FAMILY MATTERS: 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 again.

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.