

# Chronic Pain and the Family

---

A NEW GUIDE

Julie K. Silver, M.D.

HARVARD UNIVERSITY PRESS  
Cambridge, Massachusetts  
London, England  
2004

## What Is Chronic Pain?

**P**AIN is an inevitable part of the human experience. We are born frail and vulnerable, and maturation does little to change our condition. Regardless of age, we have practically no natural protection from attacks by predators or even from the environment in harsh weather conditions. What keeps us safe is our intelligence and the ability to come up with methods to protect our soft skin, easily broken bones, and vulnerable vital organs. In fact, we humans live in mortal fear of even the slightest wound, and we have devised elaborate mechanisms to protect ourselves. Ironically, our intelligence is also the reason we suffer; our highly evolved brains are able to process and interpret pain. Most living species don't experience pain at all, or at least not in the manner that we humans do. So we pay a price for our keen intellect—we know firsthand what it means to suffer physical pain.

Although we all know what it's like to feel pain, the experience means something different to each of us. Thus deriving a definition for pain, an intangible experience that differs from person to person, can be challenging. Among medical practitioners pain is defined as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage."<sup>1</sup> Despite this rather simple definition, most of us describe pain in other ways. We may describe pain by its characteristics (for example, sharp, burning, aching) or by its stimulus (hot, pricking, sharp). We can talk about pain's intensity (mild, moderate, severe) or use words to describe how we view it (miserable, annoying, intolerable). Despite the countless number of terms we can use to describe pain, however, there are only two things we can know for sure about someone else's pain: it's unpleasant and it's theirs alone to experience physically.

But just because others can't actually feel our pain doesn't mean they aren't affected by it. Family members are significantly impacted when one member is ill. When someone is *chronically* ill, as is the case with a chronic pain condition, the family is often thrown into turmoil. Defining how a family functions "normally" when everyone is healthy is nearly as impossible as defining "normal" family functioning when someone becomes ill. After all, what is "normal" when someone's world has been irrevocably altered? How do people function normally when they are plagued with pain, unable to work in their usual manner or maintain intimate relationships with their spouses? Similarly, what is normal for an "unaffected" family member such as a child who, when a parent becomes ill, must suddenly be quiet in the house or take on extra responsibilities and chores because the parent is unable to do them? Pain, in fact, is the quintessential solitary experience only in that the person affected is the only one who can *physically feel the pain*. In all other respects pain—particularly chronic pain—is a familial experience that dramatically changes the dynamics of the family as a unit and the functioning of the individual members. This book addresses the impact of chronic pain on the sufferer as well as on his or her family, and suggests ways to help everyone cope with the new reality.

### The History of Pain

Humans have been documenting their pain since ancient times. We have found evidence of suffering etched on Babylonian clay tablets, Persian leathern documents, and parchment scrolls from Troy. Chinese acupuncture originated back in 2500 B.C. to alleviate pain, and we still use it today. More recently, archaeologists have found interesting correlations between afflictions of the past and those of the present. For example, Dr. Juliet Rogers studied 3,000 skeletons from a graveyard in Barton-on-Humber, a small village in north Lincolnshire, England. The bones she studied were from the period 900–1850. Dr. Rogers found evidence of a number of arthritic conditions including osteoarthritis, psoriatic arthritis, and Reiter's and Paget's diseases. What she did not find was evidence of rheumatoid arthritis. This led to the hypothesis that perhaps rheumatoid arthritis is a fairly "new" disease or at least one that is more common now than it once was. In this way the past may help us understand ill-

nesses we encounter now, though many questions will likely remain unanswered. What is clear is that pain has been a consistent theme throughout human history.

Ancient peoples had many different belief systems to explain pain and illness in general. For example, in 8000 B.C. healers used very sharp instruments to cut holes in the skulls of people while they were still alive—a procedure now known as trepanning. We don't know for sure why this was done, but one theory is that these holes let out the "bad demons" that caused illness. Similarly, Ancient Egyptians believed that gods or spirits of the dead caused illnesses. In ancient China, people believed in two opposing unifying forces, the Yin (feminine, negative, passive) and the Yang (masculine, positive, active). Sickness occurred when these forces were out of sync with each other. Physicians were often religious men whose treatment centered on their theological beliefs and could include prayers, exorcisms, and incantations, among other things.

As the understanding of pain evolved, modern societies began to focus on the physical diagnosis of the underlying problem and then treatment, if available, for that condition. Yet despite many advances in pain medicine, there is currently no one theory to explain why pain occurs. This can be frustrating not only for the person who is suffering but for the entire family, all of whom want "answers" when they go to the doctor. Although we have come a long way since army surgeons in the 1500s treated what they thought were poisonous gunshot wounds by pouring burning oil over them, there is still much we don't know about pain and healing. It is beyond the scope of this book to discuss the current debates in pain medicine. Rather, I will focus on how pain, when it persists and becomes chronic, affects the person who is ill and his or her loved ones.

If you are living with chronic pain, it's important for you to understand how your condition and your reactions to it affect the people you love. If you are the loved one of someone who is suffering chronic pain, you need to know how best to respond to a situation that can often transform the entire family. Reading this book is a great place to begin. Obviously, you can't absorb or take over someone else's pain, but you can certainly *imagine* what pain must be like for your loved one. Great writers and artists through the ages have depicted pain with pictures and words to allow us to experience vicariously the pain of others. For example, in the *Iliad*,

Homer describes with grim detachment the gory details of brutal combat. We know from historians that Napoleon's men would continue to fight with amputated limbs, and artists have drawn great battle scenes depicting this phenomenon. Understanding chronic pain in your own family begins with empathy for the person suffering, but also involves encouraging yourself or your loved one to live as full and active a life as possible *despite the pain*.

### The Language of Pain

Descriptions of others' pain can elicit great empathy from us. The novelist Fanny Burney left a detailed account of the mastectomy she underwent without anesthesia on September 30, 1811 (ether had not yet been invented). With only a wine cordial (perhaps with laudanum) to calm her, she watched through a transparent handkerchief draped over her face as the surgeon marked the spot on her breast where he would plunge his knife. Burney writes of the knife "cutting through veins—arteries—flesh—nerves" as the surgeon began "cutting against the grain." She describes her agonized screams as he scraped at her breastbone—screams that lasted throughout the surgery. Burney writes of her primal response, "I almost marvel that it rings not in my Ears still . . . so excruciating was the agony."<sup>2</sup>

Pain has its own language. Burney's screams resonate with us, even though her surgery was approximately two centuries ago. We know how pain is expressed—grunts, roars, groans, moans, sobs, cries, screams, and shrieks. When someone we love is in pain, we want to do whatever we can to help. When we are in pain, we want to be helped, to be relieved of the "unpleasant sensory and emotional experience associated with actual or potential tissue damage." To be relieved of pain. But even more than that, we want to be relieved of *suffering*.

In the case of chronic pain, however, language can become a problem. In the pain literature, the language of pain is often referred to as "pain behaviors." In general, pain behaviors are things that people do or say to let others around them know they are suffering. Often these behaviors stem from a need to inform others that the pain is real and the suffering genuine. Pain behaviors can manifest in many ways and may include constant or intermittent moaning, groaning, rubbing the neck or back,

grimacing, limping, or constantly changing positions. People who are in pain often fall into a pattern of continually calling attention to their suffering, to no real advantage and often to their own detriment. For example, a person who moans frequently in response to pain does not change the physical experience. But the moaning may cause a spouse to respond in either an overly solicitous manner or with hostility and resentment.

Both responses tend to have negative effects on the person in pain and on the relationship in general. The overly solicitous spouse who constantly responds in a supportive and loving way to pain behaviors reinforces the disability of the person in pain and can even encourage more pain behaviors and less physical activity—all without a real change in the physical condition. At the other extreme, when a spouse becomes frustrated, resentful, or even outwardly angry, the effect on the person in pain and other family members who witness this breakdown in the relationship can be disastrous.

Pain behaviors are widely regarded as “maladaptive,” meaning they serve no real purpose and can be very detrimental. It’s critical for people in pain and their family members to recognize these behaviors and to work to change them. Effective communication comes not in the persistent moaning of someone in pain but rather in honest and loving communication.

The literature supports both a cultural and a gender role in the language and experience of pain. For example, it is well known that many more women than men seek out and receive treatment for pain. Women typically report more pain (especially musculoskeletal), a higher severity of pain, and pain for a longer duration of time. We don’t know definitively why women are more likely than men to seek help. This phenomenon may be due to psychosocial factors such as society’s willingness to tolerate “sensitive” women who express themselves and give voice to what is bothering them, and powerful social taboos against men expressing pain. Biological factors such as sex hormones and the different musculoskeletal structure of women may also play a role.

Cultural and socioeconomic differences may also be factors in how people respond to pain. For instance, some studies have indicated that certain cultural groups may be less inhibited than others about expressing their pain. Socioeconomic influences go hand in hand with cultural differences. For example, people from poor economic backgrounds may

### *How to Eliminate Chronic Pain Behaviors*

#### PERSON IN PAIN

- Use words to describe what you're experiencing. Keep in mind, though, that people don't constantly need to hear exactly how you're feeling. There are many times when "suffering in silence" will be beneficial to you and your family members.
- Don't hold your spouse or other loved ones responsible for your physical comfort. If you need something and can get it yourself, then do so.
- Try to avoid canceling plans with people—it's disappointing for them and for you. If you can manage the activity, then go ahead and do it.
- Understand that the less active you are, the more pain you'll have as a result of physical deconditioning. So try to remain as active as possible.
- If you're unable to handle household responsibilities that were once yours, then take on new ones that you can manage in order to lessen the burden on your loved ones.
- Be your own advocate and seek legitimate medical treatment. Follow your doctor's advice unless there is a compelling reason not to. If you don't want to do something your doctor recommends, then discuss this with him so that an alternate treatment plan can be implemented.
- Engage in regular, but not incessant, honest and open communication with your family members about what's happening to you and how you're feeling. Ask them how they're feeling and listen with empathy. Remember that just because you're feeling the physical pain doesn't mean they're not suffering as well.

#### FAMILY MEMBERS

- Don't constantly ask how your loved one is feeling—particularly when the person is not complaining or focusing on the pain.
- Encourage the person in pain to do whatever he can to help himself and the family.
- Avoid taking over all the responsibilities for the family—ask and expect the pain person to help whenever possible.

- Don't be the go-between for the pain person and the doctor—they should have their own relationship, and the person in pain should be responsible for following through with all treatment plans.
- Don't cancel your plans to do things just because someone else is in pain. Enjoy the things that you can do. Keep in mind that children often cope the same way their parents do. If your children see you shut down and become reclusive, they may do the same. On the other hand, if they see you enjoying yourself and having fun despite difficulties at home, they will likely respond in kind.
- Engage in honest and loving communication on a regular basis with both the person in pain and other members of the family who may be affected as well.
- Don't respond to maladaptive pain behaviors. If you can, point out these behaviors in a loving way and try to reinforce the fact that they're not useful.

view pain as a tremendous threat to their employment and even to their survival. In societies where anesthesia is not routine for dental procedures, either because it is not available or because it is not customary to use it, children and adults often undergo what many people would regard as agonizing surgery without complaint. As with the gender disparity, cultural and socioeconomic differences clearly affect the language and experience of pain, though we don't know exactly why.

### Virtuous Pain

None of us wants to experience pain or, worse yet, live daily with unrelenting pain. But is pain intrinsically bad? Is there anything redeemable about something that causes so much suffering? Obviously there are times when pain is useful. For instance, the very uncomfortable burning pain we feel when we touch a hot pan tells us to remove our hand immediately or we will suffer further injury. It's not uncommon for individuals with paraplegia and loss of sensation in their legs to inadvertently injure themselves by spilling hot coffee or some other substance without being aware that they had done so. Just about every doctor has a story about a

patient with diabetic neuropathy (a condition that causes loss of sensation primarily in the feet) who walked around barefoot and stepped on a sharp object without even realizing it.

In his book *The Culture of Pain*, David Morris describes a man named Edward H. Gibson, a vaudeville stage act billed as the Human Pincushion.<sup>3</sup> Gibson would walk on stage and allow audience members to stick pins in him anywhere except the groin and the abdomen. During one show, Gibson thought he would do a reenactment of the Crucifixion. A woman in the audience immediately fainted when a man with a sledgehammer drove the first spike into Gibson's left hand. As Morris notes, Gibson wisely canceled the show. An audience that could tolerate watching a man being pricked by small pins was not prepared to watch him mutilate himself—even if he didn't feel it.

Gibson most likely had what is known as a congenital insensitivity to pain. Children with this condition may die prematurely because they are more likely both to sustain serious injuries and to ignore the injuries when they occur. This condition has led to the belief that pain has great survival value for us. Every time we shift our legs because we ache from being in the same position or don't touch something that's hot, our bodies remind us that pain is a very useful sensation that helps us protect ourselves.

## Understanding and Classifying Pain

One way doctors classify pain is by how long it has been present. This is clearly an artificial and arbitrary classification, but it helps guide appropriate treatment. Pain is classified temporally as either *acute* or *chronic*. Although acute pain is always pain that has been present for a short period of time and chronic pain is always pain that has been present for a long period of time, there is no agreement in the medical literature about *how* long pain needs to be present to be considered chronic. The most common minimum duration for a diagnosis of chronic pain seems to be six months. However, a better, but somewhat more subjective, definition of chronic pain is pain that persists after the expected time it takes for tissues to heal from a particular injury or illness. This means that acute pain is the pain we experience during the time when the tissues are newly injured or haven't completely healed.