

**PAIN CONTROL:
SUPPORT FOR
PEOPLE WITH
CANCER**

**NATIONAL CANCER
INSTITUTE.**



Support for People With Cancer

Pain Control

National Cancer Institute

U.S. DEPARTMENT

OF HEALTH AND

HUMAN SERVICES

National Institutes

of Health



This booklet is only one of many free booklets for people with cancer.

Here are some others you and your loved ones may find useful:

- *Biological Therapy: Treatments That Use Your Immune System To Fight Cancer*
- *Chemotherapy and You*
- *Coping With Advanced Cancer*
- *Eating Hints for Cancer Patients*
- *If You Have Cancer: What You Should Know About Clinical Trials*
- *Radiation Therapy and You*
- *Taking Time*
- *Thinking About Complementary and Alternative Medicine*
- *When Cancer Returns*
- *When Someone You Love Is Being Treated for Cancer*
- *When Someone You Love Has Advanced Cancer*
- *When Your Parent Has Cancer*

These free booklets are available from the National Cancer Institute (NCI).

NCI is a Federal agency that is part of the National Institutes of Health.

To order or download, call 1-800-4-CANCER (1-800-422-6237) or visit <http://www.cancer.gov>. (See page 34 of this booklet for more resources.) For information about your specific type of cancer, see NCI's Physician Data Query (PDQ®) database at <http://www.cancer.gov>. From the home page, it is listed under "Cancer Topics."

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Pain Control

Support for People With Cancer

Cancer pain can be managed.

Having cancer doesn't mean that you'll have pain. But if you do, you can manage most of your pain with medicine and other treatments.

This booklet will show you how to work with your doctors, nurses, and others to find the best way to control your pain. It will discuss causes of pain, medicines, how to talk to your doctor, and other topics that may help you.

Your “health care team” can help you manage cancer pain.

In this booklet, your “health care team” can mean any of the professionals you see as part of your medical care. These may include your **oncologist**, your family doctor, nurses, physical therapists, pharmacists, oncology social workers, clergy members, and others.

Read what you need.

Use this booklet in the way that works best for you. You may read it from front to back. Or you may want to read different parts as you need them.

There is a list of resources toward the end of the booklet. There is also a page where you can write down notes and keep track of the medicines you're taking. This section also includes a sample pain control record.

Words in **bold** are explained at the end of the booklet in “Words To Know.” They include terms you might hear in doctors' offices or hospitals.



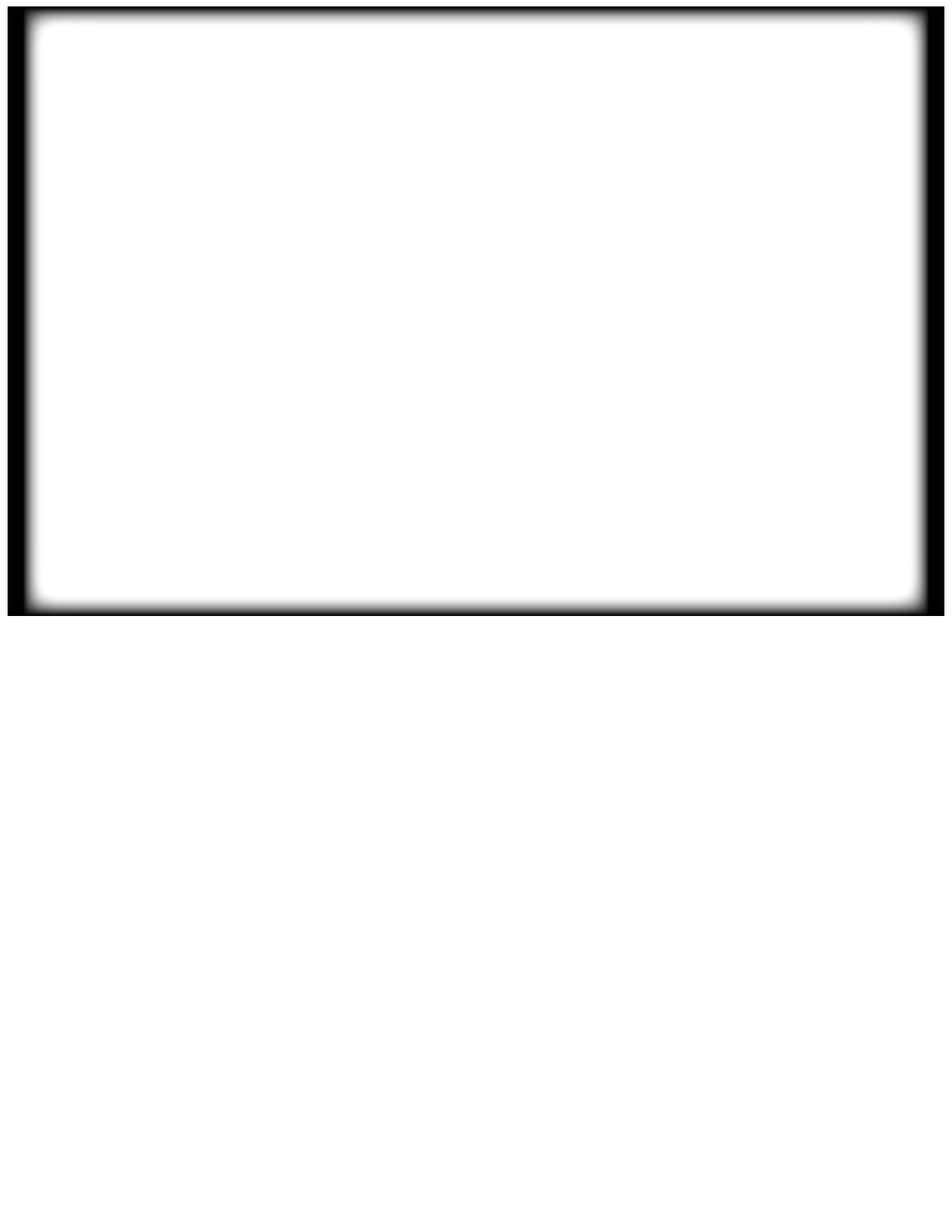




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“I thought that I had to live with the pain, but it got to the point where I just couldn’t handle it anymore. My doctor changed my medicines, which seems to be working for me. I’m not saying that I’m always pain free, but it’s a lot better now.” —John



CHAPTER 1

What You Should Know About

Treating Cancer Pain

You don't have to accept pain.

People who have cancer don't always have pain. Everyone is different. But if you do have cancer pain, you should know that you don't have to accept it. Cancer pain can almost always be relieved.

The key messages we want you to learn from this booklet are:

-
- Your pain **can** be managed.
-
- Controlling pain **is part** of your cancer treatment.
-
- Talking openly with your doctor and health care team will help them manage your pain.
-
- The best way to control pain is to stop it from starting or keep it from getting worse.
-
- There are many different medicines to control pain. Everyone's pain control plan is different.
-
- Keeping a record of your pain will help create the best pain control plan for you.
-
- People who take cancer pain medicines as prescribed rarely become addicted to them.

- Your body does **not** become immune to pain medicine. Stronger medicines should not be saved for “later.”

1





Palliative care and pain specialists can help.

Cancer pain can be reduced so that you can enjoy your normal routines and sleep better. It may help to talk with a palliative care or pain specialist. These may be oncologists, **anesthesiologists, neurologists**, surgeons, other doctors, nurses, or pharmacists. If you have a pain control team, it may also include psychologists and social workers.

Pain and **palliative care** specialists are experts in pain control. Palliative care specialists treat the symptoms, **side effects**, and emotional problems of both cancer and its treatment. They will work with you to find the best way to manage your pain.

Ask your doctor or nurse to suggest someone. Or contact one of the following for help finding a specialist in your area:

-
- Cancer center
-
- Your local hospital or medical center
-

- Your primary care provider
-
- People who belong to pain support groups in your area
-
- The Center to Advance Palliative Care, <http://www.getpalliativecare.org>

(for lists of providers in each state)

When cancer pain *is not treated*

properly, you may be:

-
- Tired
-
- Depressed

When cancer pain *is managed*

-
- Angry

properly, you can:

-
- Worried
-
- Enjoy being active
-
- Lonely
-
- Sleep better
-

- Stressed
-
- Enjoy family and friends
-
- Improve your appetite
-
- Enjoy sexual intimacy
-
- Prevent depression

2



CHAPTER 2

Types and Causes of Cancer Pain

Cancer pain can range from mild to very severe. Some days it can be worse than others. It can be caused by the cancer itself, the treatment, or both.

You may also have pain that has nothing to do with your cancer. Some people have other health issues or headaches and muscle strains. But always check with your doctor before taking any over-the-counter medicine to relieve everyday aches and pains. This will help ensure that there will be no interactions with other drugs or safety concerns to know about.

Different types of pain

Here are the common terms used to describe different types of pain:

-
- **Acute pain** ranges from mild to severe. It comes on quickly and lasts a short time.
-

■ **Chronic pain** ranges from mild to severe. It either won't go away or comes back often.

■

■ **Breakthrough pain** is an intense rise in pain that occurs suddenly or is felt for a short time. It can occur by itself or in relation to a certain activity. It may happen several times a day, even when you're taking the right dose of medicine. For example, it may happen as the current dose of your medicine is wearing off.

What causes cancer pain?

Cancer and its treatment cause most cancer pain. Major causes of pain include:

■

■ **Pain from medical tests.** Some methods used to diagnose cancer or see how well treatment is working are painful. Examples may be a biopsy, spinal tap, or bone marrow test. If you are told you need the procedure, don't let concerns about pain stop you from having it done. Talk with your doctor ahead of time about what will be done to lessen any pain you may have.

■ **Pain from a tumor.** If the cancer grows bigger or spreads, it can cause pain by pressing on the tissues around it. For example, a tumor can cause pain if it presses on bones, nerves, the spinal cord, or body organs.

3

■

■ **Spinal cord compression.** When a tumor spreads to the spine, it can press on the spinal cord and cause spinal cord compression. The first sign of this is often back or neck pain, or both. Coughing, sneezing, or other motions may make it worse.

■ **Pain from treatment.** **Chemotherapy, radiation therapy,** surgery, and other treatments may cause pain for some people. Some examples of pain from treatment are:

• **Neuropathic pain.** This is pain that may occur if treatment damages the nerves. The pain is often burning, sharp, or shooting. The cancer itself can also cause this kind of pain.

• **Phantom pain.** You may still feel pain or other discomfort coming from a body part that has been removed by surgery. Doctors aren't sure why this happens, but it's real.

How much pain you feel depends on different things. These include where the cancer is in your body, what kind of damage it is causing, and how you experience the pain in your body. Everyone is different.

Call your doctors right away

Listen to your body. If you notice that everyday actions,

such as coughing, sneezing, moving, walking, or standing,

suddenly cause new pain or your pain to get worse, tell your doctors right away. Also let them know if you have unusual rashes or bowel or bladder changes.

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CHAPTER 3

Talking About Your Pain

Pain control is part of treatment. Talking openly is key.

“At first I tried to be brave. Now I realize that the only way to handle my pain is to be open and honest about it with my health care team. It’s the only way I can stay on top of it and keep it under control.” — Janie **Controlling pain is a key part of your overall cancer treatment.** The most important member of the team is you. You’re the only one who knows what your pain feels like. Talking about pain is important. It gives your health care team the feedback they need to help you feel better.

Some people with cancer don’t want to talk about their pain. They think that they’ll distract their doctors from working on ways to help treat their cancer. Or they worry that they won’t be seen as “good” patients. They also worry that they won’t be able to afford pain medicine. As a result, people sometimes get so used to living with their pain that they forget what it’s like to live without it.

But your health care team needs to know details about your pain and whether it’s getting worse. This helps them understand how the cancer and its treatment are affecting your body. And it helps them figure out how to best control the pain.

Try to talk openly about any other medical problems and fears you have. And if money worries are stopping you, be sure to read the Financial Issues section starting on page 30 of this booklet. There may be ways to help you get the medicine you need.

Tell your health care team if you’re:

-
- Taking any medicine to treat other health problems
-
- Taking more or less of the pain medicine than prescribed
-

- Allergic to certain drugs

-

- Using any over-the-counter medicines, home remedies, or herbal or alternative therapies

This information could affect the pain control plan your doctor suggests for you.

If you feel uneasy talking about your pain, bring a family member or friend to speak for you. Or let your loved one take notes and ask questions. Remember, open communication between you, your loved ones, and your health care team will lead to better pain control.

5



Talking about your pain.

The first step in getting your pain under control is talking honestly about it. Try to talk with your health care team and your loved ones about what you are feeling. This means telling them:

-
- Where you have pain
-
- What it feels like (sharp, dull, throbbing, constant, burning, or shooting)
-
- How strong your pain is
-
- How long it lasts
-
- What lessens your pain or makes it worse
-
- When it happens (what time of day, what you're doing, and what's going on)
-
- If it gets in the way of daily activities

Describe and rate your pain.

You will be asked to describe and rate your pain. This provides a way to assess your **pain threshold** and measure how well your pain control plan is working.

Your doctor may ask you to describe your pain in a number of ways. A pain scale is the most common way. The scale uses the numbers 0 to 10, where 0 is no pain, and 10 is the worst. You can also use words to describe pain, like pinching, stinging, or aching. Some doctors show their patients a series of faces and ask them to point to the face that best describes how they feel.

No matter how you or your doctor keep track of your pain, make sure that you do it the same way each time. You also need to talk about any new pain you feel.

It may help to keep a record of your pain. See the chart on [page 37](#) for an example.

Some people use a pain diary or journal. Others create a list or a computer spreadsheet. Choose the way that works best for you.

Your record could list:

-
- When you take pain medicine
-
- Name and dose of the medicine
you're taking
-
- Any side effects you have
-
- How much the medicine lowers the
pain level
-
- How long the pain medicine works
-
- Other pain relief methods you use
to control your pain

6



-
- Any activity that is affected by pain, or makes it better or worse
-
- Things that you can't do at all because of the pain

Share your record with your health care team. It can help them figure out how helpful your pain medicines are, or if they need to change your pain control plan.

**Here are some ways your health care team may ask you
to describe or rate your pain:**

- 0
- 1
- 2

3

4

5

6

7

8

9

10

No

Moderate

Worst

Pain

Pain

Possible Pain

No

Mild

Moderate

Severe

Very

Worst

Pain

Pain

Pain

Pain

Severe

Possible

Pain

Pain

No

Pain As Bad As It

Pain

Could Possibly Be

0

2

4

6

8

10

No hurt

Hurts a

Hurts a

Hurts

Hurts a

Hurts

little bit

little more

even more

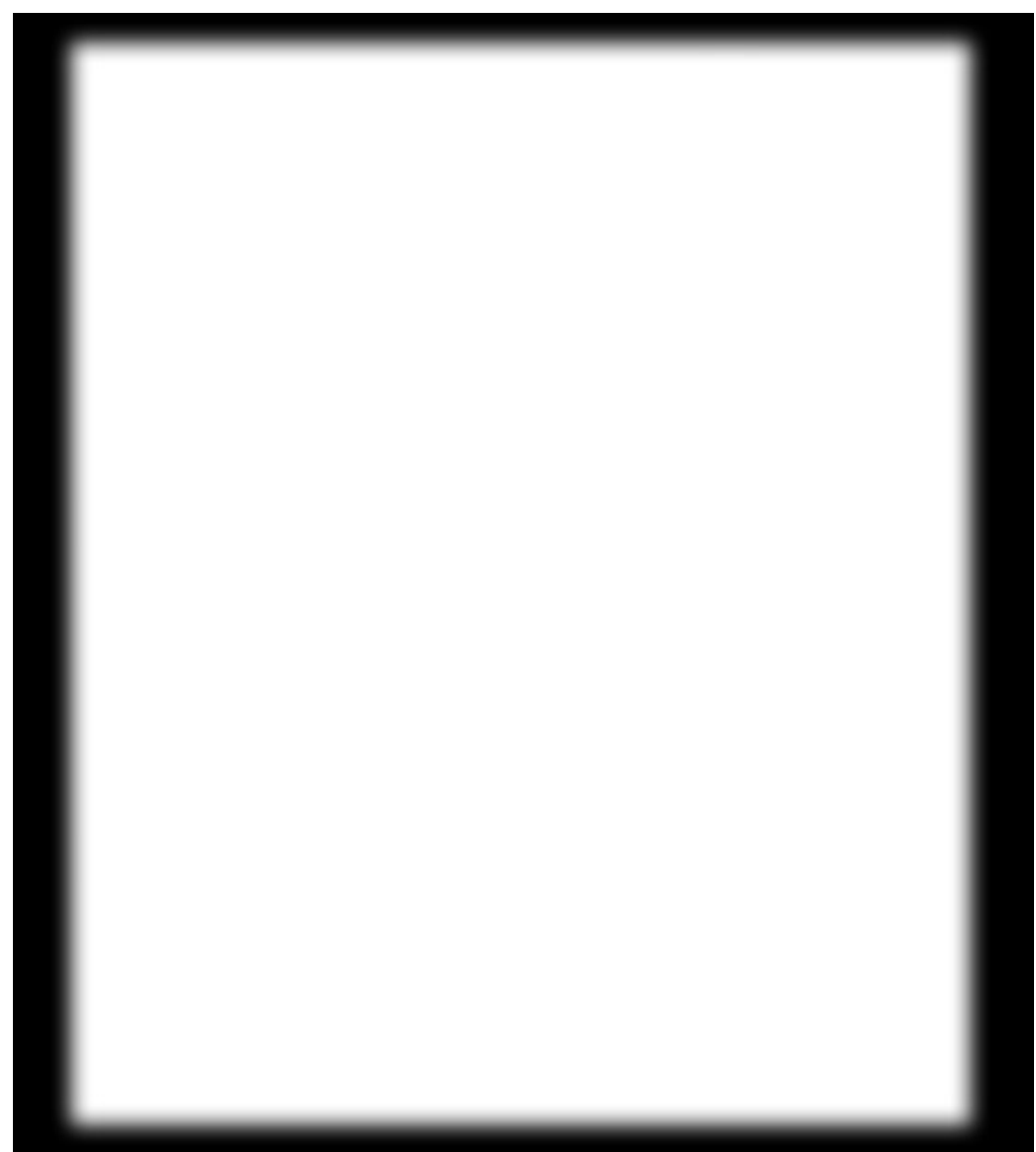
whole lot

worst

Procedures. Quick Reference Guide for Clinicians AHCPR Pub. No. 92-0019. Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, U.S. Department of Health and Human Services.

“Faces” Pain Scale adapted with permission from Hockenberry MJ, Wilson D, Winkelstein ML: *Wong’s Essentials of Pediatric Nursing*, ed. 7, St. Louis, 2005, p. 1259. Used with permission. Copyright, Mosby.

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Share your beliefs.

Some people don't want to take medicine, even when it's prescribed by the doctor.

Taking it may be against religious or cultural beliefs. Or there may be other personal reasons why someone won't take medicine. If you feel any of these ways about pain medicine, it's important to share your views with your health care team. If you prefer, ask a friend or family member to share them for you. Talking openly about your beliefs will help your health care team find a plan that works best for you.

“It makes sense. If you don't tell someone about your pain, then no one can help you! And the pain won't go away by itself.” — Joe



CHAPTER 4

Your Pain Control Plan

“It took a few visits to my health care team to get my pain under control. But by trying different medicines and doses, I now have a pain plan that works for me.” —Michelle

Make your pain control plan work for you.

Your pain control plan will be designed for you and your body. Everyone has a different pain control plan. Even if you have the same type of cancer as someone else, your plan may be different.

Take your pain medicine **dose** on schedule to keep the pain from starting or getting worse. This is one of the best ways to stay on top of your pain. **Don’t skip doses.**

Once you feel pain, it’s harder to control and may take longer to get better.

Here are some other things you can do:

-
- Bring your list of medicines to each visit.
-
- If you are seeing more than one doctor, make sure each one sees your list of medicines, especially if he or she is going to change or prescribe medicine.
-
- Never take someone else’s medicine. What helped a friend or relative may not help you. Do not get medicine from other countries or the Internet without telling your doctor.
-
- Don’t wait for the pain to get worse.
-
- Ask your doctor to change your pain control plan if it isn’t working.

The best way to control pain is to stop it before it starts or prevent it from getting worse.

Don't wait until the pain gets bad or unbearable before taking your medicine. Pain is easier to control when it's mild. And you need to take pain medicine often enough to stay ahead of your pain. Follow the dose schedule your doctor gives you. Don't try to

“hold off” between doses. If you wait:

-
- Your pain could get worse.
-
- It may take longer for the pain to get better or go away.
-
- You may need larger doses to bring the pain under control.

9

Keep a list of all your medicines.

Make a list of all the medicines you are taking. If you need to, ask a member of your family or health care team to help you. **Bring this list of medicines to each visit.** You can take most pain medicines with other **prescription** drugs. But your health care team needs to know what you take and when. Tell them each drug you are taking, no matter how harmless you think it might be. Even over-the-counter medicines, herbs, and **supplements** can interfere with cancer treatment. Or they could cause serious side effects or reactions.

How to tell when you need a new pain control plan

Here are a few things to watch out for and tell your health care team about:

- -
- Your pain isn't getting better or going away.

- -
- Your pain medicine doesn't work as long as your doctor said it would.

- -
- You have breakthrough pain.

■
■
You have side effects that don't go away.

■
■
Pain interferes with things like eating, sleeping, or working.

■
■
The schedule or the way you take the medicine doesn't work for you.

If you have trouble breathing, dizziness, or rashes, call your doctor right away. You may be having an allergic reaction to the pain medicine.

Don't give up hope. Your pain can be managed.

If you are still having pain that is hard to control, you may want to talk with your health care team about seeing a pain or palliative care specialist (see [page 2](#)).

Whatever you do, don't give up. If one medicine doesn't work, there is almost always another one to try. Also, new medicines are created all the time. And unlike other medicines, there is no "right" dose for many pain medicines. Your dose may be more or less than someone else's. The right dose is the one that relieves your pain and makes you feel better.

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CHAPTER 5

Medicines To Treat Cancer Pain

There is more than one way to treat pain.

Your doctor prescribes medicine based on the kind of pain you have and how severe it is. In studies, these medicines have been shown to help control cancer pain.

Doctors use three main groups of drugs for pain: nonopioids, opioids, and other types. You may also hear the term **analgesics** used for these pain relievers. Some are stronger than others. It helps to know the different kinds of medicines, why and how they're used, how you take them, and what side effects you might expect.

1. Nonopioids —for mild to moderate pain

Nonopioids are drugs used to treat mild to moderate pain, fever, and swelling. On a scale of 0 to 10, a nonopioid may be used if you rate your pain from 1 to 4. These medicines are stronger than most people realize. In many cases, they are all you'll need to relieve your pain. You just need to be sure to take them regularly.

You can buy most nonopioids without a prescription. **But you still need to talk with your doctor before taking them.** Some of them may have things added to them that you need to know about. And they do have side effects. Common ones, such as nausea, itching, or drowsiness, usually go away after a few days. **Do not** take more than the label says unless your doctor tells you to do so.

Nonopioids include:

■

■ Acetaminophen, which you may know as Tylenol®

Acetaminophen reduces pain. It is not helpful with inflammation. Most of the time, people don't have side effects from a normal dose of acetaminophen. But taking large doses of this medicine every day for a long time can damage your liver. Drinking alcohol with the typical dose can also damage the liver.

Make sure you tell the doctor that you're taking acetaminophen. Sometimes it is used in other pain medicines, so you may not realize that you're taking more than you should. Also, your doctor may not want you to take acetaminophen too often if you're getting chemotherapy. The medicine can cover up a fever, hiding the fact that you might have an infection.

■■ Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (which you may know as Advil® or Motrin®) and aspirin

NSAIDs help control pain and inflammation. With NSAIDs, the most common side effect is stomach upset or indigestion, especially in older people. Eating food or drinking milk when you take these drugs may stop this from happening.

NSAIDs may also keep blood from clotting the way it should. This means that it's harder to stop bleeding after you've hurt yourself. NSAIDs can also sometimes cause bleeding in the stomach.

Tell your doctor if:



- Your stools become darker than normal

-

- You notice bleeding from your rectum

-

- You have an upset stomach

-

- You have heartburn symptoms

-

- You cough up blood

Acetaminophen and NSAIDs at a Glance

Type

Other Names

Action

Side Effects

Acetaminophen

Tylenol®

Reduces pain

Large doses can damage the liver.

and fever

May cause liver damage if you

drink three or more alcoholic

drinks a day.

Lowers fever. Talk to your doctor

if your body temperature is above

normal (98.6°) and you are taking

this medicine.

NSAIDs

Bayer®

Reduces

Can upset the stomach.

(aspirin,

aspirin)

pain,

Can cause bleeding of the

ibuprofen,

inflammation

stomach lining, especially if you

naproxen)

Ecotrin®

(swelling),

(aspirin)

drink alcohol (wine, beer, etc.).

and fever

Can cause kidney problems,

Advil®

especially in the elderly or those

(ibuprofen)

with existing kidney problems.

Motrin®

Can cause heart problems,

(ibuprofen)

especially in those who already

have heart disease. However,

Nuprin®

aspirin does **not** cause heart

(ibuprofen)

problems.

Avoid these medicines if you are

Aleve®

on anticancer drugs that may

(naproxen)

cause bleeding.

Lowers fever. Talk to your doctor

if your body temperature is above

normal (98.6°) and you are taking

this medicine.

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What to avoid when taking NSAIDs

Some people have conditions that NSAIDs can make worse. In general, you should avoid these drugs if you:

-
- Are allergic to aspirin
-
- Are getting chemotherapy
-
- Are on steroid medicines

- Have stomach ulcers or a history of ulcers, gout, or bleeding disorders

- Are taking prescription medicines for arthritis

- Have kidney problems

- Have heart problems

- Are planning surgery within a week

- Are taking blood-thinning medicine (such as heparin or Coumadin®) **2. Opioids —for moderate to severe pain**

If you're having moderate to severe pain, your doctor may recommend that you take stronger drugs called opioids. Opioids are sometimes called narcotics. You must have a doctor's prescription to take them. They are often taken with aspirin, ibuprofen, and acetaminophen.

Common opioids include:

- Codeine

- Methadone

- Fentanyl

- Morphine

- Hydromorphone (e.g. Dilaudid®)

- Oxycodone (e.g. OxyContin®)

- Levorphanol

- Oxymorphone

- Meperidine (e.g. Demerol®)

Getting relief with opioids

Over time, people who take opioids for pain sometimes find that they need to take larger doses to get relief. This is caused by more pain, the cancer getting worse, or medicine **tolerance** ([see pages 20 and 21](#)). When a medicine doesn't give you enough pain relief, your doctor may increase the dose and how often you take it. He or she can also prescribe a stronger drug. Both methods are safe and effective under your doctor's care. **Do not increase the dose of medicine on your own.**

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Managing and preventing side effects

Some pain medicines may cause:

- Constipation (trouble passing stools)

- Drowsiness (feeling sleepy)

- Nausea (upset stomach)

- Vomiting (throwing up)

Side effects vary with each person. It's important to talk to your doctor often about any side effects you're having. If needed, he or she can change your medicines or the doses you're taking. They can also add other medicines to your pain control plan to help your side effects.

Keep in mind that constipation will only go away if it's treated. But don't let any side effects stop you from getting your pain controlled. Your health care team can talk with you about other ways to relieve them. There are solutions to getting your pain under control.

Other less common side effects include:

- ■ Dizziness
- ■ Confusion
- ■ Breathing problems
- ■ Itching
- ■ Trouble urinating

Constipation

Almost everyone taking opioids has some constipation. This happens because opioids cause the stool to move more slowly through your system, so your body takes more time to absorb water from the stool. The stool then becomes hard.

You can control or prevent constipation by taking these steps:

-
- Ask your doctor about giving you **laxatives** and **stool softeners** when you first start taking opioids. Taking these right when you start taking pain medicine may prevent the problem.
-
- Drink plenty of liquids. Drinking 8 to 10 glasses of liquid each day will help keep stools soft.
-
- Eat foods high in fiber, including raw fruits with the skin left on, vegetables, and whole grain breads and cereals.

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-
- Exercise as much as you are able. Any movement, such as light walking, will help.
-
- Call your doctor if you have not had a bowel movement in 2 days or more.

Drowsiness

Some opioids cause drowsiness. Or, if your pain has kept you from sleeping, you may sleep more at first when you begin taking opioids. The drowsiness could go away after a few days.

If you're are tired or drowsy:

-
- Don't walk up and down stairs alone.
-
- Don't do anything where you need to be alert—driving, using machines or equipment, or anything else that requires focus.

Call your doctor if the drowsiness is severe or doesn't go away after a few days.

- You may have to take a smaller dose more often or change medicines.
- It may be that the medicine isn't relieving your pain, and the pain is keeping you awake at night.
- Your other medicines may be causing the drowsiness.
- Your doctor may decide to add a new drug that will help you stay awake.

Nausea and vomiting

Nausea and vomiting could go away after a few days of taking opioids. However, if your nausea or vomiting prevents you from taking your medicine, call your doctor right away. You should also call if any breathing problems develop.

These tips may help:

-
- Stay in bed for an hour or so after taking your medicine if you feel sick when walking around. This kind of nausea is like feeling seasick. Some over-the-counter drugs may help, too. But be sure to check with your doctor before taking any other medicines.
-
- Your doctor may want to change or add medicines, or prescribe anti-nausea drugs.
-
- Ask your doctor if something else could be making you feel sick. It might be related to your cancer or another medicine you're taking. Constipation can also add to nausea.

Some pain medicines can make you feel sleepy when you first take them. This usually goes away within a few days. Also, some people get dizzy or feel confused. Tell your doctor if any of these symptoms persist. Changing your dose or the type of medicine can usually solve the problem.

What to watch out for when taking pain medicine

All drugs must be taken carefully. Here are a few things to remember when you are taking opioids:

■

■ **Take your medicines as directed.** Also, don't split, chew, or crush them, unless suggested by your doctor.

■ **Doctors will adjust the pain medicine dose so that you get the right amount for your body.** That's why it's important that only one doctor prescribes your opioids. Make sure that you bring your list of medicines to each visit. That way, your health care team is aware of your pain control plan.

■

■ **Combining pain medicine with alcohol or tranquilizers can be dangerous.**

You could have trouble breathing or feel confused, anxious, or dizzy.

Tell your doctor how much and how often you:

- Drink alcohol
- Take tranquilizers, sleeping pills, or **antidepressants**
- Take any other medicines that make you sleepy

How to stop taking opioids

You may be able to take less medicine when the pain gets better. You may even be able to stop taking opioids. But it's important to stop taking opioids slowly, with your doctor's advice. When pain medicines are taken for long periods of time, your body gets used to them. If the medicines are stopped or suddenly reduced, a condition called **withdrawal** may occur. This is why the doses should be lowered slowly. This has **no** relation to being addicted (see [Chapter 6](#)).

Stopping your pain medicines slowly prevents withdrawal symptoms. But if you stop taking opioids suddenly, you may start feeling like you have the flu.

You may sweat and have diarrhea or other symptoms. If this happens, tell your doctor or nurse. He or she can treat these symptoms, which usually resolve quickly.

Doctors also prescribe other types of medicine to relieve cancer pain. They can be used along with nonopioids and opioids. Some include:

■

■ **Antidepressants.** Some drugs can be used for more than one purpose. For example, antidepressants are used to treat depression, but they may also help relieve tingling and burning pain. Nerve damage from radiation, surgery, or chemotherapy can cause this type of pain.

■

■ **Antiseizure medicines (anticonvulsants).** Like antidepressants, anticonvulsants or antiseizure drugs can also be used to help control tingling or burning from nerve injury.

■

■ **Steroids.** Steroids are mainly used to treat pain caused by swelling.

Be sure to ask your health care team about the common side effects of these medicines.

How medicine is given

To relieve cancer pain, doctors often prescribe pills or liquids. But there are also other ways to take medicines, such as:

■

■ **Mouth:** Some pain medicine can be put inside the cheek or under the tongue.

■

■ **Injections (shots):** There are two different kinds of shots:

• **Under the skin:** Medicine is placed just under the skin using a small needle. These are called **subcutaneous** injections.

• **In the vein:** Medicine goes directly into the vein through a needle. These are called **intravenous (IV)**

injections. **Patient-controlled analgesia (PCA)**

pumps are often used with these kinds of injections.

PCA pumps let you push a button to give yourself a

dose of pain medicine.

■

■ **Skin patches:** These bandage-like patches go on the skin.

Patient-controlled

They slowly but steadily, release medicine.

analgesia pump (PCA)

■

■ **Rectal suppositories:** These are capsules or pills that you put inside your rectum. The medicine dissolves and is absorbed by the body.

■

■ **In or around the spinal cord:** Medicine is placed between the wall of the spinal canal and the covering of the spinal cord.

17

Questions to ask your health care team

about your pain medicine:

■

■ How much medicine should I take? _____

How often? _____

■

■ If my pain doesn't go away, can I take more medicine? _____

How much should I increase the dose? _____

■ ■ Should I call you before taking more medicine? _____

■ ■ How long does the medicine last? _____

■ ■ What if I forget to take my medicine or take it later than I was supposed to?

■ ■ Should I take my medicine with food? _____

■

■ How much liquid should I drink with the medicine? _____

■

■ How long does it take for the medicine to start working? _____

Is it safe to drink alcohol (wine, beer, etc.), drive, or run machinery after I've taken the medicine?

■

■ What other medicines can I take with the pain medicine? _____

■

■ What are the side effects? How can I prevent them? _____

■

■ What should I call you about right away? _____

18



Other ways to relieve pain

Medicine doesn't always relieve pain in some people. In these cases, doctors use other treatments to reduce pain:

■

■ **Radiation therapy.** Different forms of radiation energy are used to shrink the tumor and reduce pain. Often one treatment is enough to help with the pain. But sometimes several treatments are needed.

■

■ **Neurosurgery.** A surgeon cuts the nerves that carry pain messages to your brain.

■ ■ **Nerve blocks.** Anesthesiologists inject pain medicine into or around the nerve or into the spine to relieve pain.

■

■ **Surgery.** A surgeon removes all or part of a tumor to relieve pain.

This is especially helpful when a tumor presses on nerves or other parts of the body.

■

■ **Chemotherapy.** Anticancer drugs are used to reduce the size of a tumor, which may help with the pain.

■ ■ **Transcutaneous Electric Nerve Stimulation (TENS).** TENS

uses a gentle electric current to relieve pain. The current comes from a small power pack that you can hold or attach to yourself.

Your Pharmacist

Your Pharmacist is an important member of your health care team.

He or she can answer many questions about your medicines, such as how to take them, or what side effects they have. It's a pharmacist's job to stay up-to-date and informed about cancer drugs.

If possible, try to use just one pharmacy. This way, all your prescriptions will be on file in one system. Some pharmacies even have systems that give warnings if newly ordered medicines could interact or interfere with others that someone is already taking.







CHAPTER 6

Medicine Tolerance and Addiction

When treating cancer pain, addiction is rarely a problem.

Addiction is when people can't control their seeking or craving for something.

They continue to take medicine or do something even when it causes them harm.

Often people are taking medicines when they do not have pain. They take it for psychological reasons, not physical. But people with cancer need strong medicine to help control their pain. Yet some people are so afraid of becoming addicted to pain medicine that they won't take it. Family members may also worry that their loved ones will get addicted to pain medicine. Therefore, they sometimes encourage loved ones to "hold off" between doses. But even though they may mean well, it's best to take your medicine as prescribed.

People in pain get the most relief when they take their medicines on schedule. And don't be afraid to ask for larger doses if you need them. As mentioned on page 13, developing a tolerance to pain medicine is common. But taking cancer pain medicine is not likely to cause addiction. If you're not a drug addict, you won't become one.

Even if you have had an addiction problem before, you still deserve good pain management. Talk with your doctor or nurse about your concerns.

“If you’re worried about addiction, ask yourself one question. If you didn’t have this pain, would you want this medicine? The answer is usually no.” —Robin

20

Tolerance to pain medicine sometimes happens.

Some people think that they have to save stronger medicines for later. They’re afraid that their bodies will get used to the medicine and that it won’t work anymore. But medicine doesn’t stop working—it just doesn’t work as well as it once did. As you keep taking a medicine over time, you may need a change in your pain control plan to get the same amount of relief.

This is called **tolerance**. Tolerance is a common issue in cancer pain treatment.

Medicine tolerance is not the same as addiction.

As mentioned, medicine tolerance happens when your body gets used to the medicine you’re taking. Each person’s body is different. Many people don’t develop a tolerance to opioids. But if tolerance happens to you, don’t worry.

Under your doctor’s care, you can:

-
- Increase your dose
-
- Add a new kind of medicine
-
- Change the kind of medicine that you’re taking for pain

The goal is to relieve your pain. Increasing the dose to overcome tolerance does not lead to addiction.

Taking pain medicine will not cause you to “get high.”

Most people do not “get high” or lose control when they take cancer pain medicines as prescribed by the doctor. Some pain medicines can cause you to feel sleepy when you first take them. This feeling usually goes away within a few days. On occasion, people get dizzy or feel confused when they take pain medicines. Tell your doctor or nurse if this happens to you. Changing your dose or type of medicine can usually solve this problem.

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CHAPTER 7

Other Ways To Control Pain

Along with your pain medicine, your health care team may suggest you try other methods to control your pain. However, unlike pain medicine, some of these methods have not been tested in cancer pain studies. But they may help improve your quality of life by helping you with your pain, as well as stress, anxiety, and coping with cancer. Some of these methods are called **complementary** or **integrative**.

These treatments include everything from cold packs, massage, **acupuncture**, **hypnosis**, and **imagery** to **biofeedback**, meditation, and therapeutic touch. Once you learn how, you can do some of them by yourself. For others, you may have to see a specialist to receive these treatments. If you do, ask if they are licensed experts.

Acupuncture

Acupuncture is a form of Chinese medicine. It involves inserting very thin, metal needles into the skin at certain points of the body. (*Applying pressure to these points with just the thumbs or fingertips is called acupressure.*) The goal is to change the body’s energy flow so it can heal itself.

When receiving this treatment, you may have a slight ache, dull pain, tingling, or electrical-feeling sensation for a few seconds after the needles are inserted. Once the needles are in place, though, you shouldn’t feel any discomfort. They remain in place for 15 to 30 minutes. However, it may be more or less, depending on what the practitioner suggests.

Acupuncture has been shown to help with nausea and vomiting related to cancer treatment. And some studies have shown it may help with cancer pain. Before getting acupuncture, talk with your health care team to make sure it’s safe for your type of cancer. If it is, your health care team can suggest a licensed acupuncturist. Many hospitals and cancer centers have one on staff.

Biofeedback

Biofeedback uses machines to teach you how to control certain body functions, such as heart rate, breathing, and muscle tension. You probably never think of these body functions because they happen on their own. But learning how to control them may help you relax and cope with pain. Biofeedback is often used with other pain relief methods. If you're interested in trying this method, you must see a licensed biofeedback technician.

22



Distraction

Distraction is simply turning your focus to something other than the pain. It may be used

alone to manage mild pain, or used with medicines to help with acute pain, such as pain related to procedures or tests. Or you may try it while waiting for your pain medicine to start working.

More than likely, you've done this

method without realizing it. For example, watching television and listening to music are good ways to distract your mind. In fact, any activity that can focus your attention can be used for distraction. You can count, sing, or pray. You could try slow rhythmic breathing or repeat certain phrases over and over again, such as "I can cope."

You could do certain activities that take your mind from the pain. Some of these may be crafts or hobbies, reading, going to a movie, or visiting friends.

Heat and Cold

Heat may relieve sore muscles, while cold may numb the pain. However, ask your doctor if it is safe to use either during treatment. Do not use them for more than 10

minutes at a time. And *do not* use heat or cold over any area where circulation is poor.

For cold, try plastic gel packs that remain soft even when frozen. You can find them in drug and medical-supply stores. Of course, you always can use ice cubes wrapped in a towel or frozen water in a paper cup.

For heat, you can use a heating pad. But you also can try gel packs heated in hot water, hot-water bottles, a hot, moist towel, and hot baths and showers. Be careful not to leave heat on too long to avoid burns.

Hypnosis

Hypnosis is a trance-like state of relaxed and focused attention. People describe it as a lot like the way they feel when they first wake up in the morning. Their eyes are closed, but they're aware of what's going on around them. In this relaxed state, people's minds are usually more receptive or open to suggestion. As a result, hypnosis can be used to block the awareness of pain or to help you change the sensation of pain to a more pleasant one.

You'll need to see a person who is trained in hypnosis, often a psychologist or psychiatrist. He or she may also be able to teach you how to place yourself in a trance-like state, by making positive suggestions to yourself.



Imagery

Imagery is like a daydream. You close your eyes and create images in your mind to help you relax, feel less anxious, and sleep. You daydream using all of your senses –

sight, touch, hearing, smell, and taste. For example, you may want to think of a place or activity that made you happy in the past. You could explore this scene, which could help reduce your pain both during and after you try it.

If you have to stay in bed or can't leave the house, imagery may help. It may lessen the closed-in feelings you have after being indoors for a long time. See [page 39](#) for an exercise on how to use imagery.

Massage

Massage may help reduce pain and anxiety. It may also help with fatigue and stress. It is pressing, rubbing, and kneading parts of the body with hands or special tools. For pain, a steady, circular motion near the pain site may work best. Massage may also help relieve tension and increase blood flow. Deep or intense pressure should not be used with cancer patients unless their healthcare team says it's okay to do so.

Meditation

Meditation is a form of mind-body medicine used to help relax the body and quiet the mind. It may help with pain, as well as with worry, stress, or depression.

People who are meditating use certain techniques such as focusing attention on something, like a word or phrase, an object, or the breath. They may sit, lie down, walk, or be in any other position that makes them feel comfortable. A goal while meditating is to try to have an open attitude toward distracting thoughts or emotions.

When they occur, attention is gently brought back to breathing or the silent repeating of phrases.

“I began meditating as a way to help
relieve my pain and calm myself.

I can't avoid medicine, but I feel like

I don't have to take as much.” —

Anna

24

Relaxation

Relaxation reduces pain or keeps it from getting worse by getting rid of tension in your muscles. It may help you sleep and give you more energy. Relaxation may also reduce anxiety and help you cope with

stress.

The most common methods of relaxation are:

■

■ **Visual concentration.** When you stare at an object.

■

■ **Breathing and muscle tensing.** This is breathing in and tensing the muscles, then breathing out while letting your muscles go. See [page 40](#) for an exercise on how to use breathing and muscle tensing.

■ **Slow rhythmic breathing.** To do this, you breathe slowly in and out while concentrating on an object. You can add imagery to slow rhythmic breathing or listen to music too. See page 40 for an exercise on how to use slow rhythmic breathing.

Sometimes, relaxation is hard if you're in severe pain. You could try using some of the methods that are quick and easy. These may be rhythmic massage or breathing and muscle tensing. Some people use music or other types of art therapy to help them relax.

Sometimes breathing too deeply can cause shortness of breath. If this happens, take shallow breaths or breathe more slowly. Also, as you start to relax, you may fall asleep. If you don't want to sleep, sit in a hard chair or set a timer or alarm before you start the exercise.

Other Methods

Here are some other ways people have tried to find relief from cancer pain.

■

■ **Physical Therapy.** Exercises or methods used to help restore strength, increase movement to muscles, and relieve pain.

■ **Reiki.** A form of energy medicine in which the provider places his or her hands on or near the patient. The intent is to transmit what is believed to be a life force energy called qi (or chi).

■

■ **Tai Chi.** A mind-body practice that is a series of slow, gentle movements with a focus on breathing and concentration. The thought is that it helps what is believed to be a life force energy (called qi) flow through the body.

■

■ **Yoga.** Systems of stretches and poses with special focus given to breathing. It is meant to calm the nervous system and balance the body, mind, and spirit. There are different types of yoga, so ask about which ones would be best for you.

Make sure that you see a licensed expert when trying physical therapy, massage, hypnosis, or acupuncture.

25

To learn more about complementary treatments for pain:

-
- Talk with your doctor, nurse, or oncology social worker.
-
- See the NCI booklet *Thinking About Complementary & Alternative Medicine: A Guide for People With Cancer*. See [page 34](#) on how to order.
- Contact the National Center for Complementary and Alternative Medicine at 1-888-644-6226 or online at <http://nccam.nih.gov>.
-
- See the web site for the NCI Office of Cancer Complementary and Alternative Medicine at <http://www.cancer.gov/cam>.

Remember: Always talk with your doctor before using any complementary pain treatments. Some may interfere with your cancer treatment.

26





CHAPTER 8

Your Feelings and Pain

“At first I wasn’t able to do the things I used to do. I couldn’t mow my lawn or work in my garden. It was very frustrating.” —Juan

Having pain and cancer affects every part of your life.

It can affect not only your body, but your thoughts and feelings as well. Whether you have a lot of pain or a little, if it’s constant, you may feel like you aren’t able to focus on anything else. It may keep you from doing things and seeing people that you normally do. This can be upsetting and may feel like a cycle that never seems to end.

Sometimes things that people used to take for granted aren’t as easy anymore. These may include cooking, getting dressed, or just moving around. Some people can’t work because of the pain or have to cut back on their hours. They may worry about money.

Limits on work and everyday life may also make people less social, wanting to see others less often.

Research shows that people in pain may feel sad or anxious and may get depressed more often. At other times they may feel irritable, or angry and frustrated. And they can feel lonely, even if they have others around them.

A common result of having cancer and being in pain is fear. For many, pain and fear together feel like suffering. People get upset worrying about the future. They focus their thoughts on things that may or may not happen. You may feel fear about many things, such as fear of:

-
- The cancer getting worse
-

- The pain being too much to handle
-
- Your job or daily tasks becoming too hard to do
-
- Not being able to attend special trips or events
-
- Loss of control

This rollercoaster of feelings often makes people look for the meaning that cancer and pain have in their life. Some question why this could happen to them. They wonder what they did to deserve it. Others may turn to religion or explore their spirituality more, asking for guidance and strength.

27





Don't lose hope.

If you have feelings like these, know that you're not alone. Many people with cancer pain have had these kinds of feelings. Having negative thoughts is normal. And some people have positive thoughts, too, finding benefits in facing cancer. But if your negative thoughts overwhelm you, don't ignore your feelings. Help is there for you if you're distressed or unsure about your future.

Finding support

There are many people who can help you. You can talk with oncology social workers, health psychologists, or other mental health experts at your hospital or clinic. Your health care team can help you find a counselor who is trained to help people with long-term illnesses. These people can help you talk about what you are going through and find answers to your concerns. They may suggest medicine that will help you feel better if you need it.

Many people say that they regain a sense of control and well-being after talking with people in their spiritual or religious community. A leader from one of these groups may be able to offer support, too. Many are trained to help people cope with illness.

Also, many hospitals have a staff chaplain who can counsel people of all faiths.

You can also talk with friends or others in your community. Some join a support group. Cancer support groups are made up of people who share their feelings about coping with cancer. They can meet in person, by phone, or over the Internet. They may help you gain new insights and ideas on how to cope. To find a support group for you, talk with your doctor, nurse, or oncology social worker.

"I can't help feeling

frustrated with all that's

going on in my life. Between my cancer treatments and the pain, I get upset and angry. Sometimes I really need someone to talk to— someone who understands what I'm going through.” —

Carlos

28

How your pain affects your loved ones

Chronic or severe pain affects everyone who loves and takes care of you. It can be hard for family members and friends to watch someone close to them be in pain.

Like you, your loved ones may feel angry, anxious, and lonely. They may feel helpless because they can't make you feel better. They may even feel guilty that you have pain while they don't. Or they may feel loss, because your pain keeps you from doing things you like to do.

It's natural for family members and friends to have these emotions. It may help if everyone understands that these emotions exist and that no one needs to face them alone.

Let your family members know it's okay for them to get help. Like you, they can talk to a counselor or join a support group. Encourage them to ask the oncology social worker about the options that are available for them.

Also, they can read the NCI booklets for caregivers listed on the inside front cover of this booklet.

Talking with family members

You may want to let family members and friends know how you're feeling. For some, this can be hard or awkward. Some people say that they want to avoid upsetting those closest to them. Others say that they don't want to seem negative. But open and honest communication can help everyone. Letting others know about your pain may help them understand what you are going through. They can then look for ways to help you. Your loved ones may also feel better knowing that they're helping to make you feel more comfortable.

Family problems before your cancer

Any problems your family had before you got cancer are likely to be more intense now.

Or maybe your family just doesn't communicate very well. If this is the case, you can ask a social worker to set up a family meeting for you. During these meetings, the doctor can explain treatment goals and issues. And you and your family members can state your wishes for care. These meetings can also give everyone a chance to express their feelings in the open. Remember, there are many people you can turn to at this time.

For more about coping with your feelings, see the NCI brochure, *Taking Time: Support for People With Cancer*. See [page 34](#) on how to order or download.

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CHAPTER 9

Financial Issues

“My doctor told me about a pain control technique that he thought would help me.

I was a little worried about how I would pay for it. It took one phone call to my insurance company, and my questions were answered.”

—Terry

When you’re in pain, the last thing you want to think about is paying for your medicine. Yet money worries

have stopped many people from getting the pain

treatment they need. Talk with your oncology social

worker if you have questions. He or she should be able to direct you to resources in your area. Here are some general tips:

Insurance

When dealing with health insurance, you might want to:

■

- Call your insurance company and find out what treatments are covered.

Sometimes insurance companies pay for only certain types of medicines. If the medicine you need isn't covered, your doctor may need to write a special appeal letter. Or your doctor may need to prescribe a different treatment.

■

- Ask if your insurance company can give you a case manager to help you with your coverage.

■

- Check to make sure that your plan will cover any specialists your doctor refers you to. If it does not, check with your insurance company to see which doctors are included in your plan. Ask your doctor to refer you to someone on your plan's list.

■

- Find out whether you have to pay copayments up front and how much they cost.

■

- Find out how you should pay your balance. For example, do you file a claim?

Does the insurance company pay first? Or do you pay and get reimbursed?

■

- Tell the insurance company if you believe you've received an incorrect bill. You should also tell your doctor or the hospital or clinic that sent the bill. Don't be afraid to ask questions.

30

Government health insurance

Medicare

Medicare is health insurance for people age 65 or older. However, people under 65 who are on kidney dialysis or have certain disabilities may also qualify.

Medicare Part B only pays for outpatient medicine given by a pump or by vein.

It doesn't pay for pills, patches, or liquids.

Medicare Part D is a benefit that covers outpatient prescription medicines. It comes from private insurance plans that have a contract with Medicare. These plans vary in what they cost and the medicines they cover. Find out which medicines a plan covers before you join to make sure that it meets your needs. You should also know how much your copays and **deductible** will be.

Medicaid

Medicaid gives health benefits to low income people and their families. Some may have no health insurance or not enough, and therefore need this help.

If you have Medicaid, you should know that it pays for medicine given by mouth (**orally**) or by vein (intravenous). Each state has its own rules about who is eligible for Medicaid.

To learn more about Medicare and Medicaid talk with your oncology social worker. You can also go to the Medicare and Medicaid Web site, www.cms.hhs.gov, or call the helpline at 1-800-MEDICARE (1-800-633-4227).

Specialists can answer your questions or direct you to free counseling in your area.

Other advice

Don't be embarrassed to tell your health care team if you're having trouble paying for your medicine. They may be able to prescribe other medicine that better fits your budget.

If you feel that you're overwhelmed, the stress may seem like too much to handle. You might try getting help with financial planning. Talk with the business office where you get treatment. There are many free consumer credit counseling agencies and groups. Talk with your oncology social worker about your choices.

You can also contact the NCI's Cancer Information Service (CIS) and ask for help.

They have a database, **National Organizations that Offer Cancer-Related Services**, that may help you. See [the Resources section on page 34](#) for ways to contact NCI.



Tips for saving money on pain medicine

If the cost of pain medicine is an issue for you, consider the following tips:

-
- Ask your doctor if there are

generic brands of your medicine

available. These usually cost less than brand-name medicines.

■

■ Ask your doctor for medicine

samples before paying for a

prescription. You can't get

samples of opioids. But you can

ask your doctor to write only

part of the prescription. This

way you can make sure that the

medicine works for you before

buying the rest of it. This will

only help if you pay by the amount you buy. For some insurance plans, you pay the same amount for part of or the whole prescription. Find out what will work best for you.

■

■ Ask about drug companies that have special programs to give free drugs to patients in financial need. Your doctor should know about these programs.

■

■ Remember that pills may cost less than other forms of medicine.

■

■ Use a bulk-order mail pharmacy. But first make sure that the medicine works for you. Also, be aware that you can't order opioids in bulk or through the mail. Ask your oncology social worker or pharmacist about bulk-order mail pharmacies.

■

■ Contact NeedyMeds.

They are a nonprofit organization that helps people who cannot afford medicine or health care costs. Go to <http://www.needymeds.com>, or ask someone to do it for you.





Reflection

You can take control of your pain. Work with your doctor and the other members of your health care team to find the best plan for you.

Read the tips in this booklet and make them work for you. Don't lose hope. You don't have to accept pain as a normal part of cancer or treatment. You deserve to have the best care and support there is.

When the World says,

“Give up” —

Hope

whispers,

“Try

it

one

More

Time.”

(author unknown)

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Resources

For more resources:

See *National Organizations*

That Offer Cancer-Related

Services at www.cancer.gov.

You can get information about cancer from

In the search box, type in the

many sources. Some are listed here. You may

words “national organizations.”

also want to check for more information from

support groups in your community.

Or call 1-800-4-CANCER

(1-800-422-6237) to seek

more help.

Federal Agencies



■ National Cancer Institute

Offers comprehensive research-based information for patients, families, health professionals, and the general public. Topics include cancer prevention, screening, diagnosis, treatment, genetics, and supportive care. NCI’s web site lists clinical trials and specific cancer topics in NCI’s Physician Data Query (PDQ) database.

Toll-free:

1-800-4-CANCER (1-800-422-6237)

Online:

<http://www.cancer.gov> or <http://www.cancer.gov/espanol>

Chat online: LiveHelp, NCI’s instant messaging service, at <http://www.cancer.gov/livehelp>

E-mail: cancergovstaff@mail.nih.gov

Publications: Order online at <http://www.cancer.gov/publications>

or call 1-800-4-CANCER (1-800-422-6237)



■ Centers for Medicare & Medicaid Services (CMS)

Has information about patient rights, prescription drugs, and health insurance issues, including Medicare and Medicaid.

Toll-free:

1-800-MEDICARE (1-800-633-4227)

Online:

<http://www.medicare.gov> (for Medicare information) or

<http://www.cms.hhs.gov> (for other information)



■ **National Center for Complementary and Alternative Medicine (NCCAM)**

Part of the National Institutes of Health. It funds and studies medical practices that are not commonly used as standard care. It rates how well these different practices work and shares this information with the public.

Toll-free: 1-888-644-6226

TTY: 1-888-644-6226

Online: <http://nccam.nih.gov>

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Private/Nonprofit Organizations



■ **American Cancer Society (ACS)**

Mission is to end cancer as a major health problem through prevention, saving lives, and relieving suffering. ACS works toward these goals through research, education, advocacy, and service. The organization's National Cancer Information Center answers questions 24 hours a day, 7 days a week.

Toll-free:

1-800-ACS-2345 (1-800-227-2345)

TTY: 1-866-228-4327

Online: <http://www.cancer.org>



■ **American Pain Foundation**

Serves people with pain through information, advocacy, and support; pain and resource information, practical help and publications are available through toll-free telephone service and website.

Toll-free:

1-888-615-PAIN (1-888-615-7246)

Online: <http://www.painfoundation.org>

■

■ **CancerCare**

Offers free support, information, and financial and practical help to people with cancer and their loved ones.

Toll-free:

1-800-813-HOPE (1-800-813-4673)

Online: <http://www.cancercare.org>

■

■ **Cancer Support Community**

Cancer Support Community is a national organization that provides support groups, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Phone:

1-888-793-WELL (1-888-793-9355)

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

■

■ **Center to Advance Palliative Care**

Goal is to increase the availability of quality palliative care services for people facing serious illness. Offers training and assistance to health care professionals.

Phone: 1-212-201-2670

Online: <http://www.capc.org>

For patients

and families: <http://www.getpalliativecare.org>

35

■

■ **National Coalition for Cancer Survivorship (NCCS)**

Gives out information on cancer support, employment, financial and legal issues, advocacy, and related issues.

Toll-free:

1-877-NCCS-YES (1-877-622-7937)

Online: <http://www.canceradvocacy.org>

■

■ **National Hospice and Palliative Care Organization (NHPCO)** Has information on hospice care, local hospice programs, advance directives in different states, and finding a local health care provider. It offers education and materials on palliative and end-of-life issues through its Caring Connections program, as well as links to other organizations and resources.

Toll-free: 1-800-658-8898

Online: <http://www.nhpco.org>

■

■ **Caring Connections**

Toll-free: 1-800-658-8898

Online: <http://www.caringinfo.org>

■

■ **NeedyMeds**

Lists medicine assistance programs available from drug companies.

NOTE: Usually patients cannot apply directly to these programs.

Ask your doctor, nurse, or social worker to contact them.

Online: <http://www.needymeds.com>

■

■ **Patient Advocate Foundation**

Offers education, legal counseling, and referrals concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters.

Toll-free: 1-800-532-5274

Online: <http://www.patientadvocate.org>



Pain Control Record

You can use a chart like this to keep a record of how well your medicine is working. Some people call it a pain diary. Write the information in the chart below. Describe the amount of pain you feel using the way that works best for you. You can use words, numbers on a scale from 0 to 10, or even draw a face (see [page 7 for examples](#)). Take the chart with you when you visit your doctor.

Date

Time

Describe the pain you feel

Pain

Action taken

level

6/8

8am stabbing pain in side

9

(example)

6/10

all day dull ache in legs

5

(example)

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Medicines you are taking now

Use this form to record all medicines—not just pain medicines—that you are taking.

This information will help your doctor keep track of all your medicines.

Date

Medicine

Dose

How often How well is it

Prescribing

taken

working?

doctor

Pain medicines you have taken in the past

Use this form to record the pain medicines you have taken in the past. It will help your doctor understand what has and hasn't worked.

Date

Medicine

Dose

How often Side effects

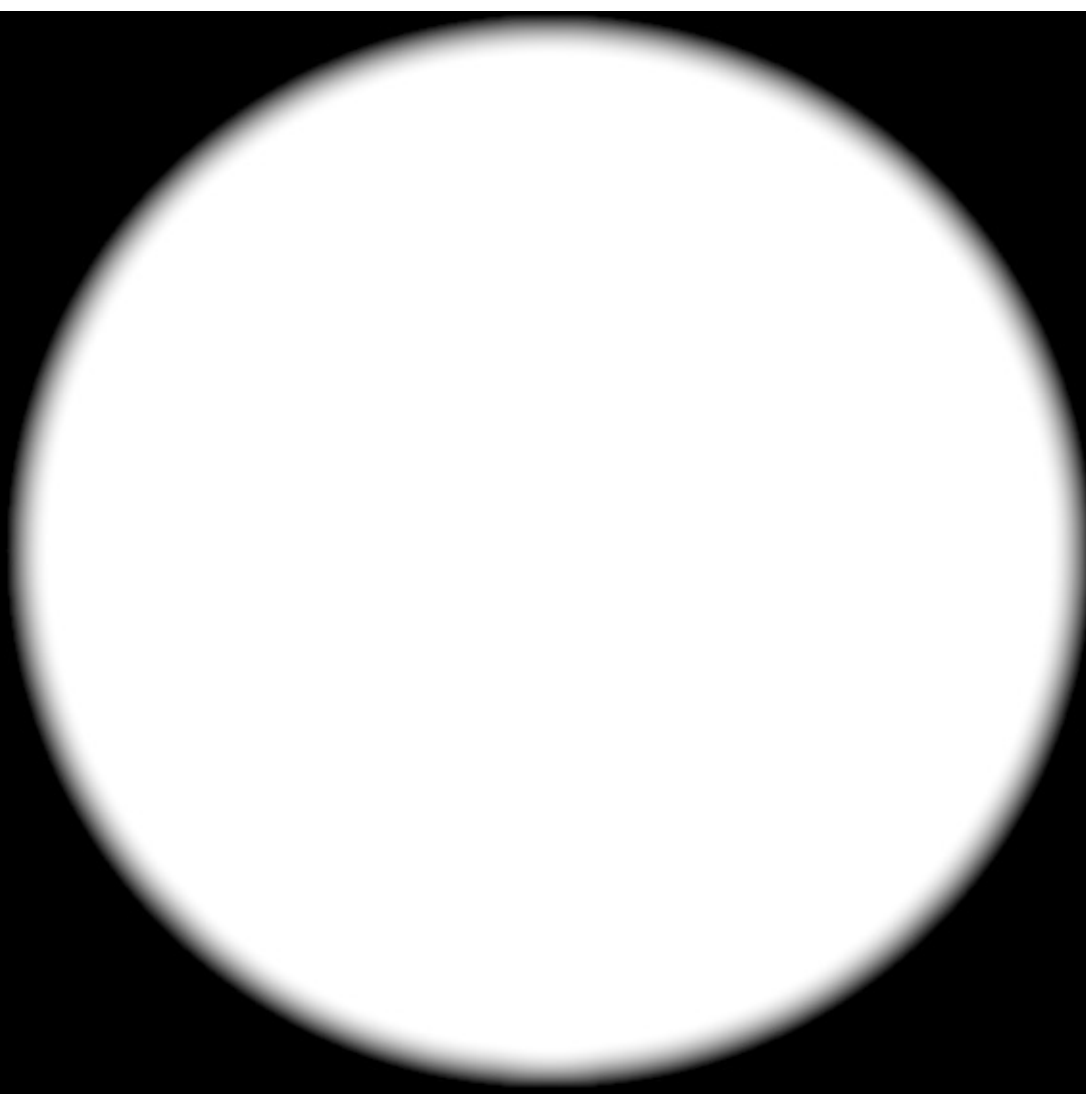
Reason for

taken

stopping

38







How to Use Imagery

Imagery usually works best with your eyes closed. To begin, create an image in your mind. For example, you may want to think of a place or activity that made you happy in the past.

Explore this place or activity.

Notice how calm you feel.

If you have severe pain, you may imagine yourself as a person without pain. In your image, cut the wires that send pain signals from one

part of your body to another. Or you

may want to imagine a ball of healing

energy. Others have found this exercise to

be very helpful:

■

■ Close your eyes and breathe slowly. As you breathe in, say silently and slowly to yourself, “In, one, two,” and as you breathe out, say “Out, one, two.” Do this for a few minutes.

■

■ Imagine a ball of healing energy forming in your lungs or on your chest.

Imagine it forming and taking shape.

■

■ When you’re ready, imagine that the air you breathe in blows this ball of energy to the area where you feel pain. Once there, the ball heals and relaxes you. You may imagine that the ball gets bigger and bigger as it takes away more of your discomfort.

■

■ When you breathe out, imagine the air blowing the ball away from your body.

As it goes, all your pain goes with it.

■

■ Repeat the last two steps each time you breathe in and out.

■

■ To end the imagery, count slowly to three, breathe in deeply, open your eyes, and say silently to yourself, “I feel alert and relaxed.”

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Relaxation Exercises

You may relax either sitting up or lying down, preferably in a quiet place. Make sure you’re comfortable. Don’t cross your arms or legs because you could cut off circulation. If you’re lying down, you may want to put a small pillow under your neck and knees.

Once you’re comfortable and your eyes are closed, you could try any of the following relaxation methods:

Breathing and muscle tensing



- Breathe in deeply.



- At the same time, tense your muscles or group of muscles. For example, you can squeeze your eyes shut, frown, or clench your teeth. Or, you could make a fist, stiffen your arms and legs, or draw your legs and arms up into a ball and hold as tightly as you can.



- Hold your breath and keep your muscles tense for a second or two.



- Let go. Breathe out and let your body go limp.

Slow rhythmic breathing



- Stare at an object or shut your eyes and think of a peaceful scene. Take a slow, deep breath.



- As you breathe in, tense your muscles. As you breathe out, relax your muscles and feel the tension leaving.



- Remain relaxed and begin breathing slowly and comfortably, taking about nine or 12

breaths a minute. To maintain a slow, even rhythm, you can silently say to yourself, “in, one, two; out, one, two.”



- If you ever feel out of breath, take a deep breath, and continue the slow breathing.



- Each time you breathe out, feel yourself relaxing and going limp. Continue the slow, rhythmic breathing for up to 10 minutes, if you need it.



- To end the session, count silently and slowly from one to three. Open your eyes. Say to yourself, “I

feel alert and relaxed.” Begin moving slowly.

If you decide to use slow rhythmic breathing as a way to relax and reduce pain, you may want to try these tips. They can add to the experience.

■

■ Listen to slow, familiar music through earphones.

■

■ Once you’re breathing slowly, slowly relax different parts of your body, one after the other. Start with your feet and work up to your head.

■

■ Each time you breathe out, you can focus on a particular area of the body and feel it relaxing. Try to imagine the tension draining from the area.

■

■ Consider using relaxation tapes. They often include each step on how to relax.

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Words To Know

Acupuncture (ACK-yu-punk-chur): Small needles are inserted into the skin at certain points of the body to relieve pain.

Acute pain: Pain that is very bad but lasts a fairly short time.

Addiction (uh-DIK-shin): Drug craving, seeking, and use that you can’t control.

Analgesic: A drug that reduces pain.

Anesthesiologist (an-uh-steez-ee-YAH-luh-jist): A doctor who specializes in giving medicines or other drugs that prevent or relieve pain.

Anticonvulsant (an-tee-kuhn-VUHL-sint): Medicine used to treat seizures that can also be used to control burning, stabbing, and tingling pain.

Antidepressant (an-tee-duh-PRES-int): Medicine used to treat depression that can also be used to relieve tingling, stabbing, or burning pain from damaged nerves.

Biofeedback: A way of learning to control some body functions such as heartbeat, blood pressure, and muscle tension with the help of special machines. This method may help control pain.

Breakthrough pain: An intense rise in pain that occurs suddenly or is felt for a short time. It can occur by itself or in relation to a certain activity. It may happen several times a day, even when you're taking the right dose of medicine.

Chemotherapy (kee-moh-THAIR-uh-pee): Treatment with anticancer medicines.

Chronic (KRAH-nik) **pain:** Pain that can range from mild to severe and is present for a long time.

Complementary treatment: Treatment used along with standard medical care.

Deductible: The amount you must pay for health care before insurance begins to pay.

Distraction: A pain relief method that takes the attention away from the pain.

Dose: The amount of medicine taken.

Generic: The scientific name of a drug, as opposed to the brand name. Also, drugs not protected by trademark.

Hypnosis (hip-NOH-sis): A person enters into a trance-like state, becomes more aware and focused, and is more open to suggestion.

Imagery: People think of pleasant images or scenes, such as waves hitting a beach, to help them relax.

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Integrative medicine: Combines standard medical care and complementary and alternative medicine, for which there is some high-quality evidence of safety and effectiveness.

Intravenous (in-tra-VEE-nus): Within a blood vessel. Also called **IV**.

Intravenous infusion: A way of giving pain medicine into a vein or under the skin. An infusion flows in by gravity or a mechanical pump. It is different from an injection, which is pushed in by a syringe.

Laxative: Something you take to help you pass solid waste, or stool, from your body. There are many different kinds of laxatives.

Narcotics (nahr-KAH-tiks): See opioids.

Nerve block: Pain medicine is injected directly into or around a nerve or into the spine to block pain.

Neurologist: A doctor who specializes in the treatment of nervous system disorders.

Neuropathic (noor-AH-path-ik) **pain**: Pain that occurs when treatment damages the nerves.

Nonopioids (nahn-OH-pee-yoidz) : Acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs), such as aspirin, ibuprofen, and naproxen.

Nonprescription: Over-the-counter drugs that you can buy without a doctor's order.

NSAIDs (Nonsteroidal anti-inflammatory drugs): Medicines that control mild to moderate pain and inflammation and reduce fever. Can be used either alone or together with other medicines.

Oncologist (ahn-KAH-luh-jist): A doctor who specializes in the treatment of cancer.

Oncology (ahn-KAH-luh-jee): The study and treatment of cancer.

Onset of action: The length of time it takes for a medicine to start to work.

Opioids (OH-pee-yoidz): Also known as narcotics. They are used to treat moderate to severe pain. A prescription is needed for these medicines.

Oral: By mouth.

Pain threshold: The point at which a person becomes aware of pain.

Palliative (PAL-ee-yuh-tiv) care: Care given to improve quality of life and/or slow cancer's growth. The goal is to prevent or treat the symptoms, side effects, and psychological and emotional problems of the disease. Not meant to be a cure.

Patient-controlled analgesia (an-ull-JEEZ-ya) (**PCA**): A way for a person with pain to control the amount of pain medicine he or she receives. When pain relief is needed, the person can press a button on a computerized pump connected to a small tube inserted into the vein or under the skin. Pushing the button delivers a preset dose of pain medicine.

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Phantom pain: When pain or other unpleasant feelings are felt from a missing (phantom) body part that has been removed by surgery.

Physical therapy: Treatment for pain in muscles, nerves, joints, and bones. This treatment uses exercise, electrical stimulation, and hydrotherapy, as well as massage, heat, cold, and electrical devices.

Prescription: A doctor's order.

Qi (chee): What is believed to be a life force energy.

Radiation therapy: Treatment with high-energy x-rays to kill or control cancer cells.

Relaxation techniques: Methods used to lessen tension, reduce anxiety, and manage pain.

Side effects: Problems caused by a medicine or other treatment. Examples are constipation and

drowsiness.

Skin patch: A bandage-like patch that releases medicine through the skin and then into the bloodstream. The medicine enters the blood slowly and steadily.

Standard treatment: The treatment that is accepted and most often used.

Stage: The extent of disease. It can also be a phase of a clinical trial.

Steroids: Medicines that reduces swelling and inflammation.

Stool softeners: Medicine that softens the solid waste in your body, making it easier to pass.

Subcutaneous (sub-kyu-TAY-nee-yus) injection: A shot under the skin.

Sublingual: Under the tongue.

Supplements: Vitamins, minerals, herbs, and other things you can take besides medicines.

Tolerance: Occurs when the body gets used to a medicine. The result is that the dose no longer works well. Either more medicine is needed to control the pain or different medicine is needed.

Transcutaneous (tranz-kyu-TAY-nee-yus) Electrical Nerve Stimulation (TENS): A method in which mild electric currents are applied to some areas of the skin by a small power pack connected to two electrodes.

Transmucosal (tranz-myu-KO-sol): Absorbed through the lining of the mouth.

Withdrawal: Signs and symptoms that can appear when long-term use of opioids is stopped or suddenly reduced a lot.



Important Names and Phone Numbers

Doctor _____

Doctor _____

Nurse _____

Clinic _____

Pharmacist _____

Other _____

Appointments

Before you go to the pharmacy—know what you’re getting!

Sometimes people get new prescriptions and are confused about how to take them and when.

If your doctor prescribes a new medicine, it’s important for you to understand what you will be taking. And as mentioned [in chapter 5](#), get to know your pharmacist. He or she can answer many questions for you.

Before you leave your visit, ask your health care team:

-
- How do you spell the name of the drug?
-
- What does the medicine look like? If there is a generic version, does it look the same?
-
- How many pills (or how much liquid) are in *each* dose?
-
- How many *times a day* do I take the dose?
-
- Should I take this medicine with food?

- Can I take it with my other medicine or supplements?

Be sure to read the printed information that comes with your medicine. If you have trouble reading it, ask a friend or family member to read it for you. **For other questions about your medicines, see [page 18 of this booklet](#).**



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Document Outline

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