

BODY

Help for Where it Hurts

BY KAREN PATTERSON

For survivors with chronic pain, being informed—and proactive—could prove life changing.

The sores on Karen Mortensen's ears were perhaps the least of her troubles, but they resulted from her greatest problem: unrelenting pain.

The ear wounds came from almost constant contact with a pillow. She hurt so much, and so bad, that she spent most of her time in bed.

Mortensen's path to such pain started one day in 1989, when her ears felt as if they'd "popped," she says, like they do on a plane. For the time being, she'd lost her hearing. Doctors eventually figured out that Mortensen, a 29-year-old mother of two, had advanced squamous cell carcinoma of the base of the tongue.

Her diagnosis led to the removal of part of her voice box and part of her tongue (the rest of her tongue was reattached). Her two surgeries plus radiation, she says, left her without evidence of cancer but with some 500 stitches and staples in her neck, and a jaw that was broken, then put back in place, in order to fully remove the cancer.

"That's where all my pain comes from, because when you put the jaw back, you can never put it back perfectly," Mortensen says, noting that she now has a dramatic overbite and severe temporomandibular joint (TMJ) problems.



Before her cancer treatment in 1989, Karen Mortensen took her two sons--Sean, 7, and Billy, 5--on what she thought would be her final vacation. Photo courtesy of Karen Mortensen.

Six months of radiation had compounded her troubles by rendering her salivary glands unable to produce saliva, causing dryness that made eating impossible and leading to chronic dental problems. "At one point I had a root canal going in every tooth in my head," she says—30 performed in a row. Eventually most of her teeth were removed.

She endured months and months of misery from the surgery, the root canals, and the misaligned bite. Mortensen had gone from having a full-time job as an office manager for a dentist to being bedridden from constant head and neck pain. The sores on her ears were so severe they required medical care. "My life as I knew it," she says, "was gone."

When Pain Persists

While surgery was a key cause of Mortensen's agony, chronic pain in cancer survivors can arise in multiple ways. A tumor can cause nerve or other damage that lasts long after a cancer's removal. Cancer or its treatments can aggravate a pre-existing pain condition. And treatments, not just surgery but chemotherapy and radiation, can cause nerve or other damage leading to persistent pain.

Chemotherapy, for instance, is commonly to blame for a condition known as peripheral neuropathy — ongoing pain, numbness or tingling due to damage in the peripheral nerves, which extend from the brain or spinal cord. Radiation might cause inflammatory responses such as chronic proctitis (inflammation of the lining of the rectum) or, occasionally, nerve damage due to radiation fibrosis, a scarring and hardening of tissue.

Surgery can lead to long-term pain syndromes such as postmastectomy syndrome and postthoracotomy syndrome, both typically due to nerve damage. But surgery can also cause chronic pain unrelated to nerve damage—for instance, the painful swelling known as lymphedema that sometimes results from lymph node dissection.

Sometimes it's unclear exactly what caused a chronic pain syndrome, but physicians are pretty sure it had to do with the cancer treatment, says Allen Burton, MD, of the University of Texas M.D. Anderson Cancer Center in Houston. Such instances are labeled “treatment-related toxicity,” a term that encompasses all the types of treatment or any combination of them.

View Illustration: Cancer Survivors' Pain

Outside of the causes, relatively little is understood about pain in cancer survivors, notes Rosemary Polomano, PhD, RN, associate professor of pain practice at the University of Pennsylvania School of Nursing in Philadelphia. Researchers would like to learn how common chronic pain is in survivors, she says, and how patients with pain are faring 10, 15, or 20 years out of treatment. Another gap in understanding is just which treatments work best for long-term cancer-related pain.

“There is more literature on patients with pain from advanced disease,” Polomano says. “There's less known about the experiences of pain among survivors. And that may be because they're lost to follow-up and there's little information we have about how these syndromes affect their lives.”

A lot of research is going on regarding chronic pain in general, says Burton, professor and section chief of cancer pain management at M.D. Anderson. Now interest is growing in cancer survivors as their own subset of chronic pain patients. “People are beginning to recognize this population as having specific needs,” he says.

From Acute to Chronic

Acute pain—pain that immediately follows an injury, operation, chemotherapy or radiation—is generally thought to serve some sort of healing purpose, Burton says, by limiting activity that might pose a risk of re-injury. Chronic pain is pain that lasts beyond that expected healing phase.

Challenges to treating chronic pain are significant. Traditional treatment guidelines for cancer-related pain were designed mostly for palliative care, or for patients with acute cancer (and pain) expected to soon resolve, Burton says. But for chronic pain after cancer, “the treatment strategies aren’t so straightforward.” For instance, with acute pain or palliative care, the strategy is almost always to increase medications as pain increases, while for chronic pain, medicines are just one of many treatment avenues.

Complicating the picture is the likelihood that a patient’s friends and family were more understanding about the troubles caused by cancer than those caused by ongoing pain. “People are constantly pouring empathy on patients with cancer, and much less so on people with chronic pain,” says Burton. “Patients are supposed to get better; they’re supposed to get on their feet. There’s a lot of mythology about ‘they’re wimps; they’re not tough enough.’ ”

❑ There’s less known about the experiences of pain among survivors. And that may be because they’re lost to follow-up and there’s little information we have about how these syndromes affect their lives. ❑

—Rosemary Polomano, PhD, RN

A crucial window for patients occurs when treatment has ended and follow-up care is beginning, Polomano says. A patient might be expecting pain to get better, but instead it remains or gets worse. “As the pain worsens, so does ... the abnormal nature of the pain, and then it becomes much more difficult to treat,” she explains. Essentially, the central nervous system has changed, becoming more vulnerable to pain or more likely to sustain pain sensations.

“If you had pain and I didn’t treat you aggressively, the next time you had pain you could have almost an exaggerated response that is above what a normal response might be,” adds Lauren Shaiova, MD, associate attending with the division of pain and palliative care at Memorial Sloan-Kettering Cancer Center in New York City. Lack of treatment often creates a much worse clinical picture later on, she says, especially if another injury occurs.

But the problem is not just the fact that pain now can beget pain later, Burton says. Untreated pain at any stage can affect a patient’s ability to walk, eat, sleep, return to work, leave the hospital, or do other life tasks. Those disabilities might contribute to other health problems—for instance, not walking might lead to a

blood clot in the leg, or lifestyle changes may cause stress, depression, or anxiety.

A Life Reclaimed

Karen Mortensen suffered for about two years after surgery before she went to a pain specialist. “The pain was excruciating. I didn’t do anything,” she says. It would start in her teeth, her mouth, her gums, then shoot to her ear, and from her ear straight into her head, like a migraine. “The more I moved my jaw to talk to the kids or whatever, that made everything in my head malfunction because nothing was lined up.”

Pain, says Polomano, crosses the line from a symptom to a condition of its own when it lasts more than three months, when its severity increases, when it contributes to emotional stress or social impairment, when it interferes with relationships or self-care—in other words, “when it becomes so pronounced that a person can tell you that their life is affected.”

Mortensen, a resident of Verplanck, New York, says her life turned around in a few months of treatment (and adjustment of medication doses) under the care of Shaiova, who prescribed Roxicodone (oxycodone). The drug contains a powerful and strictly regulated pain reliever from a class of medicines known as opioids.

“After that life was great; I did things with the kids, I got a part-time job, I got my whole life back,” says Mortensen, who takes her pain medication every day, on a round-the-clock dosing schedule. She regards her pain as a chronic disease that she has to stay on top of so it doesn’t take over her life again.

Today, she says, she might have an off-day if she talks a lot or if it’s very rainy outside, but otherwise, “I do everything you do.”

Drugs' Dual Edge

Health care practitioners have a variety of medicines in their arsenal against pain. Drugs including antidepressants and anticonvulsants are often used to treat neuropathy. Household pain relievers such as acetaminophen (Tylenol) or ibuprofen (from a class of drugs called non-steroidal anti-inflammatory drugs, or NSAIDs) can be prescribed at stronger doses than are available over the counter. Topical medicines and nerve blocks can help. Opioids, including drugs such as Oxycontin, Vicodin, and Demerol, are often needed to treat severe pain.

But opioids have some baggage. For one thing, they are a substance of choice among drug-abusing youngsters. In addition, the public at large—and even many health care practitioners—perceive the risk of opioid addiction to be unacceptably high.

In fact, for most people that risk is rather low, according to pain specialists, who draw clear distinctions between developing tolerance for the drugs, becoming dependent on them, and being an addict.

Physical dependence is merely the body’s reliance on the drug, which can be

managed by slowly tapering the medicines when they are no longer needed, says Polomano.

Addiction, however, involves aberrant behaviors associated with drug-seeking, such as misleading doctors, stockpiling or selling the drugs, or using them for purposes other than relieving pain. Addiction, Shaiova emphasizes, is out-of-control behavior that has very little to do with pain relief.

While addiction is patients' major concern, Polomano says it "should be the least of their concerns because it rarely happens in patients who are cancer survivors with no known history of substance abuse or substance dependency."

☒ You want to take a medication that is long-acting continuously and ... a short-acting medication for a 'rescue' if the pain goes above baseline. ☒

—Lauren Shaiova, MD

Yet opioids aren't the answer for everyone with uncontrolled chronic pain, Burton says. Some patients do well on opioids for the long term, and won't even need their doses increased over time. Other patients find that the medicine controls their pain for a while but develop a tolerance, needing higher doses to get the same level of pain control—a situation that can increase the risk of side effects. Still other patients never are helped much by opioids, Burton says. "Those patients are very difficult to treat," he says. "And they generally have very severe pain."

The most common side effect Shaiova sees from the drugs is constipation, sometimes requiring treatment with stool softeners or laxatives, perhaps for as long as the patient is on the medication. Patients' diets might be evaluated to help counter this, she says, or a patient might be put on a bowel regimen, a plan implementing dietary, supplement, or medication measures to counter the constipation.

With pain drugs, Shaiova says, it's important that blood levels be kept consistent in order to minimize side effects and maximize pain relief. "You want to take a medication that is long-acting continuously and then possibly a short-acting medication for a 'rescue' if the pain goes above baseline," she advises. Such spikes in pain are known as breakthrough pain.

Other side effects, such as nausea, vomiting, and sleepiness, usually improve or go away over time, or can be treated, she says.

Long-term use of opioids can have other health consequences, adds Burton, including immune suppression or endocrine suppression, with possible effects including impotence in men and absence of menstruation in women. There's also some evidence that long-term use might heighten a patient's pain signals or actually foster spontaneous pain in the nerve. But these possibilities need to be kept in perspective, he says.

On the other hand, the more-familiar NSAIDs have their share of serious side

effects too, some of which can preclude their use over the long term. These effects include gastric bleeding and damage to the kidneys, liver, or heart. So for many patients, opioids are actually a safer choice.

Burton notes, however, that there is little consensus even among experts in the treatment of chronic pain. “All this is in the chronic pain literature [and represents] very controversial topics,” he says. Some experts say everyone with chronic pain should be treated with opioids; others say no one should. “It’s almost like religious zealotry.”

Meanwhile, patients who are perceived to be cancer-free but still need powerful pain drugs for the long term can be frowned upon by the public—and by a medical system geared to handle acute illness, where a person can be treated and get well. One survey of a variety of chronic pain sufferers who had taken such pain relievers found that 44 percent had heard concerns about their use of the medicine from others, and nearly one-quarter of the patients heard concerns voiced by a doctor. The primary concern expressed was fear of addiction, the 1999 survey found.

“There’s tremendous stigma in taking chronic opioids,” says Burton. “I think it’s a fact of the world we live in; it’s unavoidable because there’s so much drug use and abuse in the community.”

But such attitudes compound patients’ suffering. “They get the raised eyebrow when they go to the pharmacy; they get the raised eyebrow from the doctor’s and nurse’s office. ... They get a lot of pushback for taking this medicine,” Burton says.

“In every case the pushback isn’t fair. People did not choose to get chronic pain; it’s a very unfortunate illness.”

Locked In

Mortensen knows well what it feels like to be looked at with that raised eyebrow. It happens to her sometimes when she visits her local emergency room. She has to go there to manage complications related to her use of a feeding tube (which she has needed for years due to her cancer treatment and its aftermath).

One time, about 10 years after her surgery, she got more than a suspicious glare. She was locked in a psychiatric ward.

She had gone to the ER for a feeding tube change, a process she says makes her throw up a lot. Lying in bed she was asked, as patients are, what medications she was on.

She told them and was promptly admitted, against her will, for detoxification. “They told me that my surgery was 10 years ago and there was no reason for me to be on that kind of medicine,” she says. It was right after Christmas, and her pain doctor couldn’t be reached. She spent a week there, unable to leave, separated from her sons because she didn’t want them to visit her there.

“Dr. Shaiova ... threw a fit when she found out all they did to me,” says Mortensen, adding that things haven’t changed a lot in 10 years. “Even if I go to

the emergency room now they look at me like I'm nothing short of a drug addict because it's a lot of medicine, my surgery was years ago," she says. "They think, 'Why do you need this?' "



Karen Mortensen at one time was virtually bedridden by chronic pain. With treatment, she says, "I got my whole life back." Photo by Max Baxter.

More Than Medication

Medication can be vital in alleviating chronic pain, but it's just one piece of an overall treatment strategy that aims beyond pain's physiological impact, Burton notes. Coping with myriad related issues can be just as challenging.

For one thing, chronic pain can have a staggering psychological impact. "It really, really stresses people deeply and in every facet of their life," he says. "It will test their psychological fiber greatly."

Because of such issues, medical science's treatment approach has been evolving, says Robert Gatchel, PhD, clinical professor in anesthesiology and pain management at the Eugene McDermott Center for Pain Management at the University of Texas Southwestern Medical Center at Dallas. No longer do specialists tackle chronic pain as if it is likely to be cured.

"That's the old biomedical approach," says Gatchel, noting that major chronic illnesses in the U.S., such as asthma or diabetes, aren't cured but must be managed instead. "Chronic pain is one of those that only can be managed." This model of care is called a biopsychosocial model, reflecting the fact that an array of biological, psychological and social issues in the patient's life are intertwined in the illness.

Biological factors include how the condition physically arose and anatomical or physiological issues that sustain it. Social aspects include stress and interpersonal support a patient has. And psychological components include how well an individual can cope or accept lifestyle changes needed to manage the illness, says Gatchel, who is also professor and chairman of the psychology department at the University of Texas at Arlington.

This model has helped healthcare providers increasingly recognize that one treatment will not fit all patients, he says. "Each patient is different in terms of this biopsychosocial context, so one needs to evaluate those biopsychosocial interactions for that person and tailor that treatment for that individual."

Basically the strategy is to attack this puzzle of chronic pain from all sides, in order to minimize suffering and maximize mobility, adaptation and understanding. Burton and his colleagues start by determining what medicines are appropriate. Then they consider how the patient thinks about and manages the pain, possibly recommending psychological care such as cognitive-behavioral therapy, which aims to change negative or counterproductive attitudes and habits related to the pain. Physical rehabilitation, including occupational or vocational therapy, might be appropriate to help the patient function as well as possible,

given any limitations the pain poses. Spiritual issues, such as views about the nature of suffering, might be addressed. Other disciplines such as neurology or surgery are brought in as needed.

Involving cooperation between practitioners as diverse as an oncologist, pharmacologist, psychologist, nutritionist, and physical therapist—is essential to treatment under the biopsychosocial model.

This multifaceted approach—involving cooperation between practitioners as diverse as an oncologist, pharmacologist, psychologist, nutritionist and physical therapist — is essential to treatment under the biopsychosocial model, Gatchel says.

Ideally a patient will have access to these different types of care—and sometimes even integrative medicine approaches such as biofeedback, hypnosis, or acupuncture—under one roof, a specialty pain clinic or center, in what is referred to as “interdisciplinary” treatment. “There is a constant interaction and communication among the providers,” Gatchel says, “so everyone knows what everyone else is doing.”

Interdisciplinary care can be hard to find, however, largely due to the fact that insurance reimbursement for it is low. “For most cases these have to be programs that are built or designed but don’t exist in some place,” Burton says. “The savvy consumer can build this kind of program by having a physical therapist, having a psychologist, having a pain specialist and having them talk to each other.” Yet the downside of this “multidisciplinary” approach is that practitioners working at different sites or on different schedules can miss important chances to communicate about a patient, Gatchel says. “If the left hand doesn’t know what the right hand is doing, then the patient might be getting unnecessary or contradictory treatment,” he says.

Where to Start

It’s important for patients to recognize that their pain isn’t an inevitable consequence of having survived their cancer, and that they are entitled to have it treated with everything medical science can offer, pain specialists say.

“A lot of people don’t realize there are a lot of treatments out there for chronic pain, and some of them are quite effective,” Burton says.

Little is known about how patients decide whether to seek chronic pain treatment, Polomano says. Some may be told by their health professionals that their pain will probably improve, so they wait and delay treatment. Many patients worry that the medicines might interfere with their lifestyle. But, Polomano adds, “we can be successful in finding a balance.”

If pain persists once cancer therapy ends, patients should promptly go back to their medical oncologist, surgeon, or radiation therapist, she advises, and clearly describe the pain, its pattern, its severity, its characteristics, and how it is

affecting their lives.

“They should expect, given their report of pain, that a treatment plan will be devised to address this pain,” Polomano says. “And if they’re not satisfied with this treatment plan they should request a referral to a pain expert, and that might be a pain clinic.”

Burton says patients can approach their general practitioner as well. That provider has very limited time with each patient, “so most will be happy to make the patient a referral to a pain specialist, a physical therapist, and a psychologist in their network.”

However, patients should be aware that many oncologists and primary care doctors are reluctant to treat—and, especially, medicate—pain other than acute cancer pain. “Without a cancer diagnosis they’re kind of scared,” Shaiova says. “They feel like their only goal is to wean [patients] off medication and keep them off medication, whereas we feel like it’s a disease state, like diabetes, where you would never have a goal to wean someone off insulin.”

Many oncologists excel in treating patients with progressive pain due to their cancer, but once the cancer is dealt with, “they’re a little bit out of their realm,” Burton adds. “Their job at that point is to make sure the cancer doesn’t come back, but a patient with chronic pain is going to need more care than that, and probably an oncologist is not the best place to get that care.”

Patients should also expect that if one course of treatment doesn’t work, the therapies will be intensified or new ones will be tried.

And survivors with any new pain or unusual flare-up should expect to be evaluated to make sure the cause isn’t a recurrence or a new tumor, Burton says.

Mortensen eagerly attests to the benefits of pursuing pain treatment. Before, she couldn’t do things like go to a Little League game or take a vacation. “I didn’t think I’d make it to see my kids turn 8 and 6, and now they’re 25 and 23,” she says.

She notes that her medicine doesn’t impair her in any way and, in fact, has made possible just about everything she’s accomplished since her cancer treatment. She earned certification as an emergency medical technician, raised her boys as a single parent, and holds a job in retail sales.

“That’s a pretty good life that I wouldn’t have,” she says.

With her cancer diagnosis 18 years behind her, and her suffering in check for 16, Mortensen urges fellow survivors hampered by pain to seek out a pain management specialist, “and if they don’t get help with one, to keep going to another till they do. Because there are people out there who will help them.

“It might not be exactly the same life you had [before your cancer],” she adds, “but it can be a whole lot better than what you have now.”