FAMILY MATTERS SERIES

FAMILY MATTERS 1: Healing the Whole Family

Penney Cowan:
Chronic Pain is a family problem, and that includes children. Children can misinterpret situations, and take blame for things that are completely out of their control. It’s important to talk with your children about the limits pain may put on family life. Help them cope with their feelings, and always remind them that they are loved.

CHILD: We used to have so much fun. Mom and Dad would take me camping, and Mom and I would ride all the rides at the amusement park together. But that was before.

NARRATOR: What if you were a child and everything about your life suddenly changed?

CHILD: Now Mom just lies in bed with the TV on all day.

NARRATOR: You didn’t know why, but it seemed you were being punished for something.

CHILD: I can’t play baseball any more, and no summer camp, either.

NARRATOR: And your parents started sounding angry and upset.

CHILD: They argue over me. Mom’s stuck in bed. Dad says, “Why don’t you help out more?” and “This place is a mess!” Mom just cries.

NARRATOR: You might try to figure out what went wrong.

CHILD: They stop talking when I come in. They say, “Go to your room and try to keep it down.” Noise gives my Mom headaches.

NARRATOR: And decide that what’s wrong is YOU.

CHILD: They’re angry with me because I’m too rough and careless and I hurt my Mom.

NARRATOR: Just as a person is more than pain, a family is more than one person’s pain. It isn’t easy, but it’s vitally important to pay attention to the needs of the whole family, especially the children, who may not understand everything going on, but see and hear more than adults think they do. It’s surprising how many children blame themselves for family troubles.

When adults don’t include children in serious discussions, the children are left to try to explain this new, painful world to themselves.
CHILD: I was fooling around and I hugged her 'round the neck and she yelled out really loud. I think that's when it happened.

NARRATOR: And what they come up with on their own can be deeply damaging to their developing selves.

CHILD: If it wasn't for me, she'd be all right now.

JOANNE SCHNEIDER – Cleveland Clinic:
Parents can use their pain to control children on occasions to try to manipulate the situation. Often times, parents lose a lot as a result of the chronic pain. They're unable to work, they have lost friendships, they're not able to get out and do the things they want to with family, friends. So it's a way of keeping children closer to them, closer to home, to help out with some of the home responsibilities; it's unfortunately, on occasion, a way of manipulating the situation.

CHILD:
I get home right after school, so I don't have a lot of friends. I do the housework and the laundry for my Mom. I try to do everything she'd be doing if it weren't for me.

JOANNE SCHNEIDER – Cleveland Clinic:
Children can get very frightened with the situation if they don't have all the facts and they don't understand what's going on. They can blame themselves. They can wonder, “If I were doing things differently, or if I did things differently, would the situation at home be better? Would my parents not suffer the way they are?” It's important for you as an adult, as their parent, to spend time explaining what chronic pain means. Letting them know that you still love them just as you did before. That they are not to blame for the pain that you're experiencing. When children become depressed by what is going on within the family situation, when they see a parent that's suffering with pain, they become very overwhelmed; they may become frightened. So with that depression that comes as a result, they may become very withdrawn. They don't participate in school, sports activities, you may see their grades tend to drop, they may lose some weight, they may not be sleeping well.

NARRATOR: If you think your child is suffering from depression, seek professional counseling. A professional will be able to help your child through feelings that your child may not be comfortable expressing to you.

CHILD: I get it now -- that it's not my fault. Since my parents started talking to me about mom's pain, I don't feel so afraid all the time now. We're even starting to find things that we can do together.
NARRATOR: The family unit is a structure that is supposed to nurture ALL the members within it, to help equip the children for launching themselves into adulthood, and to provide physical and emotional support to parents.

JOANNE SCHNEIDER – Cleveland Clinic:
Chronic pain is a family illness. It doesn’t just affect the individual who is experiencing the pain on a physical and emotional standpoint, but it also affects those around them who care about them. So they suffer on an emotional level. They may assume a lot more responsibilities at home than they had before, and whether that’s working inside the house, outside the house, more child care; they’re doing things to prevent the individual or their family member -- their loved one – who has chronic pain, from suffering. They forget to take care of themselves. and what ends up happening is they suffer. Their needs aren’t being met.

WIFE: I don’t even remember what I like to do any more. I work, I drive home, I get through the door, and sometimes I don’t even get my coat off before it begins (imitates Husband’s voice): “Honey! I need an ice bag! Honey? Did you get the pills?” So I wait on him, make dinner, drag myself to bed, drag myself out of bed, to do it all over again.

JOANNE SCHNEIDER – Cleveland Clinic:
If family members as care givers, don’t attend to their own needs, don’t take care of themselves, they are going to be incapable of tending to other people’s needs. And they are at risk for falling into a deep hole, which may consist of depression, it could consist of some substance use, so it’s very important that they step back, that they spend time tending to their own needs, their own wishes, that they go out and socialize with family and friends without feeling guilty, without feeling selfish. They should not feel responsibility, they should not feel guilt for putting themselves first in situations.

WIFE: I know I need to get away from this grind, even to go to a movie or something, but my husband needs me.

JOANNE SCHNEIDER – Cleveland Clinic:
The individual with pain, and the care givers, are so enmeshed in the situation, that they feed off each other. The care giver becomes dependent, in some respects, on the individual who’s experiencing pain, and the individual who experiences pain becomes dependent on the individual who is the care giver. You don’t have to be the primary care giver 100% of the time. You will burn yourself out if you don’t reach out, if you don’t ask for help. Don’t feel guilty. You are not the only one who can deal with the situation.
WIFE: There are only so many hours in the day, and all of mine are spoken for. If I want to take time off, I have to run faster just to catch up.

JOANNE SCHNEIDER – Cleveland Clinic:
Think of it this way: when you got married you were a team – at least that was the goal—and it’s time to reclaim that. So I think it’s beneficial to sit down and spend some time with each other so that they understand that it’s important for you to have a life, too. But it’s very important that you work on this together, and that you have some goals, some priorities. That will help the individual see that they actually can do things that they didn’t think that they could do. It will help them become more independent, more responsible. And you in turn, will start to develop your own life.

NARRATOR: In collaboration with its families, the ACPA has developed a list of rights for the family members of people with chronic pain. Too often, the rights of caregivers are forgotten. You have a right to set limits, to say no, and to be treated with respect. You have the right to ask for help -- nobody can perform at 100% constantly, and you have a right to a life of your own.

WIFE: Yesterday I had lunch with a friend and tomorrow I'm going to fit in a swim after work. If this is going to be the new normal, I have to make time for me as well as for him.

NARRATOR: Exercising your rights doesn't mean you're not a good caregiver. It means you're a BETTER caregiver. Pain may be an uninvited guest, but it doesn't have to sit at the head of the table. The ACPA wants to give families affected by chronic pain tools that you can use to put pain in its place.

We publish a Family Manual full of exercises and ideas for making your life as the family of a person with chronic pain fuller and easier. We also publish two workbooks used in each ACPA group. They contain a wealth of information about pain management and good living skills which can work for you as well, so take a look at them and get started.

There is life after pain. Let the ACPA help your family make the most of it.
FAMILY MATTERS 2: 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: If 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 then 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.

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.

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.
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.
FAMILY MATTERS 3: 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.