

Living With Someone With Chronic Pain



CAREGIVER'S GUIDE

Are You a Caregiver?

You don't have to be a trained professional to be called a **caregiver**. A caregiver is anyone who helps someone with the things they cannot do alone. People who are living with serious, chronic pain often need a caregiver. The type of pain and how serious it is may determine how much help they need.

This booklet gives you some basic information about chronic pain and pain treatment. It discusses how you can help someone who is living with pain. It explains that being a caregiver can sometimes feel like an overwhelming role and shows how you can take care of yourself.

If you are close to, live with, or care for someone who is living with chronic pain, this booklet is for you. It may help you to talk to someone with pain about how you can help.

The caregiver's role

Everyone's chronic pain has a different effect on their life. Your role as a caregiver will depend on how the person you know is affected and what they want help with.

Let the person tell you what help they need. In this way, they can feel as independent as possible while feeling supported by you at the same time.

You can offer help with everyday tasks

- Help with shopping, cleaning, cooking, and other household chores
- Help keep track of medicine schedules—make sure that the person is taking the right medicines at the right time
- Drive the person to office visits
- Sit in on appointments to ask questions, hear important information, and help understand the healthcare provider's instructions
- Make sure the person with pain tells the healthcare provider if their medicine is working, if they have any side effects, or if they have any other concerns
- You can also tell the healthcare provider if you notice any change in the person's complaints about pain or their ability to function, or if you see any side effects or other problems with their medicine

You can help by being a friend or companion

- Spend time with the person in pain
- Let them talk about their feelings
- Ask them how you can help



Chronic Pain Affects People's Lives

It can be hard for someone who does not have chronic pain to understand the effect it can have on a person's life.

Familiar activities take much more effort. Tasks that used to be simple become difficult chores. Leisure activities may become impossible. Depending on the type of chronic pain, it can affect:

- Walking
- Driving
- Doing errands like shopping and cleaning
- The ability to work
- Taking part in sports activities

A person with chronic pain may need help with the simplest tasks or may not be able to do them at all. They often rely on a caregiver, like you, for help. They may feel frustrated and dependent when they can't do the things they need or want to do. Talk to the person with pain about how chronic pain affects them and how they feel about themselves.

But chronic pain isn't just a physical problem. It can mean changes in a person's life that can affect their sense of who they are. Their work and social life may become limited, and they may even become housebound. They often describe themselves as feeling older than they actually are. This may make them feel depressed or lonely. Sometimes they may feel like a different person altogether.

Chronic pain can have even more far-reaching effects, because it can affect friends and family as well. Financial, social, and household responsibilities may fall to someone else. Family members may be disappointed that the person in pain can't do the things they used to do.

The bottom line is that it's a big adjustment for everyone—not just the person suffering from chronic pain.



What Is Chronic Pain?

Everyone feels pain at one time or another. Some pain may be short term and may need a mild medicine or no medicine at all, or it may go away on its own.

Chronic pain is different from pain that you have once in awhile. It can continue for months or even years without changing. It can be treated with life changes and medicine, but a cure is not always possible. Chronic pain can become a permanent part of a person's life.

Fifty-six percent of adults 20 years of age or older report long-lasting pain.

Common causes for chronic pain include:

- An injury that cannot be completely healed or treated
- A serious disease such as diabetes or cancer
- Obesity that puts strain on parts of the body such as the knees and back
- The natural effects of aging

Treating Chronic Pain

Chronic pain can be difficult to treat. It may require combinations of different medicines or the use of strong pain medicines called opioids. The goal of treating chronic pain is to give the sufferer as much relief from pain as possible while letting them continue to function as much as possible.

People with chronic pain may need more than just pain medicine. For example, they may need treatment for depression or anxiety that is caused or made worse by their pain.

Types of pain medicines

A healthcare provider will most likely recommend medicines a person can buy without a prescription, such as acetaminophen (Tylenol®), naproxen (Aleve®), or ibuprofen (Advil®, Motrin®).

If these do not help in treating the pain, the healthcare provider may recommend prescription medicines, including opioids. Often a healthcare provider will prescribe more than one medicine at a time.

These medicines can be one of the following types:

- **Short-acting opioids** last 4 to 6 hours and are taken 3 to 4 times a day
- **Long-acting opioids** last 12 to 24 hours and are taken 1 to 2 times a day



Treating Chronic Pain With Opioids

A person with chronic pain may take a long-acting opioid and also use a short-acting opioid between long-acting doses when pain flares up.

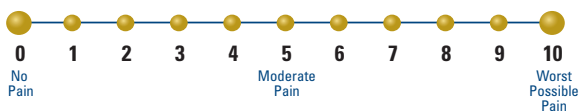
Different short-acting and long-acting opioids will work for different people. A healthcare provider may have to try several medicines to find the one medicine, or the combination, that works best. **It is important to take medicine exactly as a healthcare provider instructs—no more and no less.**

The person with chronic pain may keep a pain diary.

A pain diary usually includes:

- Location of the pain
- Intensity of the pain (using the scale below)
- What they were doing when the pain occurred
- What was used to treat the pain (medicines, supplements, etc)

The diary helps the healthcare provider understand how much pain the person has and if the medicine is working.



Side effects of opioids

Opioids can have strong side effects like nausea, constipation, dizziness, or headache. The person may feel sleepy or groggy. This may be an unavoidable effect of the medicine. It does not necessarily mean that they are taking too much.

Most of these side effects fade with time, with the exception of constipation. Someone taking opioids often needs treatment for constipation. A healthcare provider or pharmacist can give more information about using laxatives and stool softeners to prevent or treat constipation.

People taking opioids often develop tolerance. Tolerance means that a certain dose of medicine that worked before is not working as well now. This happens when a person's body gets used to the pain medicine. The healthcare provider may then prescribe a higher dose, may switch the person to a new medicine, or may try a combination of medicines. **The decision to increase or change medicines should come from a healthcare provider, not the person in pain or anyone else.**



Treating Chronic Pain With Opioids, continued

The difference between physical dependence and addiction

Many people taking prescription pain medicine, and their caregivers, are concerned about the danger of addiction. It is important to understand the difference between physical dependence and addiction while taking opioids.

When someone takes an opioid for awhile, they develop a physical dependence on it. If the medicine is stopped suddenly, the person may show signs of withdrawal, such as vomiting and shivering. Withdrawal is not pleasant but does not harm the person. To avoid withdrawal problems, it is important to work with their healthcare provider to gradually reduce the dosage.

Addiction to opioids is different; it is an uncontrollable urge to take medicine, even when it may cause harm. Typically, the medicine is being used for something other than pain control.

Most healthcare providers who treat people with pain agree that most people do not develop an addiction problem. Be sure to keep the lines of communication open. This will help the person you're caring for feel comfortable talking to you about their pain and their medicines. If you are concerned about addiction, ask a healthcare provider about the warning signs.

Remember to Care for Yourself

As a caregiver, you may take on a heavy burden of doing the things that the person in pain can no longer do for themselves. In addition, the emotional stress of living with someone who is living with pain can take its toll.

Strike a balance between helping someone else and taking care of yourself

- Make time to rest and do the things you enjoy
- Find someone you can share your feelings with
- Ask for help from others if you need it
- Talk to a healthcare provider if you need caregiving advice

Remember, even though someone else is relying on you for help and support, it's important not to lose sight of your own well-being.

Every person who lives with pain has their own issues and problems. Every caregiver has their own relationship with that person. So while this booklet gives you some basic information about chronic pain and how it affects people, it does not take the place of talking to a healthcare provider about your questions and concerns.

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Support and Resources

Sources of information about chronic pain and its treatment include:

- Books written for people living with chronic pain
- Web sites, including:
 - www.theacpa.org (American Chronic Pain Association)
 - www.painfoundation.org (American Pain Foundation)
 - www.nationalpainfoundation.org (National Pain Foundation)
 - www.ninds.nih.gov/disorders/chronic_pain/chronic_pain.htm (NINDS Chronic Pain Information)
 - www.fda.gov/FDAC/FEATURES/2004/204_pain.html (US Food and Drug Administration, Managing Chronic Pain)
- Materials that a healthcare provider may have in the office

Strengthening patient care with educational resources and support

The PROMISE® initiative includes educational resources and patient support tools to help ensure the proper use of opioid pain medicines and to minimize the risks of misuse, abuse, and diversion of these drugs.



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