

The Impact of Pain on the Family



There are two ways of meeting difficulties: You alter the difficulties or you alter yourself to meet them.

~ Phyllis Bottome

The impact of chronic pain within the family has two sides. On one side is the person with chronic pain who needs to be validated and learn to cope with daily pain. If only the person with pain could hold the pain in his or her hand, then perhaps others could understand how much pain there is. Unfortunately, this is impossible. Family members cannot feel the pain and suffering of the person in pain.

On the other side are the family members who must live with a person with pain, who must deal with the person's pain and control that pain has in their lives. Family members also need to be validated by family, friends, and co-workers. They spread their energy and resources amazingly thin in an attempt to hold the family unit together financially and emotionally.

The American Chronic Pain Association knows that chronic pain affects not only the person who is in pain, but also the entire family unit. Many daily occurrences become major problems when one member of the family is unable to assume his or her responsibilities. Financial commitments are difficult to meet when two incomes are reduced to one. Increased medical bills place heavier burdens on family the budget.

Emotions become entangled in miscommunication, resentments, and confusion. Uncertainty about the future increases stress levels far above manageable levels. Life is more difficult with each passing day.

When one person in the family unit is "ill," it places all the responsibilities of daily life on the rest of the family. Attentions are focused on the person in pain. But what about the family? Where does the family go for help with all the problems that chronic pain creates in everyday life?

We are a society of quick fixes and fast-paced lifestyles. When something is not working right, we expect it to be repaired immediately or replaced. We never give much thought to what would happen if we could not fix or replace a malfunctioning item.

Chronic pain is something that cannot be fixed or replaced. Instead it must be managed. The American Chronic Pain Association is dedicated to helping the individual with pain make the transition from patient to person through peer support and proven coping skills. The person with pain must become actively involved in recovery. But it takes more than one person's efforts. To regain control of lifestyles and restore appropriate functioning within the family unit,

everyone in the family must contribute. The family can work together as a unit to regain control of their lives.

As important as it is to help the person with pain, it is just as important to help the family members – by this we mean spouses, partners, brothers and sisters, parents, children, and others who share a committed, caring relationship with someone who has pain – understand chronic pain and achieve a better quality of life. We cannot forget to include the dilemma of chronic pain, the effects it has on families, and ways that families can begin to effectively address problems related to chronic pain.

The Family's Experience

The family's struggle with chronic pain is not given enough attention. Their lives have been turned inside out and most of them want life go back to the way it was before the pain took control. They want the person with pain to be active, happy, and pain free, but that is unlikely. Family members may think they understand what the person with pain is going through, but they cannot.

The **family** is also trapped in the complex maze of pain. Family members must assume the pain person's responsibilities. Unless the entire family learns how to effectively cope with chronic pain, life will remain difficult and uncertain. Both partners in a relationship experience pain when illness controls lives. For the pain person there is, of course, physical pain. Both partners, however, experience other types of pain that are not as easily defined.

Shifting Responsibility

Ideally, each member help to ensure that the family runs smoothly. With the demands made on personal time today, each person's contributions are necessary. When the person with pain is no longer able to contribute to the family on all levels, his or her responsibilities fall on to the well spouse. Providing financial security, emotional support, home maintenance, and child rearing may become the sole responsibility of the well spouse. Add the concern for and preoccupation with the person with pain, and life can become difficult to manage.

Emotional Isolation

Under the best of circumstances, communication within the family can break down because of busy lifestyles. But without open communication no one's needs are met. Communication between a chronic pain person and his or her family can be filled with guesses and misinterpretations. Based on physical appearances and clues, family members make assumptions about the ability and suffering of the person with pain.

The person with pain may appear to the family as if he or she has given up. Inactivity, moodiness, and sleeping too much can be interrupted by the family in many negative ways. Some families may believe that the person with pain has no interest in life. There is bewilderment in all areas of daily life for the family of a person with chronic pain. Most hurtful is the feeling that the person with pain no longer cares about the feelings and needs of the spouse, child, or partner.

Loss of Dreams and Shared Hopes

Chronic pain can mean the end of many plans. At least it does require that the family reexamine lifestyle choices and expectations in the light of new limits. Discovering how to build new dreams can be a renewal in shared experiences but it does not fill the need to mourn real losses.

Moving On From Here

What is important for you, the family member, to understand is that ***you are not alone***. In the same way that ACPA members support and learn from each other, we hope that family members will support and learn from each other. You will never truly understand what it is like to have chronic pain, but in the same respect, the person with pain will never understand what it is like to live with a person with chronic pain. Family members need the same peer support as ACPA members receive. Talking with others faced with a similar life situation who understand the circumstances of living with a person with pain can greatly reduce the isolation family members may feel.

Impact on Children

Children are the silent victims of chronic pain. With all the adjustments that need to be made by the parents, children can easily be overlooked. Parents assume that young children don't really understand what is going on. Teenagers are too involved in their own life to be concerned about the pain person, so parents think.



Children have their own needs that must be considered. Most children do not understand all the problems created by chronic pain, but they do hear much of the discussion taking place. And, unless they understand what is said in the context it was meant, they can form their own version of the truth, a version that could be harmful to them emotionally.

A child's world is built around their parents. Parents are their security and safety. When the routine of home is changed, it greatly affects the children. Perhaps a parent no longer goes to work, or the mother begins to do work that was exclusively done by the father. Sometimes children must give up regular activities that require money because of a lack of funds.

It is surprising the number of children who blame themselves for the sudden change in the family because of chronic pain. The drastic impact the pain has on the family may be viewed by children as a form of punishment. The child may try to figure out what they neglected to do, what they might have said, or what action they took that caused so much pain in the home. They may not be capable of understanding the real cause. And, they do not know how to express their fears.

When a child touches a parent and the parent reacts with pain, the child naturally assumes that he or she caused the pain. Unless an adult takes the time to explain in terms that a child can understand, that the pain was already there, a child can silently watch the parent suffer for years, believing he or she caused the pain. One approach could be to tell the child that the pain is like a cut. If you cut your finger on a piece of glass and put a band-aid on it, the cut still needs time to heal. And, if you bump your finger before it heals, it will hurt. That doesn't mean that the bump caused the cut, it only caused the cut to hurt for a little bit.

It's a great mistake, I think, to put children off with falsehoods and nonsense when their growing powers of observation and discrimination excite in them a desire to know about things. ~ Annie Sullivan

In a family where there is chronic pain, children have the right to be informed about the effects of pain and long-term restrictions it places on the person with pain. Children are more observant than adults realize. They can handle the truth when it is presented to them in terms they understand.

Healing the Family

Living with a person with chronic pain is not easy. No matter how close the family is, chronic pain can deteriorate long-standing feelings. The most important thing is to find a solution that will allow each member of the family to live with dignity.

Below are some things the family needs to keep in mind as they try to move the entire family unit from a chronic pain position to that of a functional family. These concepts can help even if only part of the family is willing to work. At some point, the pain person may be more accepting of pain management, but until they reach that point, do what can be done to help the family.

Ten Coping Mechanisms For Family Members

1. Accept their pain and your inability to change it.
2. Gain an understanding of the pain person's abilities (and disabilities).
3. Establish a working plan to involve all family members in the "recovery" process.
4. Keep communication open and honest.
5. Set aside time for yourself each day.
6. Recognize what you are feeling--how your actions and the actions of others make you feel.
7. Be willing to ask for help.
8. Keep an open mind and accept change when necessary.
9. Believe in your ability to create change in your life and accept that you cannot change another.
10. Live in the present, do not allow yourself to suffer in the past or fear the future.

For more information you can contact the American Chronic Pain Association at 800.533.3231 or visit the web site at: www.theacpa.org.