

FAMILY MATTERS: Coping Within the Family

Penney Cowan:

We all need support and encouragement. Not just people with pain, but those who live with them. Knowing that you're not alone can reduce the sense of isolation that comes with living with, and caring for, a person with pain. Talking with others who share similar situations can help in many ways. Family groups can be key to how well you cope with chronic pain.

Woman 1: We had plans. We had a good life, and it's gone. He's changed; he's not the man I married.

NARRATOR: Loss.

Woman 2: What's going to happen to him? What if it gets worse?

NARRATOR: Fear.

Man 1: Why isn't there a cure? That doctor hasn't a clue. How could this have happened to us?

NARRATOR: Anger.

Man 2: There's no end to this. I can't see a way out. It's like a bad dream.

NARRATOR: Depression.

Man 2: It feels as if our world is falling apart.

NARRATOR: In our last video, we talked about letting go of blame and guilt and accepting that a member of your family has chronic pain.

Letting go is impossible without recognizing the strong emotions families feel when they are confronted with the reality of chronic pain. Even though only one person feels the physical pain, the whole family feels the effects.

Sometimes, family members of a person with pain need to speak the truth, and speak it bluntly.

Woman 1: Living with him has been terribly draining on me. First, I have to watch him

suffering, which is very difficult to do. I feel like I have to be strong one when he's weak, brave when he's most fearful. Whatever spare energy or resources I have, I devote to making his life more tolerable. This is 365 days a year, without a break. I'm just so tired of all of this. I feel numb.

Man 1: Pain brought all kinds of changes we didn't expect. We wanted a big family, but with my wife's condition, kids aren't going to be part of the picture. We both feel cheated.

Woman 2: Pain is running our family now. We must always address the pain before we do anything else. It demands our attention. It intrudes and controls. It has drained our bank account and our freedom is gone. My freedom is gone.

NARRATOR: For many, pain is more than just an unfortunate fact of life...it is an unwelcome visitor who invades our homes, haunts our families and, unless we find a way to put it in its place, will take over.

Man 1: My wife is obsessed with her pain. She doesn't want to talk about anything else...just wants to be left alone. We used to be social people, but...our old life is gone.

NARRATOR: You may feel cut off from the world, but in fact, chronic pain affects many families. In the U.S., over a hundred million out of roughly three hundred million people suffer from chronic pain. That's right, one in three.

Modern medicine may have lengthened our lifespans and improved survival, but it also means that living with pain, or someone who has pain, isn't the exception -- it's the rule. So you are far from alone in suffering the effects of a loved one's pain.

Woman 2: His pain is so variable, I don't want to bother him on good days, I won't bother him on bad days. We have no insurance! We're living paycheck to paycheck--no cushion at all. We're also in debt, being sued for medical bills. And everything is on me.

NARRATOR: Credit counselors help families get out of debt, and might very well help you. New health insurance laws could help you as well. ACPA has links on its site that can help you find trustworthy financial information. You can go to Healthcare.gov for information on affordable insurance options.

Woman 2: I can't shut down my mind at night. I worry about the bills. I worry that my health will go too. What's going to happen if I get sick?

NARRATOR: People fear the unknown, and with chronic pain, there are many unknowns. The most powerful way to reduce fear is with information. It's important to maintain open communication within the family, and with the loved one in pain. It's common for families to try to shield him or her from worry, but this can prevent the person from taking as active a role in family life as might be possible.

Pain doesn't mean your spouse is suddenly a baby. If you married an adult, you are still married to an adult, with the same right to know the full picture as you. The person with pain is the only one who can tell the family what he or she is capable of doing...so ask.

Man 2: I have a fear I can't shake. My wife's last flare-up was really bad, and...she talked about hurting herself. If this is what the future holds, and I'm afraid she'll do it. I don't dare leave her alone. We're all taking turns watching her, but we're completely on edge.

NARRATOR: You have a serious situation that requires action. If your loved one threatens suicide, talk to their primary health care provider immediately. Family members aren't trained to deal with such a threat. It puts the family under tremendous pressure. Informed assistance from the outside is required. Counseling and medication can make a difference in many cases. Take every suicide threat seriously and ask for professional help.

Poor communication can damage families. The person with pain may be afraid to report new symptoms, the well spouse may be afraid to upset the rest of the family, and misunderstandings and grievances may build and fester.

Woman 1: My husband lashes out at me when he feels bad. I know it's the pain talking, so I can't say anything back.

Man 1: Whenever she says she's in pain, I don't always believe her. Now maybe it's just my imagination, but it seems to get worse whenever I have plans of my own.

NARRATOR: Our loved ones don't always act the way we'd like when they're healthy, so the onset of chronic pain creates extra tensions. People with pain may fear they won't get what they want if they just ask for it. They sometimes resort to methods that they think will work, but only deepen mistrust and resentment.

Man 1: I don't know. Maybe it's the stress of being alone that makes her muscles start to cramp. It seems like every time I'm out and I just begin to relax, my cell starts to ring.

Nicole Kelly 2/10/15 10:56 AM

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Woman 2: He thinks his pain trumps any trouble the rest of the family has, so he doesn't want to hear our little problems. I just bite my tongue, but I'm boiling inside. Someday, I...I'm afraid I'll burst!

NARRATOR: It's more productive to deal with your feelings as they occur, rather than letting them build up inside you. You can express your feelings without stepping on those of other people by using assertiveness.

Assertiveness is a technique for communicating your position clearly, but not aggressively, using "I" statements about yourself and how you feel, rather than attacking the other person. There are tips for learning assertiveness in the ACPA *First Steps* and *Family* manuals. When family members speak assertively, they can open channels and speak honestly without hurting each other.

Woman 1: When I feel tired or uneasy, I'll turn to online forums, but the commenters can be more aggravating than my husband!

NARRATOR: Being angry doesn't make you a monster. Chronic pain is terribly difficult to live with for the whole family. You may still feel anger that you need to express safely.

The ACPA suggests you try keeping a journal. Keeping a journal of what you feel provides not only a sense of relief, but perspective. It gives you a safe outlet for your feelings, as well as a way to review your progress through life. The ACPA manual has information on journal-keeping that you may find quite helpful.

Anger is looked in most cultures as something negative, to be avoided. Children are taught not to show anger, that it is associated with rage, violence, and irrationality. But anger isn't always something to avoid; properly channeled, anger can be useful, protective, and even healing.

Man 1: It's really done a number on our sex life.

Woman 2: We lose out to his pain meds half the time.

Man 2: We don't touch anymore. She's afraid to.

Woman 1: We tried, but it was more pain than it was worth.

NARRATOR: Sexual intimacy is a frequent casualty of chronic pain, but it doesn't necessarily have to be, and physical and emotional intimacy certainly doesn't have to stop.

Once again, the need for honest communication is clear. Not talking openly about sex can mean a couple's relationship isn't as physically pleasurable or emotionally rewarding as it could be.

The ACPA has recommendations for couples that can help, including books specifically addressing the mechanics of sex with chronic pain. People with pain and their loved ones need to mourn the losses brought on by chronic pain and what was, before going on to handle what is and will be. What was once normal isn't normal anymore, but it's possible to create a new normal, and sometimes the new normal is pretty good.

It's important to remember that you have a right to reach out and ask for help. In our next video, we discuss putting pain in its place while paying attention to the needs of ALL the members of your family.

With the collective wisdom of others who have been there, such as members of the ACPA, you can find outside resources, and resources within yourself to help you and your family carry on. We can't always heal the pain, but we can learn how to heal the family.