

Managing Cancer Pain

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Pain is a symptom that can, and should, be controlled.

If you are experiencing pain as a result of cancer or its treatment, you should know that managing pain is an important part of your overall care. Pain affects your quality of life: your ability to get a good night's sleep, your daily activities, your eating habits, even your outlook and how well you can interact with others. But your health care team can help control cancer pain. You are the expert on the severity of your pain and its impact on your daily life. Your doctors and nurses are there to help you find out what is causing it and how to treat it.



In this booklet, you will learn more about different types of pain, how they are treated and how you can work with your health care team to get the best possible pain control. There are effective ways to manage the different types of pain:

- Chronic pain, which is constant and persists for three months or longer;
- Intermittent pain, which occurs now and then, rather than continually, and is usually related to a particular event or activity;
- Breakthrough pain, which consists of intense flare-ups of pain that “break through” regular pain medication.

Causes of Cancer Pain

People with cancer can experience pain from different sources:

The tumor itself can cause pain when it presses on or grows into healthy tissues that are sensitive to pain.

Treatment can also cause pain. Sometimes there is pain after surgery. Chemotherapy can lead to pain as a result of mouth sores, for example, or numbness, tingling or burning sensations in the hands or feet.

You may experience more than one type of pain at the same time. Controlling these different types of pain may require different approaches, which is why it is so important for your doctor to understand the cause of your pain.

Talking to Your Doctor About Pain

These are some of the things to discuss with members of your health care team and some of the questions they may ask you:

When and where your pain occurs. You may experience pain in more than one place in your body. Your doctor needs to understand the cause of pain in each place. Was there a particular event that led to the pain?

What the pain feels like. For example, is it dull, sharp, burning, pinching or stabbing?

The intensity of your pain. Different pain scales can help you rate your pain:

- The simplest scale goes from 0 to 10, with 0 equaling no pain and 10 equaling the worst possible pain.
- A verbal scale uses mild, moderate and severe as key words to describe pain levels.
- A series of cartoon-like faces shows differing degrees of discomfort from 0 to 10.
- Sometimes a thermometer-type scale is used.

Whether anything makes the pain worse. For example, does standing or sitting make it hurt more? Is it worse at night and better during the day?

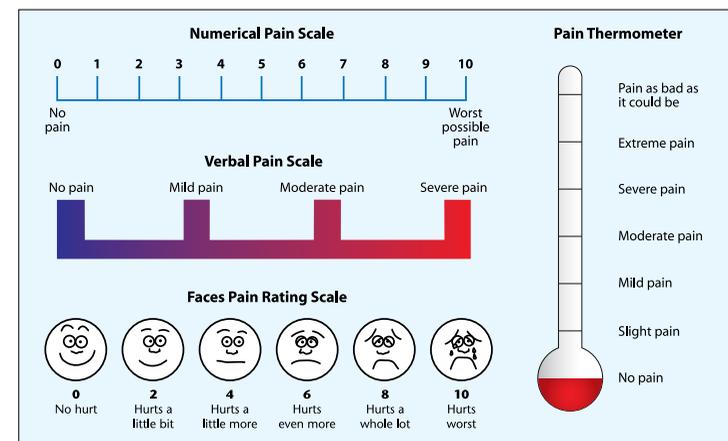
Whether anything relieves the pain. Do you feel better if you apply ice or heat to the area or if you lie down or walk around?

How much relief you are getting from any pain medications or other methods you use. Does your pain medication provide you with enough relief? Does it wear off before it's time for your next dose? Are you having any unpleasant side effects? How long does your relief last?

Whether you are having any breakthrough pain, even though your pain is usually well controlled. How many episodes of breakthrough pain do you have? When do they occur? How long do they last? What makes them better?

How the pain is affecting your everyday life. Is pain disturbing your sleep or your ability to eat? Are you able to go about your day without being interrupted by pain?

Remember that you are the expert on your pain, and your health care team is there to help you manage it. With so many advances in the field of pain management, there is no need for anyone to be in constant pain. Effective pain management improves a person's quality of life and is a basic human right. That's why it is important to be an active participant with your doctor in managing pain.



Pain Journal

Keeping a journal gives you a record of how your pain medication is working, any side effects you are experiencing, and your emotions throughout the day. Some of the things you may want to write down include:

- Where and when the pain occurs
- How long the pain lasts
- What makes the pain worse
- Whether anything, such as heat, ice or medicine, eases the pain
- How long your pain-relieving technique works and how much relief it provides
- Any side effects you experience when taking pain medication
- How the pain is affecting your quality of life—for example, is it keeping you from sleeping, eating, walking, working or exercising?

Remember that specific information will help your medical team provide the best possible treatment. Having a written record makes it easier for you to discuss with your doctor or nurse any concerns you may have.

Treating Cancer Pain

There are a number of options for pain relief, including prescription and over-the-counter medications. It's important to talk to a member of your health care team before taking any over-the-counter medication to determine if they are safe and will not interfere with your treatments. Many pain medications can lead to constipation, which may make your pain worse. Your doctor can prescribe medications that help to avoid constipation. A few ways to treat pain include

Non-opioids. These can include acetaminophen (Tylenol and others), aspirin or aspirin-like pain relievers (such as Advil or Aleve).

Medicines used to treat other conditions. Some antidepressant (Cymbalta) or seizure (Gralise and Neurontin) medications are also effective against pain in some situations.

Opioids. Opioids are the strongest pain relievers available, such as morphine, oxycodone, fentanyl and methadone. Fear of becoming addicted is common among people who are prescribed medications for cancer pain. This fear can keep some patients from talking with their doctor about the pain they are in. It can also keep them from following their doctor's orders about when and how often to take their medicines. It's important to talk with your doctor about any concerns or fears you may have. This will help ensure that pain medications are used safely and effectively.

Cannabinoids. Cannabinoids contain the active ingredient found in marijuana, and several states have legalized medical marijuana for chronic pain. A number of studies involving individuals

undergoing cancer treatment have shown that medical marijuana can work similarly to opioids when treating individuals living with cancer-related pain. Additionally, it may have anti-inflammatory effects that can help with pain. Some treatment plans may include both opioids and marijuana.

Physical therapy, acupuncture, and massage may also be of help in managing your pain. Radiation treatment is often used to manage bone pain caused by a tumor. Consult with a member of your health care team before beginning any of these activities.



Teaming Up to Manage Pain

Many hospitals and treatment centers use a pain management team—a multidisciplinary group of health care providers who work together to manage a patient's pain. These teams include:

- Pain specialists
- Physical therapists
- Nurse practitioners
- Pharmacists
- Psychologists or psychiatrists
- Health care providers who specialize in “complementary care”—techniques such as meditation, acupuncture, biofeedback, hypnosis or massage.

Your oncologist or primary care doctor can help you manage your pain. But if your pain is difficult to keep under control, ask your doctor for a referral to a pain management program. Remember, pain management is most effective when you and your doctor work as a team.

Breakthrough Pain

Even when chronic pain is well-controlled most of the time by long-acting opioids, breakthrough pain can flare up. Episodes of breakthrough pain can occur quickly, within three to five minutes, or more slowly. The discomfort can last for a few minutes or for hours.

Most patients rate breakthrough pain as moderate to severe in intensity (4 or greater on a scale of 0 to 10). This type of pain can occur several times a day. There are different types of breakthrough pain:

- **Incident pain is caused by an activity.** For example, a person with a hip problem may be comfortable sitting, but pain occurs when he or she rises out of a chair.
- **Spontaneous pain occurs for no obvious reason.** This sort of pain can come on very suddenly, even if a person isn't doing anything.
- **End-of-dose failure occurs when a long-acting drug wears off before the next dose is due.** For example, someone takes a 12-hour drug at eight o'clock in the morning, but every afternoon at four o'clock, the pain tends to begin. This suggests that the drug is providing relief for only eight hours instead of the expected 12. To avoid this problem, your doctor may recommend a change in dose or the time between doses.

Doctors may prescribe a short-acting or "immediate-release" opioid for breakthrough pain. The choice usually depends on which long-acting opioid is being used to manage chronic pain.



Palliative Care

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness, including cancer. The goal is to improve quality of life for both the patient and their loved ones.

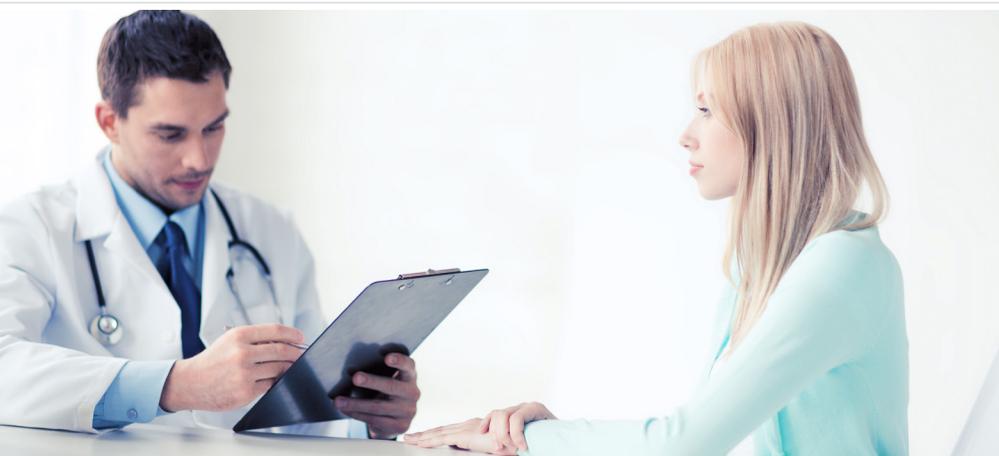
Palliative care is provided by a team of doctors, nurses, social workers and other specialists (e.g., massage therapists, pharmacists, nutritionists, chaplains) who work together with other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and can have it along with curative treatment.

Palliative care controls symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. It also helps you gain the strength to carry on with daily life. It improves the ability to tolerate medical treatments. And it helps you have more control over your care by improving communication so that you can better understand treatment options.

Talking to Your Doctor About Palliative Care

Your doctor can guide you in making a decision about whether palliative care is right for you. Here are a few things you should discuss with your doctor:

- How do I know if I need palliative care?
- What palliative services are in my area?
- Where would I receive my care (in a hospital, home, nursing home or hospice)?
- How can palliative care benefit me?
- What does quality of life mean to me? This can include spending time with loved ones, making your own decisions on treatment options or whether you want to be treated at a home or hospital.
- Does palliative care align with my values? Let your doctor know of any personal, religious or cultural beliefs, values or practices that are important to you.



Questions to Ask When Starting New Pain Medicine

Research shows that patients who have good communication with their health care team are more satisfied with their medical care than patients who do not. They are also more likely to take their medicines as directed by their doctor. It always helps to have someone with you, if possible, when you talk with your doctor. They can listen and take notes. When starting any new medication, here are some questions you may want to ask your health care team, especially your pharmacists:

How should I take my medication? Always check if your medication should be taken with food or on an empty stomach. Some pills may need to be taken with a certain amount of liquid, or they may work better if taken at a specific time of day. Asking these questions will help you get the most from your treatment. It can also help open the lines of communication with your health care team.

What are the possible side effects? All medicines can cause side effects. Sometimes, side effects keep people from taking their medicine as directed. Ask your doctor or health care team about what physical or emotional changes may occur during treatment. Asking about side effects before they happen will help you prepare for them. You and your doctor may be able to find ways for you to avoid or reduce any side effects. Also, ask if there are any side effects that you should call your doctor or health care team about.

Additional Questions to Ask Your Pharmacist

Pharmacists often provide information on how to take medications, potential drug interactions and tips on taking prescription medication on schedule.

- How does this medication work?
- What time of the day should I take this pill?
- Should I take it with or without food?
- How much water should I drink when I take this pill?
- What side effects require my calling the doctor?
- What type of co-payment assistance is available?

What should I do if I miss a dose? Many people forget to take a dose of their medicine at some point. Ask your doctor what you should do if you miss a dose. Make a note of what to do in a diary or journal. Try to know ahead of time what to do, rather than trying to reach someone after missing your dose. It is always better to ask your doctor or health care team than to guess at what to do next.

What does my insurance covers? An insurer may require that a generic (or biosimilar) version of the drug be dispensed, if one exists. Your pharmacist can help you determine if this is the case, and explain any differences between the original drug and the covered drug, including any out-of-pocket cost implications.

Reminder Systems for Taking Medication

For your pain management to be effective, it is important to stick to the treatment plan your doctor prescribed for you. Simply forgetting to take a dose of medicine is the most common reason that doses are skipped. Thankfully, there are many simple and helpful ways to remember to take your pills:

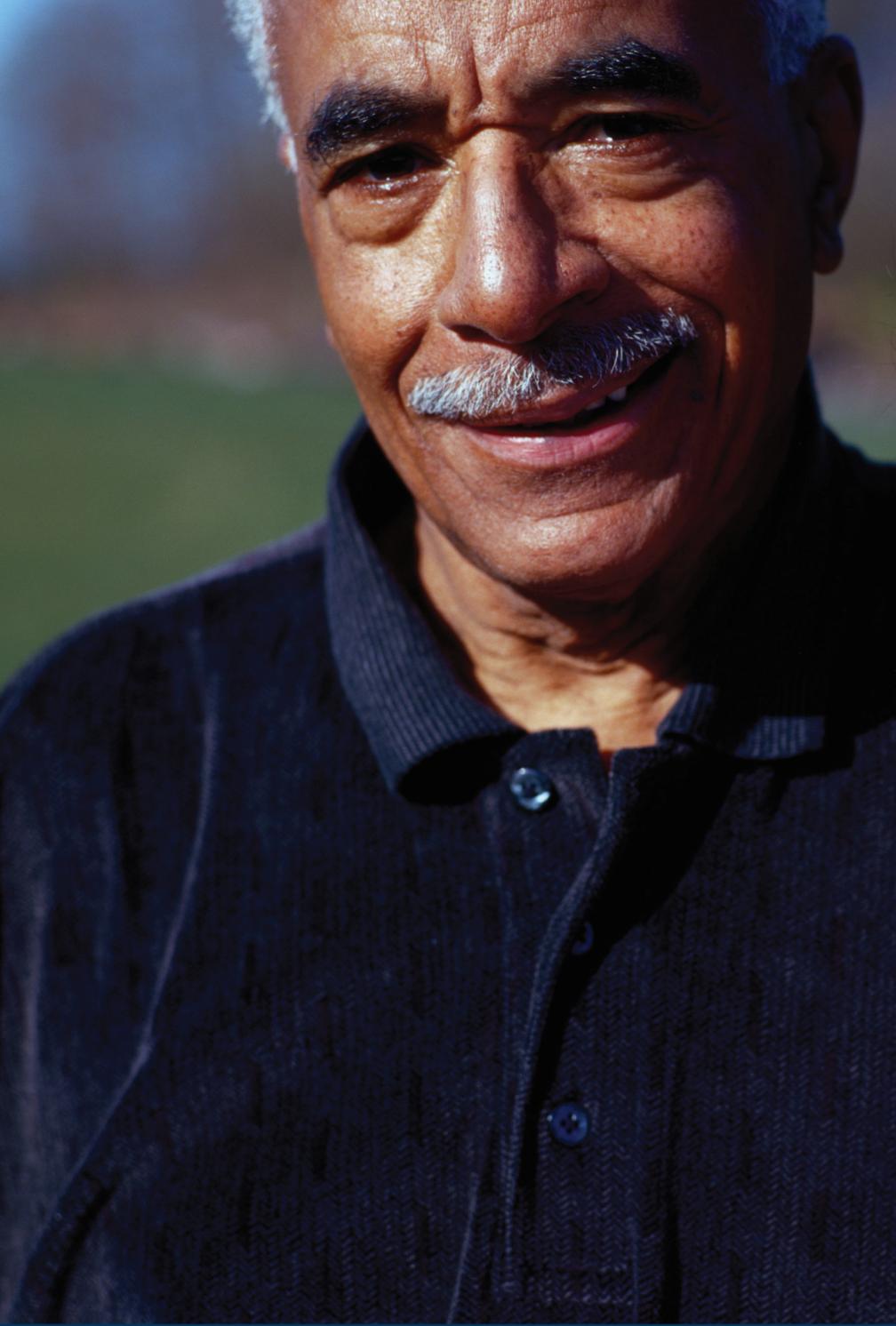
- Pillboxes
- Alarms on phone, computer, watch, or pillbox
- Reminder calls from family, friends, or pharmacy
- At-home health services
- Printed schedules
- Treatment diaries
- Pairing your medication with a time of day or a daily routine

How much will my medication cost? While you are at the doctor's office, ask about the medicine's cost. Your health care team may be able to give you more information about your insurance and what medicines it covers. If you cannot afford your medicine, ask about financial help for people with cancer. Many drug companies have programs that provide their medicines for free or at low-cost to patients who qualify. CancerCare and other organizations also offer patient programs to help with co-payment costs of some medicines (see Resources section).

What if I cannot remember how to take my new medication?

Although everything may seem clear in the doctor's office, you might not remember some of the details later when you start taking your medicine. Ask any questions you have while you are with your doctor. Write down the answers, or ask your doctor or someone else to write them down for you. If you forget to ask a question when meeting with your doctor, you can also ask the other members of your health care team. Your nurse or pharmacist may be able to help.





CancerCare Can Help

When you are diagnosed with cancer, you're faced with a series of choices that will have a major effect on your life. Your health care team, family members and friends will likely be an invaluable source of support at this time. You can also turn to these resources:

Oncology social workers provide emotional support for people with cancer and their loved ones. These professionals can help you cope with the challenges of a cancer diagnosis and guide you to resources. CancerCare offers free counseling from oncology social workers on staff who understand the challenges faced by people with cancer. We can work with you one-on-one to develop strategies for coping with pain and other side effects of cancer and its treatment. Oncology social workers can help you talk to your doctor about pain management and finding a treatment plan that is right for you.

Support groups provide a caring environment in which you can share your concerns with others in similar circumstances. Support group members come together to help one another, providing insights and suggestions on ways to cope. At CancerCare, people with cancer and their families can take part in support groups in person, online or on the telephone.

Financial help is offered by a number of organizations to cover cancer-related expenses such as transportation to treatment, child care or home care.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit www.cancer.org.

Frequently Asked Questions

Q. I've heard that taking too much Tylenol can harm the liver. How much is too much?

A. It's true that too much acetaminophen—the active ingredient in Tylenol—can cause liver damage. People who are healthy can usually take up to 4,000 milligrams a day. However, those who are frail or elderly or whose liver is not working well should take no more than 2,000 milligrams per day. It's important to talk to members of your health care team who will advise you about your particular situation and the dose that is safe for you.

Carefully check the labels on bottles of acetaminophen pills. Some “extra-strength” formulations contain 500 milligrams per tablet. If you are taking other medications, check to see whether they also contain acetaminophen. Some drugs, such as Percocet or Vicodin, contain a combination of both an opioid and acetaminophen, which you need to factor into your daily tally. Even some cough and cold medications contain acetaminophen. Your total intake of acetaminophen from all sources should not exceed the dose your health care team has recommended.

Q. My husband resists taking his pain relievers until the pain becomes excruciating. I keep trying to tell him that he should take his medication regularly to get a jump on the pain before it becomes unbearable, but I can't seem to get through to him. What can I do?

A. Sit down with him and try to find out why he doesn't want to take his pain relievers. People often have false beliefs about pain medications: “If I take my medication now, it won't work later.” “If I take opioid drugs, I'll become an addict.” Once you identify the concern, you and your husband's doctor or nurse practitioner

can address it with him. For example, your husband may need reassurance that even if a particular drug stops working, there are a number of other pain-relieving drugs and different ways of delivering them. If his pain persists, his health care team can tailor these drugs and methods to his needs.

If your husband fears addiction, his health care team can explain that addiction among drug abusers is a psychological dependence on a drug. This is different from needing drugs to relieve physical pain caused by cancer. Someone with no history of substance abuse is unlikely to misuse medications prescribed for pain. In addition, your husband's doctor or nurse practitioner will be monitoring him to make sure that his pain is controlled and he is not running into difficulty with his medications.

Q. I have had a tingling and numbness in my feet for a long time, and it seems to have gotten worse since I had chemotherapy. What kind of medications might help me?

A. What you are experiencing is probably peripheral neuropathy—a type of nerve damage that can result from some chemotherapy treatments. As you describe, it often feels like tingling, weakness or numbness in the hands and feet. In addition to using opioids for neuropathy, doctors have used medicines designed to treat depression and seizures. These medicines are also effective against pain in some situations. Which of these drugs or combination of drugs is most appropriate for managing your pain depends on your particular situation and current use of other medications. A number of new drugs have been developed and are being tested for their effectiveness against peripheral neuropathy pain. It's important to work with your doctor or nurse practitioner to see whether different medications might provide relief for you.



Resources

CancerCare

www.cancercare.org
800-813-HOPE (4673)

CancerCare Co-Payment Assistance Foundation

866-55-COPAY (866-552-6729)
www.cancercare.copay.org

Academy of Integrative Pain Management

209-533-9744
www.integrativepainmanagement.org

American Cancer Society

www.cancer.org
800-227-2345

Cancer.Net

www.Cancer.net

National Cancer Institute

800-422-6237

National Comprehensive Cancer Network

www.nccn.org
215-690-0300



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