

# Chronic Pain and the Family

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A NEW GUIDE

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HARVARD UNIVERSITY PRESS  
Cambridge, Massachusetts  
London, England  
2004

## Effect on the Couple

**C**HRONIC pain affects the spousal or other committed long-term relationship perhaps more than any other. Spouses often spend more time with each other than with anyone else, and the profound feelings they have for each other contribute to the significant effect that illness has on their marriage.

As with all relationships, chronic pain impacts a marriage in many ways. Although every relationship is different, there are some important factors that all partners should consider when their significant other suffers from chronic pain. First, the effect on the relationship is usually directly proportional to the frequency and intensity of the pain as well as the degree of disability. Someone with occasional severe migraine headaches may function normally most of the time, and so the impact on the spousal relationship will probably be minimal. By contrast, for someone who suddenly sustains a severe back injury, say, and is thereafter in chronic pain and unable to work, the effect on the couple may be very significant. Second, no two couples will handle the situation in the same way; some will adjust well despite a severe and debilitating injury, whereas others will find it difficult to cope after a lesser injury.

Research has shown that patterns of behavior for both the spouse and the person in pain may positively or negatively impact the marriage and the family dynamics. Couples facing chronic pain must consider what expectations each spouse has for the relationship. They would also do well to tap into any previous experience they have had in dealing with chronic illness. All of these things will likely influence how couples respond to living with chronic pain as a component of their relationship.

## Loss of the Original Relationship

For most people, the wedding vows are said during a time of good health, when the words “in sickness and in health” do not have ominous overtones. As we age with our loved ones, however, we begin to realize that eventually we will have to face the “sickness” part of those vows. In fact, doctors in my specialty, physiatry (physical medicine and rehabilitation), are fond of saying that “being able-bodied is a temporary condition.” So what happens if you’re forced to live with chronic pain or you’re a well spouse who is faced with a partner who has chronic pain?

One of my patients is a newly married young woman who was hit by a car while jogging. Since her accident she has suffered from chronic pain and fatigue. Although she was out of work for months, she has now returned to her job as a buyer for a large department store chain. She finds the daily work taxing and the travel impossible. By the time she gets home from the office she’s ready for bed. She has been struggling with depression resulting from the loss of her marriage as she knew it. When she married she had thought this time in her life would be filled with happy outings with her husband as well as a lot of shared intimacy. Instead, she comes home exhausted, barely speaks to her husband, and sleeps for at least twelve hours each night. Her husband is unhappy because he is saddled with most of the chores; at the same time he feels as though he has lost his best friend. He rarely sees his wife between working and sleeping, and their sex life has suffered. Although they had planned to start a family soon, they have decided to wait because of the accident.

Most newlyweds enter marriage with certain expectations. We anticipate defined roles. This doesn’t mean that one person always does the cooking or that only one person is gainfully employed; it just means that there’s typically agreement about how the daily responsibilities of married life will be handled. Although these roles may change over time, in marriages in which illness is not a factor, the roles change because the couple agrees to restructure the marital and family tasks. When one person becomes ill, however, the roles may change suddenly or gradually change over time without the consent or sometimes even the recognition of either partner. This can be devastating for both the well spouse and the person in pain. In general, the more disabled one partner becomes, the

greater the impact on the family and in particular the spousal relationship. This is why treatment for chronic pain is so *function-oriented* (during my medical training, the psychiatrists who taught the residents would routinely remind us to “focus on function”). The reasoning behind such an approach is that if someone continues to function well, despite having pain, his or her life will be much more fulfilling.

In 1960 the Holmes-Rahe Social Readjustment Scale was developed by physicians Thomas Holmes and Richard Rahe to describe the disruptive and stressful events that can occur in someone’s life.<sup>1</sup> Despite the fact that this scale was first introduced half a century ago, it continues to be useful. I have modified the scale considerably to reflect what might happen in a family where one person has chronic pain. The scale is pertinent to chronic pain because it’s easy to visualize the enormous stress that a couple (and family) might encounter when someone is chronically ill. Of the forty-three life events that may cause considerable stress, thirty-four may happen as a direct result of chronic pain. The relevance of some of these events to chronic pain might not be immediately obvious. For instance, we might wonder how a minor violation of the law could be connected to chronic pain. When I asked one of the psychologists I work with whether she would include this category, however, she said that she often sees people with chronic pain who have become so frustrated that they run into trouble with the law. Common infractions can include a traffic violation, public disturbance, or domestic violence. Simply put, if you or your partner experiences chronic pain, you are particularly vulnerable to experiencing 75 percent of the most common and stressful life events. Given this reality, it’s easy to recognize the enormous impact that this condition can have on your marriage and your family.

Maggie Strong is one of the first people to give voice to well spouses in her book *Mainstay*. Strong lives with a husband who is chronically ill, and she has become an advocate for well spouses (she’s the founder of the Well Spouse Foundation). Strong documents the enormous impact that a chronic illness of any kind has on the healthy spouse. She describes what she and her husband expected from their marriage: “we wanted a marriage in which we both felt like equal partners. We’d each paid homage to an older sibling and neither of us ever wanted to feel like the smaller or weaker part of a twosome again.”<sup>2</sup> According to Strong, the

### *Major Stressors*

RANK	EVENT
1	Death of spouse
2	<b>Divorce</b>
3	<b>Marital separation</b>
4	Jail term
5	Death of a close family member
6	<b>Personal injury or illness</b>
7	Entering a new marriage
8	<b>Loss of job</b>
9	Marital reconciliation
10	<b>Retirement</b>
11	<b>Change in the health of a family member</b>
12	Pregnancy
13	<b>Problems with intimacy and sex</b>
14	Gaining a new family member
15	<b>Business readjustment</b>
16	<b>Change in financial state</b>
17	Death of a close friend
18	<b>Change to another line of work</b>
19	<b>Increased arguments with spouse</b>
20	<b>Difficulty paying household bills</b>
21	<b>Foreclosure of a mortgage or loan</b>
22	<b>Change in responsibilities at work</b>
23	Son or daughter leaving home
24	<b>Trouble with in-laws</b>
25	<b>Lack of outstanding personal achievement</b>
26	<b>Spouse beginning or stopping work</b>
27	<b>Going back to school or retraining</b>
28	<b>Change in living conditions</b>
29	<b>Revision of personal habits</b>
30	<b>Trouble with boss</b>
31	<b>Change in work hours or conditions</b>
32	<b>Residence move</b>
33	<b>Change in school</b>
34	<b>Altered recreational activities</b>
35	<b>Diminished involvement in church</b>

(continued)

- 36 Fewer social engagements
- 37 Minor financial worries
- 38 Change in sleeping habits
- 39 Fewer family get-togethers
- 40 Change in eating habits
- 41 Loss of vacation plans
- 42 Change in holiday traditions
- 43 Minor violation of the law

\*Life events that may be specifically related to chronic pain are in boldface.

stress of chronic illness is particularly debilitating because partners expect to be equal. She writes: “You lose your expected future, first, and then your marital equality.”

Often the well spouse must carry an increased workload. In some cases the person in pain simply can't do the tasks that he or she used to do; in others, the pain person needs to spend time and energy seeking medical treatment. The side effects of medications can also mean a reduced energy level for someone in pain, with the result that household chores and errands such as shopping are no longer possible. Although the chores themselves are usually interchangeable (for example, men can fold laundry as well as women, and vice versa), most people enter a relationship with the expectation that their partner is going to carry his or her weight. Well spouses may also have to increase their hours at work, take on additional employment responsibilities, or even obtain a second job if the bills begin to pile up. Invariably, when illness strikes one partner, the dynamics of the spousal relationship change, and the well partner often has to do much more than originally anticipated.

Parenting roles can also change drastically when one parent becomes ill. Raising children is a difficult job even for two committed and healthy parents. For the well spouse of a chronically ill parent, sole responsibility for getting the children dressed and bathed and then attending to homework and chauffeuring duties can be overwhelming. When one parent is

not able to participate as actively as in the past, the pain condition not only adds increased burdens to the well spouse, but also takes something important and meaningful away from the person in pain. Both partners suffer as a result. (Chapter 6 discusses childrearing issues in detail.)

In a memoir entitled *Beyond Chaos: One Man's Journey Alongside His Chronically Ill Wife*, Gregg Piburn satirically summarizes his increased workload as a result of his wife's chronic pain.<sup>3</sup> He imagines the following newspaper ad:

Wanted: Someone to assist chronically ill person with demands of life. Must be dependable, caring and organized. In addition, applicant must be creative, humorous and romantic. Willingness to drop everything to assist in crises is a requirement. Applicant must also be a great conversationalist who knows how to have fun. Counseling skills are a major plus. An emphasis on group and family dynamics is desirable. Prefer Jungian to Freudian school of thought. Advanced first-aid certification is a plus. Must be good with kids, know how to prepare a decent meal, have exceptional housecleaning skills and be great (yet sensitive) in bed. Since this is a part-time job, applicant must also hold down a full-time job. Apply only if willing to make a lifelong commitment.

Piburn effectively uses humor to diffuse what obviously is a difficult and emotionally charged home situation. Humor can be a wonderful tool even in very serious times. Laughter is a powerful antidote to stress and helps us cope in a variety of different circumstances. In all likelihood, there is a physical basis for why laughing is good for us—our bodies release certain chemicals when we are mirthful that may promote healing.

### Loss of Intimacy

The loss of a loving and sexually fulfilling relationship is very common in marriages in which one partner suffers from chronic pain. Although this topic is discussed in more detail in the next chapter, it's important to point out here that a loss of physical intimacy can profoundly affect a

marriage. In studies and surveys of couples living with chronic pain, as many as 50–75 percent of couples report having little or no sexual contact.

The reasons for the decline in sexual intimacy may be numerous. Obviously, pain itself can be a contributing factor—the person in pain might fear having more pain, and the spouse may worry about inflicting more pain. Men sometimes are unable to sustain an erection because of the pain or medication-related issues. Women might have a decreased sexual interest secondary to the pain, or side effects from medication. A well spouse who is overworked and tired might resent sex as just another chore—one easily avoided. In addition, partners struggling with anger, depression, anxiety, and guilt may have difficulty participating in a loving physical relationship. Even in strong marriages, physical intimacy can be lost when one partner develops chronic pain.

### Loss of Financial Status

In *Mainstay*, Maggie Strong has a chapter titled “Downwardly Mobile”—which is exactly what happens to many families when one partner becomes ill. Even if the pain partner is not out of work, the family may experience a loss of wages because of a breadwinner’s inability to work overtime, failure to be promoted, or absenteeism owing to doctor’s appointments or sick days. Medical bills can also contribute to the financial woes. Even in families that are not experiencing financial challenges, both partners may live in fear that their current situation will worsen if the pain person becomes increasingly disabled. Couples may curtail their usual activities such as dining out or taking vacations in order to pay the mortgage or save for a rainy day. Chronic illness brings uncertainty, and financial uncertainty—or worse yet, the loss of one’s usual financial status—can be devastating.

Money is one of the main causes of discord among married couples. Even without the burden of illness, people worry and argue about financial issues. Couples often come to a relationship with individual ideas about earning, spending, and saving money, which can make tackling finances difficult in the best of circumstances. Unexpected financial burdens can strain even the strongest marriages and may destroy marriages

that are already unstable. When one spouse becomes chronically ill, both partners can feel angry, resentful, or guilty about the financial problems the family must face. Parents might worry about how money issues will affect their children, and children in turn might blame their parents for not providing them with what they believe they need. As Strong points out, the downwardly mobile spiral in families coping with chronic pain can precipitate a major crisis in a marriage.

### Loss of Emotional Balance

The emotional toll that any chronic illness takes on an individual and the family is enormous. In a marriage, the emotional roller coaster can be exhausting. A chronic illness can bring a couple closer together—an illness might unite partners in new ways. For example, couples may work with each other to research treatments or seek out specialists. They may spend more time together at home or going to health appointments. For such couples, the recognition that life is fragile and that they have limited time to be together can spark a more nurturing relationship.

The family brought together by illness is a favorite topic and familiar cliché of movies, television, and popular fiction. This happens in real life, too, but far less often than the opposite—usually families, and in particular couples, face more difficulties in their marriage once someone becomes sick. In some instances, a sick partner changes the focus of the marriage and allows the original conflicts to take a back seat or to resolve. For instance, one of my patients is a middle-aged woman whose husband had been out of work for more than a year. For months, the focus of their marriage had been on helping him deal with unemployment and the associated loss of self-esteem. He was depressed, and they were battling because he wasn't actively seeking a new job. Then, rather suddenly, my patient developed severe low back pain that jeopardized her ability to work. Both partners focused less on his depression and more on her pain, which in turn helped mobilize him to begin actively looking for work. He found a job, and she was able to concentrate on getting medical treatment for her back. The conflicts surrounding his unemployment took a back seat and ultimately resolved when the focus of the marriage shifted from his issues to her medical condition. Of course, the problems

in a marriage don't always resolve so neatly. When issues are shelved and partners shift their focus, the relationship may worsen rather than improve. Chronic illness is a delicate balancing act for both partners.

Perhaps the most common emotions that couples must deal with are grief and loss. Elisabeth Kübler-Ross has described the five stages of grief that a dying person experiences. These same emotional stages apply to those persons in chronic pain, though not everyone experiences them all, or in the order that Kübler-Ross lists them. The stages include denial, anger, bargaining, depression, and acceptance. In the first stage (denial), both partners might be thinking that the illness or injury isn't really happening or will be over soon. During the second stage (anger) the couple may be wondering, "Why is this happening to us?" The third stage (bargaining) can involve thoughts such as, "just let me work until I put the kids through college," or "if I go to church regularly, then let this pass." In the fourth stage (depression), the couple must face the fact that the illness is not likely to go away. They must come to terms with that reality before they can move onto the final stage of acceptance. It's only by working through the grief that couples can come out on the other end of the cycle and figure out how to live their lives in a different but meaningful way. Just knowing that the feelings they are experiencing are shared by many people dealing with chronic pain can be a comfort to those in crisis.

The anger stage of the grieving cycle can be particularly destructive to a relationship. Both partners may be angry at the illness itself and wonder why they have been chosen to deal with such a blow. We all question why some people have terrible afflictions while others enjoy good health throughout their lives. There are no obvious answers to this question, and the only thing that we or our loved ones who are struggling with chronic pain can do is rise to meet the challenge.

Partners who are angry at each other often manifest their feelings in a variety of ways (for example, verbal or physical abuse, emotional withdrawal, substance abuse, and so on). Each partner might in some way feel that the other has contributed to the illness or the problems in the marriage. For example, a well spouse may believe that the pain person can participate more fully in sharing the workload. On the other hand, the person in pain may feel that the well spouse is asking too much of him. Both partners often feel angry with themselves, the situation, or