

## **FAMILY MATTERS: The Impact of Pain**

### **Penney Cowan:**

Chronic Pain is a family matter. When someone's life is consumed by pain, he may not be aware of the significant impact on the family. What are their needs? What impact does chronic pain have on their quality of life? Let's see what it looks like for family members when chronic pain becomes part of their daily life.

**Woman 1:** Sometimes, I feel like this pain is the only thing in my life.

**Man 1:** Sometimes, I feel her pain is the only thing in our lives.

**Man 2:** My physical pain makes me feel like I'm living in solitary confinement.

**Woman 2:** Pain adds all kinds of invisible barriers to life...and they're smaller and more restrictive than the ones that were there before.

**NARRATOR:** Chronic pain can define our life as a patient, or define the lives of the family members who are caring for the person with pain. The impact of pain cannot be minimized or ignored. It is a very real thing. There are two basic types of pain: acute and chronic. Acute pain is sudden, intense pain that is typically associated with a disease or illness.

Chronic pain is different. It may start like the acute pain of illness or injury. However, chronic pain does not get better over time the way you might expect it to. It may fluctuate, but it just won't go away.

**Woman 3:** There was a time when acute pain prevented me from even being able to carry a garbage can. Today, I'm doing much better. It feels really good getting back to normal.

**Man 3:** I have chronic pain and life is a crapshoot. I took care of all the heavy lifting for the family, and now they have to take care of me while I watch them struggle.

**Woman 4:** Since he got hurt, our whole life is different. I'm afraid we're never going to get back to normal.

**NARRATOR:** It's difficult enough to be the one suffering from chronic pain. Pain can't

**be seen, weighed, or measured by ordinary means. But how about the family of the person with chronic pain? They may not be able to feel the pain itself, but they suffer from its effects as well, in ways friends, other family members, and the medical community often don't understand, and frankly, sometimes don't try to understand.**

**In these three videos, the American Chronic Pain Association wants to address the needs of the caretakers and family of the person with pain, to give you tools and techniques for coping, to let you know that you're not alone, and to give you hope that yes, you can rebuild and manage life as a family even after a loved one develops chronic pain.**

**Girl::** How was that?

**Dad:** Nice shot honey. Let's wrap it up for today, okay?

**Girl:** But you weren't even watching!

**Dad:** I said, let's wrap it up okay?

**Girl:** But we just started. You hardly ever play with me anymore. You don't come to the games like the other kid's parents. Nobody's out there cheering for me.

**NARRATOR:** Because it often fluctuates, chronic pain can be confusing and frustrating for the whole family. Your loved one may look and feel all right one day, and be out of commission the next. An active day may bring on pain, but inactivity may cause pain as well. A number of variables including times of day, weather and assorted medications can make it hard to know what's going on, and even harder to explain to others.

**Man 1 (speaking on phone):** We're going to have to cancel dinner tonight, Joe. She's just not up to it...Oh come on now, you know better than that!

**Man 1:** I've had to cancel on Joe and Barbara the last two weeks, but then we bumped into them grocery shopping on Saturday. I've tried to explain that my wife's having a flare-up, but...sometimes I just have to wonder myself. It seems like her pain gets her out of a lot of social situations.

**Woman 1:** My pain gets worse at night, but I'm afraid to ask for more medication--I can tell my doctor already thinks I'm a hypochondriac. It doesn't make me very pleasant company. I'd rather just stay home when I feel so bad, but it's affecting our social life.

**(Voice on phone):** Well, give her our best, but tell her we're counting on her next week.

**Man 1:** We'll try. I can't make any promises though. You know how it is.

**(Voice on phone):** Hey, if I could get on disability like you guys, I'd sit home and watch TV, too!

**Man 1:** (hangs up) Or maybe you don't know how it is.

**Man 1:** We've broken a lot of promises since the pain began. She backs out at the last minute. I just can't just leave her at home by herself.

***(Different Voice Overs)***

-- *I'm sorry, I have to stay home and take care of Mom.*

-- *I need to make sure he takes his meds.*

-- *How are you feeling, honey?*

-- *Are your pills running low?*

-- *Let me get that for you.*

-- *Don't get up; I'll do it.*

-- *I'm calling the doctor!*

-- *Not today, my husband needs...*

-- *My wife needs...*

-- *My son needs...*

-- *Not today.*

-- *Not today.*

-- *Not today.*

**NARRATOR:** There's another difference between acute and chronic pain. When your loved one is acutely ill, naturally the family tries to do everything possible to comfort the sick person, from rescheduling their lives to be there, to waiting on the person. It's an emergency.

When pain becomes chronic, life must still go on for the whole family. You have to find a way to shift out of “emergency mode,” and settle into a new reality in a way that makes sense.

While one family member may feel the pain physically, the stress is felt by the whole family, and the whole family must deal with it, or else it may become too much to handle.

**Man 2:** You got the gallon-size milk again? You know I can't lift that jug. I'd like to be able to pour milk over my bran without flooding the place.

**Woman 2:** I sure know when he's feeling bad. Sometimes he's very short with me, and I have to remember: it is not me he's yelling at -- it's his pain. Sometimes I wish I could just yell at his pain, too!

**Man 2:** She comes home from work and she's totaled. And I'm still dealing with the kids and the housework and getting meals on the table. And right now, I'm hurting.

**Woman 2:** My husband's on disability now, so we've had to cut way back. We used to travel, we used to entertain, we used to have savings and plans for retirement. Those days are over!

**Man 2:** I couldn't get along without you. I need you so much.

**Woman 2:** This is a terrible thing to say, but I used to love to hear those words. Now, it's...just what I'm afraid of.

**NARRATOR:** No, you are not a terrible person for having these thoughts. You're experiencing natural, and common emotions. Anyone shouldering a burden of responsibility once shared by two is likely to feel stress and anger at the situation, and often, at your spouse. This doesn't mean you are a bad person and don't love your

partner. It does mean that you need help to continue to function as a family member and as an individual, and furthermore, you have a right to ask for help, including help from your family member with pain. The ACPA has ways to strategize so that the burden of responsibility doesn't just fall on you. Everyone, including the person with pain, has something to contribute.

Chronic pain doesn't have to rule your family. You can move on, and learn to manage it. You will need to accept that this is not something that's going to go away; this is a new reality. Accept the fact that it has happened and deal with the feelings arising from it.

***(Different Voice Overs)***

*-- If I'd only been there when she fell.*

*-- If I'd just told him that box was too heavy!*

*-- If we'd just gotten a second opinion.*

*-- In a moment, our lives changed forever.*

*-- I feel so guilty.*

*-- We should have known what was happening!*

*-- I should have seen there was something wrong.*

*-- There must be something I could have done.*

**NARRATOR:** The first step in the ACPA's Ten Steps From Patient To Person is **“Acceptance.”** Before any person with pain can move on in recovery, he or she must accept that the pain exists, and no amount of anger, guilt, or blame can change that fact. While it's understandable that you might want to know why your family seems to have been singled out, you're not likely to get that answer. Even if you were given that answer, would it help you to handle what lies before you? Family members need to support each other. When your family works together as a unit, you can improve your own lives as well as that of your loved one with pain.

In the videos to come, we will look in-depth at the emotions brought up by chronic pain, and how the family can deal with them. We wish you the peace that can come

**from accepting the fact that some things are beyond your control, and the healing that can come from letting go of blame and anger.**