You want to ask for relief. Explain to the health care provider, 'This is my life. I can't get out of bed. I can't do laundry. I can't pick up my child. I need quality of life, that's why I'm here.'"

Shaffer adds, "You have to be upfront and honest and build that relationship of trust with your doctor."

Shaffer also notes that it is the patients' responsibility to store opioids in a locked box safely: Many people who abuse and overdose on these medications get them from friends and relatives who do not secure them.

## Acceptance and Hope

Shaffer and Young both recommend a mix of realism, mutual support and fighting

spirit when it comes to facing pain. Young runs her Rheumatoid Arthritis Warrior website and Shaffer moderates online discussion groups for people in pain at the American Pain Foundation site. Experts agree that support from family, friends and people facing similar problems—so long as there's some type of social support—is essential.

"You have to accept what your life is going to be, but you don't have to give up," says Shaffer, "OK, yes I have pain but that pain doesn't own me or define who I am today."

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HEALTH BEHAVIOR NEWS SERVICE

Kelly Malcom, Editor

Written by Maia Szalavitz, Contributing Writer

Design by Brandon Moore, Dir. of New Media

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