

SECTION 6

FAMILY AND SOCIAL INTERACTIONS

This section addresses families and significant others. Often the forgotten clients, spouses, and children are greatly affected by the chronic pain experienced by a loved one. This section hits the highlights of how families are affected, including disruption to sexual intimacy. How to assess these areas and suggestions to improve coping are considered.





LIVING WITH SOMEONE WITH CHRONIC PAIN

BY ELLEN WEISS

My husband's chronic pain began more than four years ago after the removal of a spinal cord tumor called an ependymoma. The hotdog-like growth that was lodged inside the cervical region of his spinal cord had already caused damage to his sensory tracts by the time it was removed, and the surgery, while saving his life, probably added to the damage. After surgery, while still in the hospital, he thought he was having a heart attack—so powerful was the constricting feeling he had in his chest. But all heart-functioning measurements were normal. Over time, in addition to feeling like his chest was being crushed, new types of pain would emerge—deep bone pain in his arms, stabbing pain in the middle of his back, and tingling pain in his left leg.

Interestingly, my husband's stoicism probably made things worse. In retrospect he realizes that the odd aches and pains he felt for several years were probably harbingers of what was to come—an unrelenting, searing pain in his neck that led him to demand an MRI. I also can look back and realize that there were signs that I ignored, which has only made me super-vigilant to his present state. Unfortunately, this has been a source of tension between us over the years, and I'm finally learning how to be helpful yet distant, attentive but not obsessed about the pain that is so obviously a part of his and my daily life. One of our long-standing issues concerns talking about his pain. After he got home from the hospital, I remember that I wanted to know how he was feeling all of the time, and, therefore, I constantly verbalized my need to know. Months later, exasperated, Jon told me two things that I failed to note myself. One is that I probably could tell roughly how he was feeling by how he looked and acted. This was true. My senses had sharpened since his surgery, and I could detect subtleties in his voice, his face, and his body language that did provide cues as to whether he was having a good day or an awful one. The second important lesson is that he didn't want to talk about his pain all of the time because it reminded him how of much his life had changed. When it became clear that the pain in all its variations was only somewhat responsive to pharmacological, physical, and mental interventions, my husband applied for disability—an emotionally draining process.

So now I try to take cues from him regarding if and when he wants to talk about his pain, but it isn't easy. I've discovered that talking about his pain is an opportunity for me to feel that I'm doing something, even if it is only being empathetic and supportive. A particularly difficult subject to stay quiet about is that of pain management. Over the years I have read a lot of information, observed Jon's reactions to stimuli and drugs countless times, and therefore developed my own theories about what he should and shouldn't do. Unfortunately, Jon's pain has proven to

be highly unpredictable, which makes me want to scream. I have been humbled many times when my hunches do not pan out. Nevertheless, once in a blue moon I do come up with a valuable suggestion. But I've had to learn how to present such suggestions and ultimately leave the final decision to Jon.

A final observation about living with someone with chronic pain: Despite everyone's universal experience of pain, I find that most people can't conceptualize what it is like to live with severe pain all of the time, especially when one looks healthy, like my husband. Since I'm the only one who sees how his pain manifests day and night, I often feel defensive when someone comments about "how good Jon looks" or "how well he is doing." "Yes, but..." I reply as I try to provide some kind of reality check. But then I feel guilty for forcing people to face our personal struggles and difficulties. But how would they otherwise learn what chronic pain is really like?

Ellen Weiss works on HIV/AIDS issues at the International Center for Research on Women and is the current secretary of Pain Connection. She is interested in talking with other spouses/partners of people with chronic pain and can be reached via e-mail at eweiss@icrw.org

FAMILIES—THE UNIDENTIFIED CLIENTS

There are many issues that are not adequately addressed when dealing with chronic pain. Perhaps one of the most important is the family. Family members are the unidentified, forgotten, and even dismissed, casualties of an “invisible” health care crisis. Limited resources, insurance restrictions, lack of multidisciplinary treatment teams, and a poor understanding of the interpersonal dynamics influenced by chronic pain are some of the factors that contribute to this under-treated population.

Consider the following:

- ◆ Family members are up to four times more depressed than patients. (Turk and Melzack 2001)
- ◆ Studies show that 25% to 65% of individuals in chronic pain relationships note a decrease in marital satisfaction.
- ◆ Well spouses are more likely to report dissatisfaction with the relationship.
- ◆ Some researchers report divorce rates of up to 75%.
- ◆ Women, more than men, seek out treatment for pain. Women typically report more pain than men. Some factors possibly contributing to this gender gap include biological/hormonal factors and social factors in which it is more acceptable for woman to report pain.
- ◆ Cultural and socioeconomic differences may impact how people respond to pain (for example, there are cultures where higher levels of pain must be tolerated due to economic factors).
- ◆ Perceived partner support may be linked to lower levels of depression in people with chronic pain.
- ◆ Family support may be linked with better outcome of pain treatment.
- ◆ Histories of physical or sexual abuse or of neglect may be relevant to coping ability and adjustment to chronic pain. It may also be linked to higher utilization of health care.

It is important to assess family issues that can impact treatment and quality of life:

- ◆ Is the relationship stabilized or destabilized by chronic pain? Does caretaking enhance or diminish the sense of closeness? Is there a fear that improvement could destabilize the relationship?
- ◆ Are there beliefs that the pain signals harm or damage? Does this contribute to limited activity level or increased partner activities?
- ◆ Does the family discourage well behaviors due to fear of injury? Does this interfere with functional improvement?
- ◆ Could depression be contributing to decrease in sexual activity?
- ◆ What are the strengths and resources of the family that can be utilized, such as humor and religious beliefs?

Interventions:

- ◆ Assess family.
- ◆ Educate regarding chronic pain.
- ◆ Normalize changes and support role adjustment.

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ASSESSING FOR FAMILY ISSUES

Consider the following

When assessing clients and families, the outline below can be used to highlight some important areas.

Quality of the partner relationship

- ◆ Is the partner/family supportive, blaming, stressed?

Adaptability—how well has the family adapted to change?

- ◆ How have roles been strained/changed?
- ◆ How does the family perceive these changes?
- ◆ Sexual adjustment—it is important to assess the level of sexual, physical, and emotional intimacy.

Communication

- ◆ Does the family talk about how pain has affected relationships?
- ◆ How is pain communicated?
- ◆ Does the family know how to communicate when pain levels are high?
- ◆ How has communication changed since the onset of chronic pain?

Activity

- ◆ How has chronic pain affected individual and family activity level?
- ◆ What traditions have been maintained?
- ◆ How has chronic pain affected family vacations or travel?
- ◆ How has it affected social activity level?

Belief/perceptions of chronic pain

- ◆ Is the family educated on chronic pain? Do they believe that chronic pain indicates ongoing physical damage?
- ◆ Do they still value the family member?
- ◆ How did the families of origin for both partners deal with pain?

Finances

- ◆ Is there a loss of income?
- ◆ Has disability been approved?
- ◆ Have there been career changes?
- ◆ Is there litigation?

History of each family member influences adaptability, beliefs, and perceptions

- ◆ Substance abuse history.
- ◆ Mental health/trauma.
- ◆ Chronic pain, illness, disability.

CHILDREN WHO HAVE PARENTS IN PAIN

by Mary French, RN, MSW, LCSW-C

We know that children are directly affected by parental mood and health. Children of parents with depression are at a much greater risk of becoming depressed, experiencing behavioral problems, and slowing cognitive development (Beauchesne 2006). When mothers have been treated for depression, children have less psychopathology.

Depending on their developmental stages, the children may experience vicarious traumatization based on witnessing parental distress. They may be frightened unnecessarily due to a lack of age-appropriate information. They may feel abandoned by both parents as energy in the family shifts from the children to the sick parent. They may experience a profound sense of loss for the parent they had before chronic pain.

Children need reassurance that they will be cared for by loving adults. Education of family members to limit exposure to age-inappropriate information can assist in maintaining the mental health of children in a highly stressed system. It is important for children to be assessed for emotional, behavioral, and cognitive problems when a family system is stressed by chronic pain.

Useful information is noted below:

- ◆ Children are affected by parental emotional states – treat the parent, and you are treating the child.
- ◆ Educate parents and providers about identifying childhood depression.
- ◆ Irritability and anxiety are more prevalent in children who experience depression than in adults.
- ◆ Infants may experience failure to thrive, withdrawing or self-comforting behaviors, avert eyes, lose postural control.
- ◆ Preschoolers may have enuresis or encopresis. Playing may become aggressive or destructive. They may demonstrate repetitive behaviors.
- ◆ In older children and adolescents, you may notice irritability, mood swings, acting-out behaviors, substance abuse, running away, influenced more easily by negative peer pressure.
- ◆ Educate parents not to “parentify” children.
- ◆ Safety of environment – work with parents to ensure medications are out of reach.
- ◆ Find ways to maintain physical contact – provide transitional objects such as special “hug me dolls” wrapped in parent’s clothing.
- ◆ Suggest parents’ record books and soothing stories if hospitalization of parent occurs.
- ◆ Notify school counselors to widen support circle for children.

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Pain Man



Drawing by Debbie Hammack, daughter of a support group member.



FEEL LEFT OUT?

HANDOUT INSTRUCTIONS

The following handout can be used to prompt a discussion on how family members, significant others, and friends are affected by the client's pain.

Notes:



FEEL LEFT OUT?

BY *MAYAN HERMAN*

Many children have parents who cannot do anything with them because of the chronic pain. Then children start to feel left out. When your child is younger, at least 3 through 6, your child will not understand what chronic pain is and why you feel the way you do. Children may think you are mean. This is because the pain makes you act angry. The pain can cause you to say mean things to your family and children that you will feel bad about later. Your child could soon start saying the usual words, “I hate you” or “You are the meanest mommy or daddy in the world” back to you. Once the child starts to say it, it can quickly become a habit for them. This is when talking is so important. When the angry words are thrown at you, talk to your child. Remember, your child does not know how terrible and horrible your pain is. Sit down with your child and explain what chronic pain is and how it makes you act. It is good if your child asks many questions because then they can get a better understanding of how you feel. When the child gets older, it gets harder for the parents. Children want to go out with friends but the parents say no. The child can start to say their usual words of anger. Maybe your child will burst out in tears and say, “You never do anything with me” or “You miss all my field trips in school.” Parents suffering with chronic pain have a hard time being at their child’s activities. The pain stands in the way.

It hurts to hear your child say these things. It hurts when you feel left out of your child’s life and watch your child feel left out of your life as well. This is why you must talk to your child about chronic pain. But instead of just giving the facts, give tips. Let your child write down some tips for him or herself. Tips could include relaxation, meditation, or coloring. Get together with your child and come up with tips to help both of you cope. Sometimes just letting yourself cry can help. It is better to let out what you feel than to keep it inside. When your child finishes the tips, you should read a chronic pain book together. Take your child to a support group. Remember to spend quality time with your child and explain to your child when you cannot do certain things because of the pain. It is very important that your child understands what chronic pain is. Don’t let yourself or your child feel left out.

Mayan is age 10 and is the child of a chronic pain sufferer.



WHAT YOU CAN DO TO HELP

HANDOUT INSTRUCTIONS

Many times, family members, significant others, and friends are at a loss as to how to help their loved one. The following handout provides guidelines and suggestions for helping.

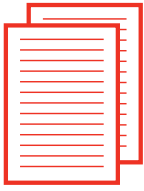
Notes:

WHAT YOU CAN DO TO HELP

by Gwenn Herman, LCSW-C, DCSW

Advice for family and significant others of chronic pain sufferers

- Don't tell the injured person the pain is in his head. It is real. The physical pain eventually creates emotional problems, but they are usually secondary to the pain.
- Help the injured person set realistic priorities. Look at the day's events and help plan out the logistics.
- Don't let the person in pain go to the doctor or undergo any medical test alone. Frequently, the person is asked to make medical decisions concerning his life when he is totally overwhelmed by what he heard or when the pain is too great to make a major decision.
- Support the person's rights to get the best medical treatment and to seek second, third, or even fourth opinions until medical questions are answered.
- Regarding medications: if the doctor is unreachable, you can always call your local pharmacist to find out about the medication and its side effects. Usually, sufferers are given insufficient information and side effects can be devastating.
- Read literature about the person's condition so you are knowledgeable and can ask appropriate questions.
- Help the person prepare a list of questions for the medical provider and encourage him to insist on obtaining complete answers. Don't feel intimidated by medical providers for your concern; you are looking out for someone's welfare.
- Help organize family and friends to do errands and give support.
- Don't forget the children. Their needs are just as great because their sense of security is shaken. Explain to them what they can understand, which is more than you may think.
- Take care of yourself and try not to get too enmeshed.



INTIMACY AND SEXUAL RELATIONSHIP

HANDOUT INSTRUCTIONS

Helping professionals

Use this article with your clients to discuss how the couple is dealing with intimacy and their sexual relationship. Help them think of ways of getting close again, how to develop friendly, usable positions, and deal with unrealistic expectations and disappointments. Talk to your single clients about how this affects them as they develop new relationships.

Notes:

INTIMACY AND SEXUAL RELATIONSHIP

by Gwenn Herman, LCSW-C, DCSW

It was just one more loss I had to deal with but this one was ripping me apart. Ever since my husband and I were together, I always slept on his chest with his arm around me. And now I couldn't even do that.

Chronic pain enters every aspect of a person's life, especially intimate and sexual relationships. This subject is rarely talked about with medical providers, mental health professionals, or even in support groups. Sex is still a taboo subject; add pain to that and the silence becomes deafening.

What components interfere with a normal sexual relationship when you have pain? The pain itself, effects of medications, and emotional fears.

There are many side effects from medications which inhibit sexual enjoyment and performance. Taking pain medications is always a balancing act of the benefits, quality-of-life issues, and side effects—only you can make those decisions. Sometimes the side effects do go away with time, and patience is needed by both partners. Talk to your doctor about other methods of enhancing your sexual life or the possibilities of changing medicines if you are unable to live with these changes.

Pain takes out the spontaneity, romance, and fun of being with your partner. Pain depletes energy, causes depression, and can deaden sexual desire. It's hard to feel pleasure when you have pain. You feel you have nothing left to give; after sex you are exhausted from the effort and need time to recuperate. This creates another loss, deeper depression, and a wider gap between you and your partner.

Over time, you learn to cope with your pain on a daily basis. You also need to learn to cope with pain and your sexual life. Just the way you re-created and re-learned, how to live with pain, you need to re-create your intimate and sexual life.

Your spouse/partner is also affected by the pain—exhausted from taking on extra chores, worrying about you, then angry and resentful at you, and fearful of hurting you during an intimate/sexual act. Your spouse/partner has feelings of guilt that he/she can go on with his/her life and feel pleasure while you are unable.

The first step to re-creating your sexual life is to talk to each other about these feelings. If you are unable to do this, seek counseling. The next conversation needs to be what you are able to do sexually. Decide if touching, kissing, or simple massages are okay. Pick a part of the body that does not hurt. Brainstorm about which props need to be used to enable closeness, such as pillows, wedges, special lubricants, non-fragrant oils, etc. What time of day is better for you?

Experiment using different positions. Remember the first time you ever kissed someone, the first hug, the first touch? The awkwardness and the fear of not knowing if what you were doing was right? This is the same thing on a new level. This is the first time you have had to deal with intimacy and pain. It will be awkward, and it won't be spontaneous at first. It is a learning process. Allow yourself to learn about your body, about your partner's body. Pretend that

you are writing a book for chronic pain and handicapped people and inventing new “friendly, usable positions.” Don’t take yourself so seriously – enjoy the humor of your clumsiness.

*... now I hold his hand as we fall asleep, touching his pulse to feel his heart beat.
I am truly blessed...*

For more in-depth information

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THE EMOTIONAL ASPECT OF DISABILITY AND CHRONIC PAIN

by Gwenn Herman, LCSW-C, DCSW

Filing for disability is an emotional endeavor for someone in chronic pain.

- Admitting that you have changed is devastating.
- Admitting that you cannot go back to work is devastating.
- Admitting that the life that you dreamed of has been destroyed by the pain is devastating.

The actual paperwork is grueling. It is time-consuming. It takes great concentration, which is hard for someone suffering from pain.

Very few people get accepted for disability the first time they apply. Getting turned down is awful. Reapplying breeds resentment. Getting turned down again is totally crushing. Many stop here.

The search for a disability lawyer is the next step, and it is difficult. Going to the meetings creates an emotional upheaval because you have to tell someone that you are unable to work. You have to prove that you are sick. You have to accept being seen as disabled, a label that you have fought for a long time.

Contacting your doctors and having them fill out your papers is crucial. Some doctors refuse to get involved because they don't want to do the paperwork. Organizing your medical records and making sure you have everything is difficult. Reading what some of the doctors think of you can be horrifying! Words are often used like: guarded, malingering, no medical evidence why he/she is not getting better, shopping for doctors, wants a miracle cure, drug seeking, angry, won't follow treatment—and you may not have even told them half of your symptoms for fear they won't take you seriously.

You finally admitted that you are unable to work, and now someone will try to prove that you are lying or malingering. You question yourself for the hundredth time— is my pain really real? Or could it be that I am imagining it all?

People may tell you not to take it personally, that it is all a game. That is true—it is a game, but you do take it personally. It is your life that you lost. It is real.

Going to court is Judgment Day. A judge will declare if you are lying or not, whether he believes you or not. You are afraid and wonder if you will survive the ordeal of just getting to court. How will you sit for so long?

You also can't believe that this is actually happening. You worked hard all your life, and probably did not plan to stop working. Early retirement was never an option.

The way they treat you, you would think that you could actually get rich on disability! To be real—it's poverty level. It doesn't come close to what your paycheck once was. You can't understand why anyone would lie to go through this.

Is there any justice when it comes to pain? How can anyone judge how much pain you are in? The only one who can define your pain is you. You know how much the pain has changed you.

The decision is in. Two scenarios:

Yes, you won. Someone finally believes me. After the euphoria, it hits you, “I am disabled.” Depression overcomes you. Now what?

OR

No. Another humiliation, another defeat. Do you stop here or fight? Appeal?

Aftermath

You’re thinking: “Now what do I do? I’m not dead. I don’t function like I used to. I don’t like myself this way.” It doesn’t matter in the end if you won or lost because the real question you must answer is: “**How do I not become my disability?**”

Say goodbye to self-pity – it really doesn’t help you; it keeps you disabled. It’s time to pick yourself up and become “abled” again.

You will need a lot of help. Don’t think that you can do it alone. Find a mental health professional who can and will help you pull through this nightmare and make sense of it all.

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TIPS FOR DEALING WITH PEOPLE IN CHRONIC PAIN

COMPILED BY DENNIS JAMES CAPOLONGO/
END DEPO NOW CAMPAIGN (EDNC)



1. Those of us with chronic pain may appear to be unreliable. When we are feeling better, we promise things (and mean it); but when in serious pain, we may not be able to follow through on what we so very much wish we could do. We find it difficult to count on ourselves at times, but it doesn't mean we wish it to be this way.
2. An action or situation may result in pain several hours later, or even the next day. Delayed pain is confusing to people who have never experienced it.
3. Pain can inhibit listening or distract from other communication skills. Imagine trying to talk over a fire alarm or have a productive conversation while people are shouting in the background. The effect of constant pain on the mind can mimic an attention deficit disorder because of the constant distraction the pain causes. So you may have to repeat a request or write things down for a person living in chronic pain. Please don't take it personally or think that we are stupid or careless.
4. The senses can easily become overloaded while living with pain. For example, noises or stressful arguments that wouldn't normally bother you can be overwhelming for someone in chronic pain.
5. Patience may seem short with those who live in pain. We can be misinterpreted as being rude and impolite at times. We find it difficult to keep sharply focused on what we are saying so it can be hard to tolerate long drawn-out conversation or fun debates. We do wish to participate and enjoy your company, but sometimes we may not be able to.
6. When we are asked, "How are you doing?" be genuinely prepared to listen to a horrific response because otherwise we must deny the truth to you about our daily lives. That question can mix up the emotional knots that we keep locked up inside as we learn to hide, tolerate, and live with our pain.
7. Pain can sometimes trigger physical or psychological disabilities. When in pain, a small task like doing the laundry can seem like a huge wall too high to climb at that time. But in an hour or so, the same job may be quite possible! It is sane to be depressed occasionally when you constantly hurt. We sometimes simply require more time to get it under control.
8. Pain can come on fairly quickly and unexpectedly. Pain sometimes abates after a short rest. When people with chronic pain are invited