

## Living with Chronic Pain: Effects on the Partner

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*Pain Practitioner pp 20-30, Spring 2009.*

If you consider that two common consequences of chronic pain are difficulty getting around and concentrating, it is no surprise that people in pain are often accompanied to their clinician's office by a spouse, partner, or close friend. In many cases, this person is the most significant member of the patient's treatment team, and often the only reason he or she is able to lead a meaningful life at home. Yet, all too often, the practitioner's focus is limited to the patient, without fully appreciating the role of the partner and how the patient's chronic pain affects him or her. An issue devoted to comorbidities of chronic pain would be incomplete without a section on the fallout for the patient's family and friends. One woman explained:

*Since Paul's accident five years ago, he doesn't drive, so I take him to his doctors' appointments. I'm always in the examining room with him, but when the doctor asks me a question, it is always about how Paul is doing. My life was also changed drastically by the accident; it's practically a full-time job taking care of him. In the doctor's office, I feel like I'm invisible. No one asks me how I'm coping, or what my life is like! Counseling would have really helped us, but no doctor ever suggested it to us.*

Based on interviews with the partners of patients in my practice, this article addresses common challenges encountered by partners of people with chronic pain, and includes suggestions to help the partner to obtain the support they need.

### **Effect on the Partner's Life**

People with chronic pain may experience significant losses, such as decreased mobility; the inability to continue with sports activities, travel, or even go to the movies; job loss and decreased income; loss of ability or interest in sex; and a shift from well-being to depression. Such changes also significantly impact his or her partner. A 40-year-old woman related:

*Ever since I was a little girl I dreamed of getting married, having children, and being a housewife. I didn't go to college, since I planned on staying home and raising kids. I married this gorgeous guy with a good career, but after Cal's second back operation, and shortly after my second child was born, it became clear that I needed to get a job. It was overwhelming, taking care of the two babies and him, and working, too. I was very depressed for a long time, and I'd cry and cry when I was alone, so that the kids and Cal wouldn't see. Cal was also very depressed about losing his former life—he was in so much more pain after the surgery. He lost his mobility and his function was minimal. He couldn't be the dad he wanted to be.*

When one partner's ability to function is diminished, the partner's responsibilities increase; the partner may need to make an unanticipated career change—to begin an income-producing job or, alternatively, to stop working to take care of their children and/or the patient. If the couple is older, the healthy partner may be doing more physical activity than is comfortable. A 66-year-old woman reported:

*I wait on my husband more than I used to. We used to eat at the table, but now he likes to eat in a chair, and I serve him. When we're going on a trip to visit the kids, I'm the one who packs everything and loads up the car. I've had a lot of operations, too. Sometimes my bones hurt, I get tired, and I can't do things, so I just let it go.*

Other changes that partners may experience include a decrease in social and recreational activities. Since most of these activities also involved the patient, it is common for the partner to stop participating in these activities, rather than going alone or with other friends.

Friendships can also be adversely affected. It's easy for friends to empathize with someone who has an acute pain problem, but when conversations with friends repeatedly turn to the patient's chronic pain, friends tend to fall away. This problem worsens when the patient's pain and fatigue are unpredictable. Partners are likely to find themselves making excuses to friends at times when the patient does not want company or feel up to traveling. The couple may become isolated.

## Effect on the Partner's Emotions

Partners frequently report feeling helpless at their inability to solve the problem:

*My wife injured her foot and was almost bedbound for two years, with several operations and infections. Before, she had always been so active and full of life, but now she couldn't do much for herself. She was so weak and didn't feel well. Seeing this change was hard for both of us. I felt helpless whenever she had another setback, infection, or operation.*

*I would escape through my work—although I enjoy what I do, when I was at work I would worry. Once I got a call from a friend that my wife had to go to the emergency room. I was three hours away and felt so helpless! By the time I got there she was in the midst of emergency surgery.*

Partners also report feeling grief over the loss of their previous life. Such feelings are socially acceptable, but other common emotions are not, including: anger at the patient for the losses experienced by the partner; anger at the patient for personality changes, such as short-temper and irritability; and anger and resentment at people not in their situation. An evident disability—such as a leg deformity resulting from an injury—is easier to remember than a patient with an invisible illness, such as fibromyalgia, who may look perfectly healthy—making it easy to forget that a simple task, like reaching into the dryer to take out clothes, may be very painful. The partner may also feel resentful, and guilty for doing so, when the patient keeps asking for help with these

ordinary tasks. On the other hand, the patient may also feel guilty for constantly asking for help, and instead do too much, causing an increase in pain levels.

### **Effect on the Partner-Patient Relationship**

Chronic pain often has a major impact on their relationship, since both the partner and the patient may experience significant loss. Not only are they unable to share many activities they had enjoyed in the past, but conversations are now focused on medical problems, doctors' appointments, and financial concerns. For the patient, sex could be physically uncomfortable, and depression can decrease the libido. Many men believe that if you cannot have intercourse, your sex life is over. Sometimes couples cease all forms of affection. The partner may feel sexually unfulfilled or even rejected. When a man developed unremitting chronic back pain, his wife went into a prolonged depression:

*My depression was grieving for what we lost. I still love him with all my heart, but we haven't had sex for three years [she begins to cry]. We were very sexually active, and it is hard to live with this change. He thinks that if you can't have intercourse, you shouldn't even kiss. I've tried talking with him, but he doesn't seem to understand. I've been thinking maybe if we could go to the counselor together, but it's difficult to talk about sex with someone else. This loss isn't something that you just get over. I thought I was okay, but it's obvious to me now that I still have strong feelings about these things.*

In some situations, there is a gradual transition from an adult-adult to a parent-child relationship, a transformation that makes for a difficult marriage situation, and creates another potential problem. This is more likely to occur if affection is minimal and the couple's interactions are primarily ones of giving and receiving care. One wife reported:

*Since his head injury, it's like dealing with a child. We went to the store and he started opening packages. I told him he shouldn't, and he got upset with me. We both got angry with each other. Also, he feels angry with me because I'm no longer interested in sex. We need counseling for this. We have to come to terms with it, but we've been too busy up to now.*

The challenge for caregivers is that the more attention the patient needs, and the more the family is financially dependent on him or her, the less time he or she has for a counselor or support group.

Whereas some types of chronic pain syndromes involve a fairly stable pattern of pain, others are associated with often unpredictable periods of more or less pain and disability. This can result in significant frustration for the partner. One husband explained:

*When I ask my wife to participate—pay a bill, make a phone call, buy something—she usually agrees, but often doesn't follow through. If I later [learn](#) that the bill didn't get paid or the purchase wasn't made, and I ask or remind her*

*about this, she gets upset at being questioned. She says she fully intended to do it, but then she had a flare-up of her fibro pain or fatigue, and couldn't do anything but rest. This has become a real source of conflict between us. I hate to ask her to do anything, because I can never be certain it will actually get done.*

Although clinicians generally lack the time to do ongoing counseling, it behooves them to ask couples if follow-through is a problem—couples can set up rules regarding follow-through. The partner can give the patient a timeline in which to complete a task, and if the patient cannot complete the task, he or she will tell the partner. If the patient agrees to perform a task, he or she should make every effort to complete the task, even if it becomes difficult, rather than using illness as an excuse. If such agreements are unsuccessful, the couple should be referred for counseling, as ongoing disagreements can result in major resentments.

### **Frustrations with Compliance: When to step in, and when to step back**

Although the partner naturally wants to help the patient—and feeling helpless to remedy the situation is very uncomfortable—a big issue for partners is knowing when to intervene, and when to allow the patient to make his or her own decisions and to deal with the consequences. Dilemmas arise when the partner sees the patient doing too much or too little activity, or not complying with medications:

*The most frustrating thing for me was my husband still trying to do more than he was capable—like climbing ladders, knowing that doing so would aggravate his back. When this happened, all of us paid the price.*

Just as common is the opposite situation—when a caregiver is tempted to do too much, especially when he or she knows activity is painful for the patient. Maria related:

*Even getting dressed was painful for my husband. He couldn't reach his feet, so I helped him with his trousers. He was able to get his shirt on, although it hurt. I couldn't stay in the room when he was getting dressed. If I watched, it was extremely difficult not to help him. Yet, I knew that the squirming to get the shirt over his head was good exercise for him, and it was important for him to feel some independence.*

Another potential source of conflict is noncompliance:

*Kurt has severe osteoarthritis of his hips. When he did consult a physician, he self-managed his pain medications—he would raise or lower the dose on his own. I was terribly frustrated. I believe that if you consult an expert, at least work with him or her. We had lots of arguments about this.*

*The best advice I can give others in my situation is to stay out of the mix unless invited. I have also taken the position with him, however, that I find it difficult to hear his continual, repetitive complaints unless we are going to engage*

*in problem-solving. I encourage him to vent to a therapist, or someone else who does not live in our household. These changes on my part make for a more harmonious marriage.*

### **Holding in One's Feelings**

Partners are likely to develop strong feelings about their situation—sadness, anger, resentment—and subsequently develop guilt about having these feelings! All too often the spouse holds back these feelings in and says nothing. This is particularly true of men—a man whose wife has chronic back pain explained:

*My wife can't go places with me any more, or do things with me. I almost lead a single life. I'll go camping with my friend or go to a movie with my daughter. When I feel frustration or resentment, I just bury those feelings. I don't resent Ilene—it wasn't her fault! This isn't how I thought my life would be, but I just deal with it. How? I just suck it up. I don't bitch with my friends about it.*

It would be good for the partner to have open discussions with the patient the about the partner's fears, but frequent venting to the patient about the situation is also not good. The issue remains finding an appropriate forum for partners to express and work through their feelings, which is often not easy. Several partners reported that the time involved in caring for the patient, and the difficulty making plans to see friends, results in a falling away of friends, resulting in isolation. Others found communicating with family

members difficult. A woman whose husband was already disabled when she married him reported:

*I'm afraid to go to his family. I think they know I'm frustrated and unhappy right now, but if I said anything to them directly, they'd accuse me of being disloyal. I've tried talking with my mother, but she says, "I told you so, but you married him anyway."*

### **How Clinicians Can Help Partners of Chronic Pain Patients**

One of the most moving situations a physician can witness is how a partner supports and assists a patient with a chronic illness, injury, or disability. It is as though over the years, each member of the couple has built up a "bank account" based on shared experiences, loving gestures, and positive feelings. The partner draws on that account to give to the other what is needed, but if the account is not replenished, the partner risks "caregiver burnout," feelings of discouragement, anger, and depletion. It is important for partners to nurture themselves, so that the account does not run dry. How can this be done? The box below lists some possibilities. Recognizing that one cannot be an effective caregiver 24/7 is important. The partner needs to take some time out for him- or herself—to go to a movie, have a meal with a friend, or take a short trip—on a regular basis. Do this, even if means asking for help if the partner feels uncomfortable leaving the patient alone. Ask a friend or relative to stay with the patient, or hire someone.

**Tips for the Caregiver**

- Communicate with your spouse
- Plan enjoyable activities with spouse
- Make time for yourself (hire a helper if possible)
- Nurture friendships with sympathetic people
- Get a loving pet
- Have a sense of humor
- See a counselor
- Go to a caregiver support group
- Join a 12-step program (like AA or Al-Anon) or equivalent
- Look for the positives, but avoid unrealistic expectations
- Don't sweat the small stuff
- Ask for help
- Consider when to intervene and when to back off

Talking with others who are going through a similar experience, and who have similar feelings, both positive and negative, can alleviate guilt and help partners realize

that their feelings are normal and to be expected. Learning what has helped other caregivers might also result in solutions the partner may have never considered. Many cities have caregiver support groups, led by a professional, which provide caregivers with a safe place to vent and an audience who really understands and can give helpful feedback. Members can learn what has helped others to cope with their situation, and they can see that others who appear to have it worse have found ways to focus on the positive aspects of their situation.

Before you recommend a support group to the partner, however, be sure that the group's focus is on the members of the group, rather than the needs of the patient. One partner explained:

*I first went to a group for family members of people with my husband's disease, but the trouble was that the people who came were only able to focus on the ill person. They did not understand the need to take care of their own needs. They acted like I was selfish when I talked about my feelings. Where I really got help was my 12-step support group for my family addiction. There, I was able to talk about all my losses—my loneliness about my decision to not share my burdens with him, my anger about my losses, and my anger about my relentless, unending duties to him. I am sure I would not have survived otherwise. I certainly couldn't have taken care of him at home. The right support group can make all the difference.*

Finally, many partners benefit from seeing a counselor or other professional, who can validate their feelings, and help figure out ways to get the support they need, so that they can get positive meaning from a life that turned out differently from what they had expected.

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