



PATIENT EDUCATION

*Chronic Pain or Illness: Relationships
and Communication*

learning **EDUCATION** EXCELLENCE
HEALTHY CARING INTERACTION
LIVING

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Introduction

Chronic pain or illness can affect every area of a person's life, including home, work, school and recreation. The stress of living with pain or other recurring symptoms also can strain personal relationships.

You need family, friends and social activities to help you manage chronic symptoms and move on with your life. Family and friends can give you encouraging words and assistance. They also can buffer you from stress, anxiety and depression.

You can have healthy, satisfying personal relationships despite a chronic condition. This material discusses the impact of chronic conditions on relationships and suggests ways to build and maintain strong bonds with family and friends.

How Chronic Symptoms Affect Relationships

Chronic pain or illness can frustrate you, your friends and your family. How you and others respond to the physical and emotional stresses of your condition can affect the quality of your personal relationships.

Your responses

You may have various reactions to chronic pain or other symptoms that impact your interactions with other people. Managing a long-term condition can reduce your desire to interact, socialize or have close contact with others. Coping with chronic symptoms can be tiring and time-consuming. You may have little energy or time to focus on relationships.

Chronic conditions often affect communication. Effective communication can be a challenge in the most comfortable situations, so it is not surprising that lack of communication is often identified as a problem for family and friends of those who have chronic pain or illness.

Trying to tell others what you are experiencing can be frustrating. You may feel that, no matter how supportive your friends and family are, they will never understand a chronic condition unless they experience it. Thus, you may become irritated easily and find yourself lashing out at those closest to you. Or, you may decide that it's easier to withdraw and say little than to repeatedly explain your symptoms, thoughts and feelings.

Even if you avoid talking about your experiences, however, your actions can communicate with others. For example, your withdrawal from social events or family activities may tell friends and family that you no longer wish to see them. Similarly, withholding your emotions and affections from your intimate partner may send the message that you do not want your partner's affection. Or you may use pain behaviors (such as limping, groaning or grimacing) as a way of seeking help or attention.

Reduced desire, time and energy for social interaction, and changed communication patterns can lead to increasing isolation. You may feel distant from or misunderstood by others. You may feel a sense of loss or inadequacy as your duties and responsibilities are taken over by friends and family members. You may experience grief, anger, depression or denial about changes in your relationships.

Intimacy

Isolation can happen in the most intimate relationships. A chronic condition may lead to the roles of caregiver and patient first, and intimate partners second. Many people who have a chronic condition withdraw from their spouse or intimate partner to avoid that person's efforts to be affectionate, and to shield themselves from their partner's reactions to the chronic condition.

Some people avoid intimacy and sexual activity because they do not feel attractive or they that fear sexual activity will increase their symptoms. Others experience sexual difficulties due to pain, stress or medications.

For more information, see the Mayo Clinic publication, *Intimacy, Sexuality and Chronic Pain or Illness*, MC5511.

Other people's responses

Your family and friends likely share similar feelings of frustration and confusion. Many of their responses to your condition may fall into two categories (figure 1):

- Caretaking — trying to ease your symptoms by assuming additional responsibilities (for example, taking on all household chores).
- Punishing — blaming you for your symptoms or unhealthy coping efforts (for example, pain behaviors or increased medication use).

Caretaking responses

When chronic symptoms first become a problem, friends and family members generally show a great deal of support. They may try to take care of you or do things for you. They often focus more on your symptoms than on the healthy parts of your life.

If you isolate yourself and do not express your thoughts and feelings, friends and family can feel rejected and upset. They may not know how to interpret your withdrawal. They may hesitate to interact with you for fear of angering, frustrating or hurting you, or because they feel unable to help.

Punishing responses

If your symptoms do not improve, family and friends may begin to wonder what is happening. Their situation is particularly difficult. They see you in pain (or facing other symptoms), but can do little to help you feel better.

In time, people who were supportive and always offering to lend a hand may not come around as much. They go on with their lives and seem to have less time for you.

Your family's patience in particular may start to wear thin. Though most family members realize that your condition is not your fault, they can become frustrated by how it has changed your life and theirs. They may resent the extra burdens they've assumed on your behalf. Some might question whether you are exaggerating the problem to shirk your previous responsibilities. Your family members may begin to withdraw and pay less attention to you. Later, they may feel guilty about these reactions and behaviors.

The middle ground

Punishing and caretaking responses encourage you to focus on pain and symptoms rather than on rehabilitation. The most helpful response is for others to remain neutral. Being neutral means not responding to symptoms or behavior, but instead encouraging your efforts to use effective coping strategies.

Reactions to Pain/Illness Behaviors

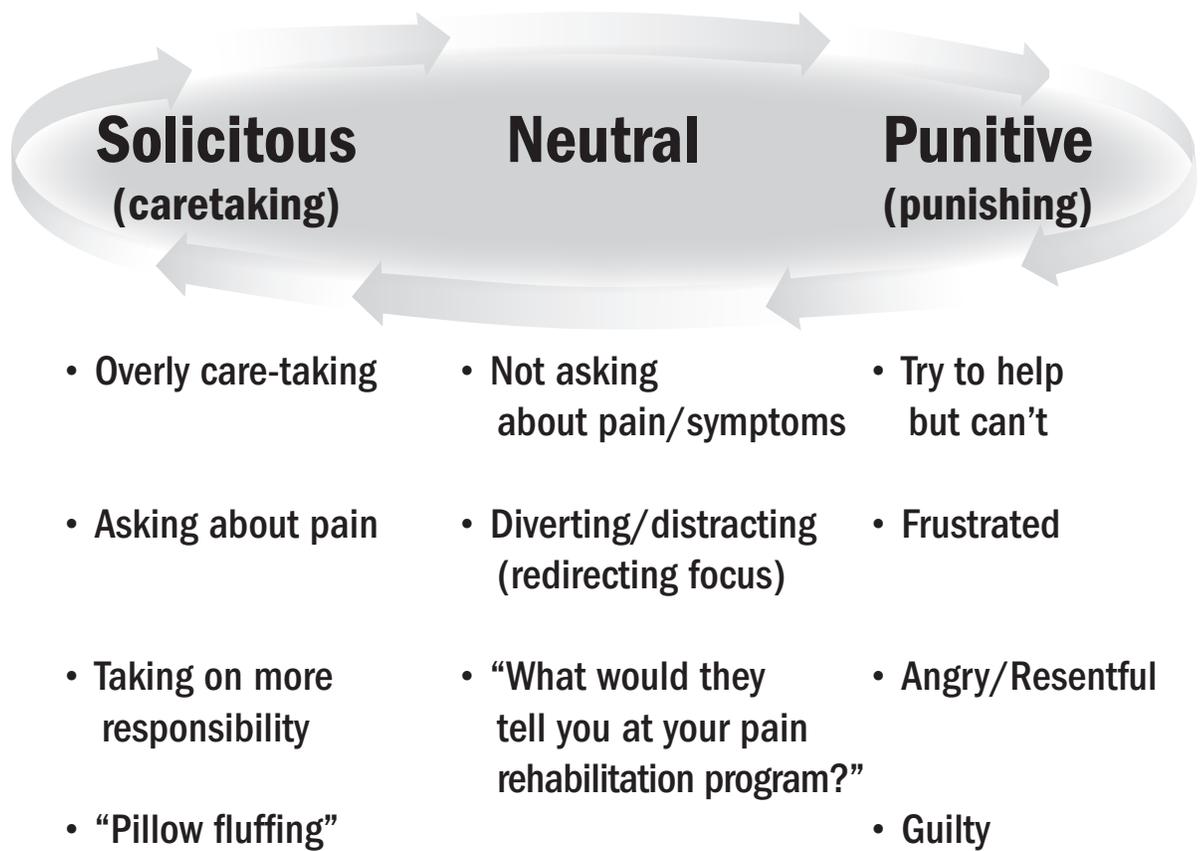


Figure 1. Reactions to pain/illness behaviors

Sustaining Relationships

A supportive family and good friends can encourage you during tough times and offer help when you need it. Being around others brings a sense of belonging and can help you forget your troubles for awhile.

Building and maintaining relationships takes work. You may need to improve communication patterns and resume appropriate roles and responsibilities, especially at home. You also may wish to broaden your social network. The time and effort you spend nurturing a solid social support system can pay off in better health and a more positive outlook on life.

Improving communication

Good communication is the glue that holds relationships together. Communication lets others know your thoughts and feelings.

Improving your relationships often begins with improving communication. Taking the first step can be difficult, but these suggestions can help:

- **Be open and honest.** People only understand what you are thinking or feeling if you tell them.
- **Be concise.** You don't have to talk at length about your symptoms or experiences. For example, simply saying "I'm having a rough day" or "I need some space" lets others know you need time to yourself.
- **Be assertive, not aggressive.** Assertive communication expresses needs, feelings and ideas honestly and directly, without putting down or hurting others. This promotes mutual respect and encourages openness in relationships. Aggressive communication blames, hurts or offends others. When you speak aggressively, others become defensive and relationship difficulties increase.
- **Don't lie about your symptoms.** Close family and friends may know not to ask how you're doing every time they see you. But some people won't understand that you may always have some degree of pain or other symptoms. When they ask how you're doing, don't pretend your symptoms are gone, but don't exaggerate them, either. You might respond, "I still have pain, but I'm learning to manage it."
- **Use "I" statements to describe problems.** The listener avoids feeling blamed or criticized, and the focus becomes your needs and wants. For example, "I am feeling stressed about preparing for the party. Could you help me with the housework today?" or "I feel sad when you tell me I'm not fun to be around anymore."
- **Avoid endless complaining.** Nonstop complaining is tiresome and drains relationships. Talk instead about how you can change the parts of your life that you're unhappy about.
- **Adopt a positive outlook.** Try to find the humor in situations. Laughter is infectious and appealing.

- **Be a good listener.** Talk about what other people are interested in. Make eye contact, nod your head and lean forward to signal that you are paying attention. Show interest by repeating the other person's messages and acknowledging his or her feelings.
- **Write down tough problems.** Use a journal to record feelings you have trouble talking about. Write your family member/friend a letter (even if you don't intend to send it) that details what is missing in your relationship and what you want or need.
- **Ask for help when you need it.** You may have been taught to cherish your independence, so asking for help can be hard. But sometimes you need help. Try asking in a way that explains your situation. For example, "I've invited friends over for dinner, and it's taking longer to prepare the meal than I expected. Could you please come over and lend a hand for awhile?"
- **Be a gracious receiver.** When someone helps you or compliments your progress, say thanks. Try not to feel depressed that you needed the help or the emotional boost.
- **Discuss communication roadblocks.** If the flow of communication between you and a family member or friend becomes one-sided, talk about it. Set aside your pride and risk saying exactly what you feel.
- **Seek professional help.** If communication is difficult, consider seeing a therapist or another member of your health care team for suggestions on ways to open communication channels.

The importance of social support

A strong social support network is crucial to coping with the stresses of chronic illness. Friends and family members can offer compassion, acceptance, assistance and a place to share your concerns and needs. They can make you feel important and needed by allowing you to offer them comfort and companionship, too. Social support provides a sense of belonging, security and comfort.

A good support system also has health benefits. People who have good friends and a supportive family generally:

- Cope better with chronic pain and other symptoms.
- Are less likely to become depressed.
- Are more active and independent.
- Have stronger immune systems and recover faster from illness.
- Have lower blood pressure and cholesterol.
- Live longer.

Developing a support system

If you have withdrawn from social events that once connected you with friends and family, it is important to reestablish ties. These suggestions can help you build and nurture supportive relationships:

- **Appreciate your friends and family.** Say thank you and tell your support person(s) how important they are.
- **Stay in touch.** Attend family gatherings. Answer phone calls and respond to mail and e-mail. Accept invitations to activities, even if this is hard at first.
- **Take charge.** Don't wait for someone else to make the first move. If you meet a potential good friend, invite that person for coffee. Strike up a conversation while in line at the grocery store.
- **Be a good listener.** Ask what's happening in the lives of friends and family. Don't always talk about your own problems. Allow others to express how your symptoms affect them.
- **Explore new options.** Take part in community organizations, volunteer work and neighborhood events. Join a health club or hobby group or take a class.
- **Don't give up on existing relationships.** Good relationships require patience, compromise and acceptance.
- **Ask for support from family and friends.** Tell them specifically what support you need.
- **Know your limits.** Don't use pain or other symptoms as an excuse not to attend a function, but allow yourself to say "no" if you really don't want to accept an invitation.

Setting limits

Relationships sometimes can be difficult. Some family members or friends may want more time and energy than you can spare. Others may tempt you to return to bad habits. Spending time with people who aren't supportive can add stress and waste valuable time.

The goal of improving your social support network is to reduce, not add to, your stress level. To keep relationships nurturing and healthy, you may need to set some boundaries. Think about the following when assessing your relationships:

- **Avoid harmful relationships.** A support system with people who are engaged in the unhealthy behaviors that you're trying to overcome — whether it's substance misuse or simply a negative attitude — can damage your well-being. Give yourself permission to limit contact with people who do not support your efforts to change.

- **Manage necessary interactions.** Some studies show that the negative results of maintaining necessary, but troubling, relationships (such as with certain relatives or co-workers) can outweigh the benefits. Although you may not be able to cut ties with a nagging in-law, look for ways to manage the relationship so it doesn't become a stressor. For example, meet at a restaurant, park or other neutral place rather than the person's home.
- **Avoid a sense of duty.** The best support systems have no strings attached. If others constantly demand repayment for their efforts, or you feel pressured to conform to their beliefs, you may be better off without them.
- **Pick the right supporter.** If you need help through a hard time, consider carefully which friend or family member to ask. Choose people who understand and support your use of coping skills. A sibling might not be the best choice, for example, to remind you to moderate your activity level at a family reunion because he or she is too invested in the event. Similarly, calling your mother when your symptoms flare may not help if she tends to dwell on your physical condition.

Reestablishing family roles

A chronic condition can affect family dynamics, particularly the sharing of household tasks. In an attempt not to be a burden, you may try to do too much around the house. Or, you and your family may view you as a patient first, and a spouse, parent or sibling second. As a result, you may have few, if any, responsibilities at home.

Maintaining a healthy balance of responsibilities is important for everyone living in your house. Sharing household tasks allows family members to feel needed and creates a sense of belonging and purpose. It also may keep resentments from building up by ensuring that no one carries an overly heavy load.

To help restore balance, talk with your family members about the division of chores. Decide together what's fair and reasonable to expect of each person. You may need to resume some responsibilities you had before pain or other chronic symptoms affected your life. Or, some of your jobs may be reassigned to others.

How Family and Friends Can Help

Chances are your family and friends have asked you how they can help. Perhaps you didn't know what to say, or you felt guilty admitting you needed assistance. Or maybe others have tried to help in ways that irritate you. They think their actions will make you feel better, but they don't.

Often, the best thing other people can do is to remain neutral — not respond to your symptoms or pain behaviors, but instead support your efforts to use effective coping strategies. Figure 2 lists examples of helpful and non-helpful responses. Consider showing this to family and friends.

How Others Can Help

Helpful Responses

- Neutral response
- Buddy system
- Offer encouragement
- Praise your efforts
- Compliment you

Non-helpful Responses

- Punitive (punishing) or solicitous (caretaking) response
- Nagging
- Discouraging comments
- Criticizing
- Reminding you of failures

Figure 2. How Others Can Help

When people ask how they can help, you might suggest:

- **“Learn more about my condition.”** Chronic symptoms are hard to understand. Reading about a condition can help other people better understand what you’re going through, how they can help and when they shouldn’t help.
- **“Don’t always talk about my condition.”** Friends and family easily get caught up in discussing your symptoms and their possible causes, and the latest treatments for your condition. But that usually frustrates you and others. It is also a reminder of your condition and draws attention to your pain or symptoms — something you’re trying to avoid. Focus discussions on activities and feelings instead.
- **“Try not to hover over me.”** Being overly attentive to someone with persistent symptoms can interfere with effective coping. For instance, allowing others to continually do tasks that you can do yourself contributes to your loss of independence and reduces your self-confidence. To manage chronic symptoms, you need to learn to do things for yourself. Tell your family members and friends that you appreciate their concern, but that they needn’t do everything for you.
- **“Be patient.”** Chronic conditions may not go away, and symptoms can affect your whole life. Accepting this can be difficult for family and friends, but it is best if they resist the urge to “rescue” you. Ask them to focus on positive changes you make.
- **“Join me in activities.”** Having friends and family members accompany you for a walk or go with you to health care visits or other events offers many benefits. You can talk and share time together. It can help distract you from your symptoms. And friends and family can learn more about your needs.
- **“Be available to listen to me.”** Sometimes, you simply need someone to listen. Family members and friends who understand that you’re not asking them to fix the problem can lend support just by listening. As they listen, they can recall your progress and help you focus on making positive choices.
- **“Don’t give up things you enjoy for my sake.”** Those closest to you may change their lifestyle because of your symptoms. But that doesn’t encourage you and may make you feel guilty.
- **“Take care of yourself.”** Your pain and their worry about you can take a toll on friends and family members. They must take care of their health as well.