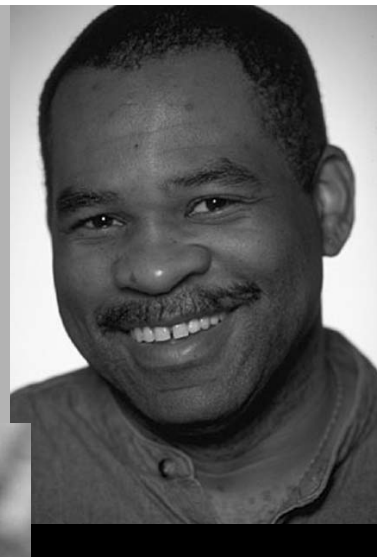


CANCER

PAIN



CAN BE RELIEVED



A Guide for Patients and Families

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Preface

In this booklet, you will find information about cancer pain - and how to manage it. Pain medicines are often needed, but other treatments may be helpful as well. You don't have to "go it alone." For best results, you need to work as part of a team with family and friends, and your doctor, nurse, pharmacist and social worker.

Questions

1. How does cancer cause pain?

Cancer can cause pain when it presses on or grows into normal body tissues. For example, if cancer replaces parts of a bone, it can cause deep aching pain. If cancer presses on the gut, it can cause cramping and bloating. If cancer presses on a nerve, it can cause sharp, shooting pain.

The treatments you've had for your cancer may also cause pain, as may problems you had before you got cancer.

2. Why is pain relief so important?

Pain puts a lot of stress on the body and mind. This is especially true for pain that is moderate or severe. Pain prevents people from being able to take part in life. Pain gets in the way of sleep, everyday activities, enjoyment, and relationships and may make it difficult for you to work or even to move about. It may keep you from having a treatment or exam for your cancer. For example, pain can make it difficult to lie on a table for an x-ray. Pain can also decrease the body's natural ability to fight cancer and can put you at risk for other medical problems such as pneumonia.

3. What do I need to tell my doctor and nurse about my pain?

First, be sure to tell your doctor or nurse if you are having pain. It is important to tell them even if they don't ask about it.

■ Tell them how bad the pain is. The most common way to do this is to use a 0-10 scale. Think of 0 as no pain at all and of 10 as the worst pain you can imagine. It may help you to look at a scale to help you decide on your number.



If you find the 0-10 scale hard to use, talk with your doctor or nurse about other ways to describe how much you hurt. Some prefer a faces scale, and others prefer to use words such as "mild," "moderate" or "severe."

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- Tell them where the pain is and what it feels like. Which of the following describe your pain? You may need to use more than one word.

| | | | | |
|-----------|-----------|----------|----------|-----------|
| Aching | Burning | Cramping | Cold | Deep |
| Dull | Gnawing | Hot | Numb | Pressure |
| Radiating | Sensitive | Sharp | Shooting | Squeezing |
| Stabbing | Throbbing | Tingling | | |

Fill in your own words:

- Tell them what makes the pain better or worse. Does it change with your position or when you move? Is the pain there all the time or does it come and go? Does it change with the time of day? Does it wake you up at night?
- Tell them what medicines you are taking for pain, including any over the counter medicines, herbal remedies, or supplements. Do the pain medicines give you side effects, such as nausea or a sleepy feeling?
- How much relief are you getting from your pain medicines or other treatments? You can describe relief with a number such as “one hour after I take my pain medicine, my pain score is 3 on a scale of 0 to 10.” You can also report activities that have become less painful, for example “I can now go for a short walk.”
- Finally tell them how much pain relief you would like to have. You might choose a number from the 0-10 scale as a goal. For example: “I would like my pain to be no more than 3 on the 0-10 scale.” Or, set a goal based on what you would like to do such as: “I would like to be able to sleep through the night” or “I would like to be able to play with my grandchildren.”

4. What can be done to manage my pain?

Sometimes it is possible to treat cancer pain by treating the cancer itself with chemotherapy (the use of drugs to kill cancer cells), radiotherapy (the use of x-rays to kill cancer cells), or surgery. However, pain relief may not start right away. Ask your doctor or nurse about ways to relieve your pain while you are waiting for these treatments to work.



Fortunately, many pain medicines are available.

- Drugs for mild pain, including acetaminophen and NSAIDs (aspirin-like drugs) such as ibuprofen and naproxen, are available without a prescription.
- Opioids relieve moderate to severe pain. These drugs are sometimes called narcotics. They include morphine, codeine, oxycodone, fentanyl, methadone and others. They are available in many different forms including pills, liquids, long-acting tablets and skin patches. Or, a small machine can pump medicine into a vein or into the area around the spinal cord.

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- Opioids may also be helpful for “nerve pain” - pain that is caused by pressure on or damage to a nerve. Some of the drugs that treat depression or seizures may also provide relief of nerve pain. There is also a skin patch that contains numbing medicine. If your doctor’s efforts to use medicines to control your pain don’t work, ask if a higher dose, a different way of giving the drug, or another kind of drug is needed. If your doctor can’t help, ask to see a pain specialist. Just as your oncologist has special knowledge of how to treat cancer, other specialists may know more about the use of different or higher doses of medicines, or be able to put medicine in or around a nerve to block pain.

5. Are there ways to manage pain without medicines?

While pain medicine is almost always needed when pain is moderate or severe, other treatments can bring comfort and reduce the stress that can make pain worse. Heating pads, hot or cold packs, or massage can soothe the body. Talk with your health care provider, who may have specific advice or refer you to a physical therapist or other specialist. Sometimes you find out by trial and error what works best.

Managing pain involves striking a balance between activity and rest. Learn how to pace yourself, how to remain active without exhausting yourself.

You may also want to explore ways to use your mind and spirit to help with your pain and to help you to deal with your illness. For some, it may be turning to spiritual faith for prayer or meditation. Others might seek the help of a counselor or therapist to learn methods such as breathing exercises, relaxation, creative visualization, and imagery, or for help with grief and loss. Sometimes, simple pleasures like laughter, talking with friends and family, listening to music, watching a movie or comedy can help distract you from pain.

6. Should I take my pain medicine on a regular schedule or only when I have pain?

Most of us tend to take medicine for pain after the pain occurs. If you have pain most or all of the time, you need to think about taking your pain medicine on a regular schedule, so that you stop your pain before it starts. The exact schedule will depend on the medicines you are taking. Some medicines last for 3-4 hours, others for 12 hours or even longer.

If you have pain only once in a while, take your medicine as soon as the pain starts. Remember to take your pain medicine before you start any activity that you know causes you pain. For example, if you have pain when you take walks or have physical therapy, you would take your pain medicine about a half an hour before that activity starts.

7. What is “breakthrough” pain?

Breakthrough pain is a sudden and often severe flare of pain that can occur in persons who are taking medicine on a regular schedule. The pain flare “breaks through” the pain medicine you are taking. It may occur with increased activity or come on totally unexpectedly. It is best treated with medicines that work quickly and last for a short period of time. Ask your doctor to give you something for breakthrough pain.

8. How much pain relief should I expect?

Pain should not prevent you from going about your daily routine, and doing those things in life that are important to you. If pain makes it hard for you to take part in normal life, call your doctor or nurse to discuss ways to get more relief. Talk with your doctor and nurse to set your goals for pain control.



9. What if I am allergic to pain medicine?

A person who has an allergic reaction to a pain medicine will have a skin rash and/or have difficulty breathing and should not take the medicine again. Allergic reactions to opioids are rare. Don't confuse allergic reactions with side effects, which can be treated or may go away over time.

Some persons have allergic-type reactions to aspirin. They should not take aspirin or other NSAIDs (aspirin-like drugs).

10. What are the side effects of pain medicines?

Many medicines can cause unwanted effects, which are also called side effects. The aspirin-like drugs can cause bleeding or stomach or kidney problems. Opioids cause constipation, and may cause nausea and vomiting, itching and sleepiness. The good news is that most of these, except constipation, go away after a few days.

10a. How can I treat constipation?

Constipation is almost always a problem with opioids. Your bowel movements can become dry and hard to pass. This side effect does not go away, so as soon as you start an opioid, you should start and stay on a plan to keep your bowels moving regularly. Drink lots of water and eat foods that are high in fiber if you are able. Most people will also need to take something regularly to soften the stool and to help move the bowels. Your doctor, nurse, or pharmacist will be able to give you advice on which medicines to use and how often. The goal is to have your bowels work in the way they have in the past. Even someone who is not eating at all needs to have regular bowel movements.

10b. What can help nausea?

Nausea can happen during the first few days after starting to take an opioid. You may have a feeling of mild stomach upset or, more rarely, vomiting. Tell your doctor or nurse if you feel nauseated, and ask for a medicine to treat the nausea. It may also be helpful to lie down. For most people, nausea will go away after a few days. For a very few people, the nausea may be more severe or long-lasting. In this case, it may be best to switch to a different opioid.

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10c. Won't pain medicines make me feel sleepy or "out of it?"

It is not unusual to feel sleepy for the first few days to a week after starting to take an opioid. The same thing can happen if your doctor increases the dose. Part of this is because your body is getting used to the medicine and part of it is probably because the pain has kept you from sleeping well and it is finally possible to catch up.



The good news is that this sleepy feeling usually goes away after a few days. Many people actually feel more alert during the day because they are finally getting a good night's sleep. But for a small number of persons the sleepy feeling may not go away, in which case the doctor may prescribe a stimulant, or perhaps switch to a different opioid. If there is poor pain relief as well as persistent drowsiness, it may be a sign that a different medicine is needed. If you still feel sleepy or "out of it" for more than a week after you start taking an opioid on a schedule, you should call your doctor.

10d. Do the pain medicines that I can buy without a prescription have side effects?

Aspirin and ibuprofen (Advil®, Nuprin®, others) and other NSAIDs cause the blood to clot more slowly and also can cause stomach upset. They can cause kidney problems and stomach ulcers. Because of these side effects, it is important to discuss their use with your health care provider, even if you are getting them without a prescription.

Acetaminophen (Tylenol®) has few side effects, but if you take too much it may be hard on your liver. Don't take more than eight extra strength tablets in 24 hours. If you have liver problems or a history of alcohol abuse, you should talk with your doctor before taking this medicine.

It is important to remember that many prescription pain medicines may also contain acetaminophen. Read the label on your pill bottle, and ask your pharmacist if your medicine contains acetaminophen.

10e. Do the medicines used to treat nerve pain have side effects?

Pain that comes from pressure on or damage to a nerve is sometimes treated with drugs that are used to treat depression. Some of these can cause you to have a dry mouth, feel sleepy, or to feel dizzy when you first sit up or stand. Drugs used to treat seizures can also relieve nerve pain. These can also cause you to feel sleepy or make it hard for you to think clearly. There may be other side effects too. Ask your doctor, nurse or pharmacist for information about the particular drug you are taking, and for suggestions about how to treat side effects.

11. Shouldn't I save my pain medicine for when the pain gets really bad?

Sometimes people worry that their pain medicine will stop working if they take it too soon or too often. Years of experience in treating persons with cancer have shown us that this is not the case. Persons often get good relief from the same dose of opioid for weeks or months. If the pain gets worse, your doctor can give you a larger dose of opioid and/or other types of pain medicine. Your doctor can gradually increase the dose of opioids as much as is needed to control the pain. There is no “ceiling” dose, which means there is no maximum dose above which the medicine stops working. So, there is no need to endure suffering for fear that your body will stop responding to the pain relieving effects of opioids.



12. Will I become dependent on my pain medicine?

For as long as you have pain, you should also get treatment for that pain. For many people with cancer, this means taking pain medicine. This does not mean you are a weak or bad person. It does mean that you are getting the care you need to live your life to the fullest. Remaining on an opioid to control pain is no different than depending on medicine to control high blood pressure.

There are many kinds of medicine that you shouldn't suddenly stop after you've been taking them on a regular basis, such as some medicines for high blood pressure or depression, and also opioids. Over time, the body adapts to the medicine, which is a normal process called *physical dependence*. Don't suddenly stop your opioid medicines if you have been taking them for a while. If you do, you could have symptoms of withdrawal, which include muscle aches, watery nose and eyes, feeling irritable, sweating, and diarrhea. If your pain decreases or goes away, you may no longer need an opioid. Your doctor will help you slowly reduce and stop the medicine.

Physical dependence is a normal, expected part of regularly taking opioids. It is not the same as psychological dependence: it does NOT mean that the person has become an addict.

13. What is addiction and is it common?

Persons who are addicted can't control their drug use. They take drugs to “get high,” not to get pain relief. Their drug use makes their quality of life worse.

Addiction is a common concern, but in fact, it rarely occurs in persons with cancer who take opioids for pain control.

The vast majority of people who take an opioid for pain relief are able to take the medicine as prescribed and never have any difficulty controlling its use. In fact, the fear of addiction is often a bigger problem than addiction itself. This fear can keep people from asking for pain relief, with the result that the person has to cope with the harmful physical, mental, and spiritual effects of the pain itself. If you have any worries about addiction, it is often helpful to talk these over with your doctor, nurse, or social worker.

Persons with pain who have a history of addiction to alcohol or other drugs need special care, which may include more frequent office visits, written agreements, and urine testing.

14. Do pain medicines shorten life?

There is no evidence that using opioids for pain relief shortens life. It is true that opioids can slow breathing during the first days of use. Because of this effect, doctors usually start the medicine at a low dose and gradually increase it as needed to control pain.

However, within a week or two the body gets used to this effect, so it no longer responds with slowed breathing even with higher doses of the opioid.

15. What if my family or friends are worried about my taking pain medicine?

Family and friends are important in your life, and your health care providers will want to help them with their worries. While your friends and family want what is best for you, they may not know much about pain and the medical use of opioids, or they may have past experiences which affect their thoughts, fears and feelings. There have been many stories in the news about drug abuse, but very little about how helpful pain medicines can be. If they have worries, ask them to read this booklet so they can understand why it is important for you to have pain relief. Talk with them, or ask someone who understands your needs to talk to the others to set their minds at rest. It is often very helpful to have a meeting with your health care providers, family and/or friends to discuss their concerns. Support from your family and friends is very important to your comfort. The stress of dealing with cancer can bring up many difficult fears and feelings, and talking about them can open up a helpful sense of connection and support.

16. Do “good” patients complain about their pain?

Many of us were raised to believe that it is best to keep our troubles to ourselves, and that if we talk about them, people will think we are “whiners” or “complainers.” We may have been taught that pain should be suffered in silence. In the past, we have not realized the harm that can come from unrelieved pain. While talking about your pain may be new to you, it will help your doctor provide the best care for you. No one can know what another person’s pain is like just by looking at him or her. Your health care providers want to do a good job, and to do so they need to hear about your pain.

17. Is complaining about pain a sign of weakness?

Talking to your health care providers about your pain and asking to get relief is not a sign of weakness. It is a useful way to take care of yourself. Being “stoic” or “putting up with it” can wear you down and make you less able to take part in your treatment and in your daily activities.

18. How do I make sure I don’t run out of my pain medicine?

Planning ahead will help you avoid the problem of running out of medicines.

If you are taking an opioid you may need to get a new prescription written by your doctor each time you need more medicine. Your pharmacist can tell you for sure. It is always best to get your prescription from your regular doctor or nurse practitioner and

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from the same pharmacy. They know you and the reasons why you need the medicine. Contact your doctor's office at least one week before you are likely to run out of medicine. This will give your doctor time to write the prescription and you or someone else time to pick it up. Check with your pharmacist to make sure the medicine is in stock.

Develop some system to help you know when you are running low. For example, you might want to count out a week's supply of your medicine and put it in a separate bottle or pillbox. Use the rest of your medicine first and call your doctor as soon it runs out.

19. What should I do if my pain medicine isn't working?

You should call your health care provider if you are not getting the pain relief you want. If you are feeling stressed, you may want to ask a family member or friend help you make the call. Make some notes before you call. Describe how bad your pain is; how it affects your life; the name and dose of your pain medicines; how often you are taking them; and any side effects you might be having. Try filling in the blanks in the following sentences to use as a guide when you call:

1. I am calling because I am still having pain. In the last day, my pain has usually been ____ on a scale of 0-10.
2. At its worst my pain has been _____ on the 0-10 scale.
3. Because of the pain, I am unable to _____
4. I take my pain medicine (name) _____ every ____ hours
5. One hour after I take my pain medicine, my pain is ____ on the 0-10 scale.
6. I have had to take ____ doses of medicine for breakthrough pain in the past day.
7. The side effects I am having are _____

It may be helpful to keep a diary about your pain, medicines, side effects, and relief. Use your notes to help collect your thoughts when you talk to your doctor or nurse.

20. How can my family and friends help?

The support of family and friends is an important part of managing pain. Support can be very practical. You may be spending a lot of energy dealing with your cancer, your treatment or the pain itself. Friends and family can help by picking up your prescriptions, going to the grocery store, or doing cleaning, laundry, yard work, or errands. Perhaps they can even help with pain treatments, such as setting up a heating pad or massaging a sore muscle. Friends and family often need your suggestions as to how they can make a difference in your life.



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Sometimes, learning the facts about pain and its relief, either from this booklet or from talking with health care providers, can reassure family and friends and help them feel a part of your care. Family and friends might wrongly assume that pain treatment is risky and likely to cause you to become an addict or to be “out of it.” They can be most helpful by learning the facts and being supportive.

Sometimes you might simply need to talk about your fears, concerns and hopes. Other times, especially when you are tired or in pain, you might need them to be your advocate. Ask them to help with gathering information, setting up appointments, or going with you to see your doctor to help you ask questions and to take notes on the answers.

21. What should I do if my doctor or nurse says nothing more can be done for my pain?

You have the right to attentive care for your pain. While it may not be possible to completely get rid of pain, it is almost always possible to get pain down to a mild level. The dose of medicine can be adjusted as many times as is needed. If your doctor or nurse says there is nothing more to do for your pain, ask to see a different health care provider or ask for a referral to a specialist.

Cancer pain can be relieved.

Glossary

acetaminophen: a medicine for mild to moderate pain available without a prescription. Brand names include Tylenol®, Anacin Aspirin Free®, Excedrin®, and others. Store brands, sometimes called “non-aspirin,” are also available. Cold medicines may also contain acetaminophen. Many prescription pain relievers combine acetaminophen with another pain reliever. On prescription bottles, acetaminophen is sometimes called “APAP.”

addiction: craving a drug or other substance, and not being able to control its use in spite of harmful effects. Addiction is NOT a common condition in persons who take opioids for relief of cancer pain.

breakthrough pain: a sudden and often severe flare of pain that can occur in persons who are taking medicine on a regular schedule.

chemotherapy: the use of drugs to kill cancer cells

constipation: having less frequent bowel movements (stool) than usual, as a rule less than three times a week. The stool can be small, hard or dry. If constipation is very severe, there may be small, watery bowel movements.

dose: the amount of medicine taken

ibuprofen: an NSAID. Brands include Advil®, Motrin®, and Nuprin®

naproxen: an NSAID. Brands include Aleve® and Naprosyn®.

nausea: feeling sick to your stomach, as though you are going to throw up.

NSAIDs (non-steroidal anti-inflammatory drugs): medicines for mild to moderate pain, especially bone pain. Several kinds are available without a prescription, including aspirin, ibuprofen, naproxen, and ketoprofen. Higher doses of these and other NSAIDs are also available by prescription.

oncologist: a doctor who specializes in cancer treatment

opioids: a group of pain medicines for moderate to severe pain, including morphine, codeine, oxycodone, fentanyl, methadone and others. Available by prescription only.

pain scale: used to help describe how severe pain is. There are many different scales. Some use numbers (0-10 or 0-5), faces (calm, sad, crying), or words (mild-moderate-severe).

physical dependence: a normal process that occurs with many medicines, including opioids, when they are taken for more than several days. The body adapts to the medicine, so you may feel sick if the medicine is stopped suddenly. Physical dependence is a normal, expected part of regularly taking opioids. It is not the same as psychological dependence; it does NOT mean that the person has become an addict.

physical therapy: the use of exercise, electrical stimulation, ultrasound, water therapy, massage, heat, or cold to treat pain and other problems in muscles, nerves, joints and bones.

prescription: a doctor’s written order

radiotherapy: the use of x-rays to kill cancer cells

side effects: unwanted effects from a medicine or treatment

stimulant: a medicine to help you feel more alert

stoic: a person who bears pain without complaint or outward signs of discomfort.

withdrawal: the process of stopping a drug. Stopping an opioid too suddenly can cause muscle aches, watery nose and eyes, irritability, sweating, and diarrhea. These symptoms of withdrawal do not by themselves mean a person is an addict.

Resources

Cancer Information Service

Toll-free: 1-800-4-CANCER (1-800-422-6237)

Web site: <http://cis.nci.nih.gov>

American Cancer Society

Toll-free: 1-800-ACS-2345 (1-800-227-2345)

Web site: <http://www.cancer.org>

American Pain Foundation

Toll-free: 1-888-615-PAIN (1-888-615-7246)
Automated Information & Order Line

Web site: <http://www.painfoundation.org>

The AGS Foundation for Health in Aging

Web site: <http://www.healthinaging.org>

To download this booklet:

Visit <http://wiscinfo.doit.wisc.edu/trc/> and click on Patient/Public under Materials.

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