COPING WITH CANCER PAIN

A handbook for patients

DANA-FARBER/BRIGHAM AND WOMEN'S CANCER CENTER
Introduction

This booklet is about pain and how to control it. Many patients with cancer fear that they will have pain. Although pain is a common problem, it does not happen to every patient, and it can be controlled. If you or someone you love has pain, you should know how to talk about it with your doctors, nurses, and other health-care workers. You also should know how to use medications and other pain-relieving methods.
The nature of pain

Pain is the body’s way of telling us something is wrong. It tells us to move away from a hot stove, limit activity after an injury, or see a doctor if the discomfort becomes worse.

Pain can become a concern if it continues for a long time and begins to interfere with sleeping, eating, and enjoying life in general.

Uncontrolled pain may:
• slow recovery from illness or surgery;
• decrease activity, which can lead to more weakness and fatigue;
• make you feel discouraged, sad, or depressed; or
• interfere with your body’s ability to fight infection.

Not everyone with cancer has pain. You may experience pain that is caused by your disease, your cancer treatments (such as surgery, radiation therapy, or chemotherapy), or by problems unrelated to cancer. Cancer causes pain by growing in or near bones, nerves, or organs, such as your liver or stomach. If you have pain, there are many ways to manage it so that you feel better.

Pain is personal

Pain cannot be measured like weight or blood pressure. Although X-rays, blood samples, and other tests can find problems that might cause it, pain cannot be seen.

Each person feels pain differently. This happens because your brain mixes the pain signals with all the other messages coming from your body and mind. How the brain interprets the pain signals is influenced by many factors, such as:

• past experiences with pain
• beliefs about pain
• genetic makeup
• physical makeup
• personality
• mood and emotions
• other health problems
• medications
Reporting your pain is the first step to controlling it

Don’t assume that your doctor or nurse knows that you are hurting or what your pain feels like. Doctors and nurses depend on you to report how you feel. Remember, pain is not always part of having cancer, and if you do have pain there are many ways to manage it.

What to tell your doctor or nurse about your pain

P is for PLACE
Where does it hurt? Is there more than one place? Does the pain move around?

A is for AMOUNT
How long have you had pain? Is it always there? Does it come and go? How bad is the pain? Use a number (0 =no pain, 10=worst pain) or words like mild, moderate, or severe.

I is for INTENSIFIERS
What makes your pain worse? Position, movement or activity, time of day?

N is for NULLIFIERS
What makes your pain better?

E is for EFFECTS
Any side effects from your medications? Nausea, constipation, sleepiness? How does the pain affect your life? Activity, eating, sleeping, mood?

D is for DESCRIBE
How does the pain feel to you? How do you describe it? Dull, sharp, throbbing, aching, stabbing, burning, gnawing, cramping, tight, squeezing, shooting
Options for pain management

It is not always possible to make pain go away completely. But the goal is to reduce your pain so that you can live as comfortably as possible.

There are many ways to manage or control pain. Although the use of pain-relieving medications is the most common way, treatments such as radiation, chemotherapy, and special procedures like nerve blocks may also help. The use of heat or cold, exercise, psychological and spiritual support, and integrated therapies – including relaxation, massage, Reiki, and acupuncture – may reduce pain as well.

Common medications used to manage pain include:
- Acetaminophen (Tylenol)
- Non-steroidal anti-inflammatory drugs (NSAIDs)
  - Ibuprofen (Motrin, Advil)
  - Naproxen (Naprosyn, Aleve)
  - Rofecoxib (Vioxx)
  - Celecoxib (Celebrex)
- Opioids (sometimes called narcotics)
  - Morphine
    - Short-acting form is MSIR or liquid morphine
    - Sustained release forms are MS Contin, Oramorph, Kadian, Avinza
  - Hydromorphone (Dilaudid)
  - Oxycodone
    - Short-acting form is Roxicodone, Oxy IR, Oxyfast, or oxycodone
    - Sustained release form is OxyContin
  - Fentanyl
    - Short-acting form is Actiq
    - Sustained release form is the Duragesic patch
- Methadone
- Codeine
- Hydrocodone
- Tricyclic antidepressants for nerve pain
  - Amitriptyline (Elavil)
  - Nortriptyline (Pamelor)
  - Desipramine
• Anti-convulsants for nerve pain
  Gabapentin (Neurontin)
  Phenytoin (Dilantin)
• Topical pain relievers (those applied to the skin)
  Capsaicin
  EMLA
  Xylocaine jelly
  Lidocaine patches

Some pain medications – such as Tylenol, Advil, or Aleve – do not require a prescription. Be sure to tell your doctor or nurse if you are using these medications, and follow the package directions carefully. Others, like opioid pain medications, are available only with a written prescription. If you are using an opioid, check your supply before meeting with your doctor or nurse so that you can ask for the prescriptions you need during your visit.

The most common way to take pain medication is by mouth as pills, capsules, or liquids. Pain medications can also be taken:
  • by vein (IV)
  • by injection under the skin (subcutaneous)
  • through the skin as patches or creams
  • through the lining of the mouth or under the tongue
  • by suppositories in the rectum
  • through catheters placed into the spine (epidural or intrathecal)
  • by breathing (inhaling) into the lungs.

**Different pain requires different medication**

If you have mild to moderate pain, acetaminophen (Tylenol) and/or non-steroidal anti-inflammatory drugs (NSAIDs) may bring relief. If these medications do not control your pain, adding an opioid may help.

Some common pain medications combine acetaminophen and an opioid into one pill, such as:
  • Percocet (acetaminophen and oxycodone)
  • Vicodin (acetaminophen and hydrocodone)
  • Tylenol #3 (acetaminophen and codeine)

When you are using these medications, do NOT take any additional acetaminophen without talking to your doctor or nurse.
Managing constant and break-through pain

If you have fairly constant pain, you may use a sustained release or long-acting opioid, which releases medication over a set period of time. These medications are taken on a regular schedule and include MS Contin, Oramorph, Kadian, Avinza, OxyContin, Duragesic patch, and methadone.

If your pain comes and goes, or “breaks through” your long-acting medication, adding another medication – a short-acting opioid – can help. These medications usually last 2–6 hours and can be taken every few hours, as needed. Break-through pain may happen with physical activity or just because you have more pain at certain times. MSIR (morphine immediate release), oxycodone, hydromorphone (Dilaudid), and Percocet are examples of short-acting pain medications.

Managing nerve pain

If you have neuropathic (nerve) pain caused by damage to the nerves, other kinds of medications may bring relief. Nerves can be harmed by some types of infection (shingles), surgery, certain chemotherapy drugs, tumors, or injuries. Nerve pain is helped most by medications that soothe the damaged nerves. These medications have been used for other reasons, but are especially helpful in controlling nerve pain.

They include:

- Tricyclic antidepressants
  - Amitriptyline (Elavil)
  - Nortriptyline (Pamelor)
  - Desipramine (Norpramin)
- Anti-convulsants
  - Gabapentin (Neurontin)
  - Phenytoin (Dilantin)
- Steroids
  - Dexamethasone (Decadron)
  - Prednisone
- Anti-spasmodics
  - Baclofen (Lioresal)
Sometimes a combination of pain medications is needed to control pain. Such combinations may include an NSAID, a short-acting opioid, a sustained-release opioid, and a medication for neuropathic pain. Your doctor and nurse will help find the right combination for you.

Based on your pain and condition, you and your health-care provider will decide which medication you need, how you should take it, how much you should take, and how often.

**Pain medications may cause side effects**

**Constipation** is a change in bowel movements that causes less regular movements or makes it hard to pass stool from the bowel. You can avoid or reduce constipation by drinking plenty of fluids, eating fruits and vegetables each day, exercising or being physically active, and using stool softeners and mild laxatives. Talk to your doctor or nurse to come up with a plan that works for you.

**Sleepiness or fatigue** may be caused by pain medications. This may be worse in the first 3–4 days after starting a medication or increasing the dose. It often clears up on its own. If you feel sleepy, do not drive a car or operate other equipment. If sleepiness continues, tell your doctor or nurse.

**Nausea and vomiting** also may happen in the first 3–4 days after starting a medication or increasing the dose. Although these effects often go away on their own, medications that settle your stomach can help. Tell your doctor or nurse if you have nausea or vomiting.

**Other ways to manage pain**

Although medication is the most common way to manage pain, other methods might bring you relief as well:

- Heat packs and/or cold packs
- Gentle massage or rubbing
- Comfortable positions
- Exercise/physical therapy
- Pet
- Relaxation
- Distraction
- Emotional support
- Laughter/humor
- Music
- Reading
- Prayer
- Visitors
Myths and facts about pain medication

Many patients, family members, and friends have fears or believe myths about pain medications, especially opioids (narcotics). Learning the facts can reduce these fears.

**Myth:** I will become addicted to pain medications by using them.

**Fact:** Simply using an opioid pain medication will not result in addiction. About 3–18 percent of patients using opioids for pain management will develop a problem with drug addiction. These patients often have had previous addiction problems. So, not surprisingly, this is the same percentage of people in the general population that have drug-addiction problems.

**Myth:** If I use pain medication now, it won’t work later if I have more pain.

**Fact:** When you use a pain medication over a long period of time, you may eventually need a higher dose or a different pain medication to get the same relief. This response is called tolerance and has nothing to do with addiction.

**Myth:** Over time, I will become dependent on the medications.

**Fact:** Dependence means that you will experience “withdrawal symptoms” if you stop taking medications suddenly. This happens because your body has gotten used to the medications. Withdrawal symptoms include nausea, diarrhea, sweating, anxiety, and irritability. If you need to stop a medication, you can avoid these symptoms by cutting down on the medication slowly. It’s important to remember that withdrawal has nothing to do with addiction.

**Myth:** Opioid (narcotic) pain medications are used only at the end of life.

**Fact:** Opioid pain medications are used whenever they are needed to control pain. The purpose is to improve your ability to do things and be comfortable. Many patients take these medications for months or years.

**Myth:** Using pain medication will cover up new problems.

**Fact:** If new pain occurs, or a pain you already have gets worse, you will know it even if you are taking pain medication.
**Myth:** Pain medications cost too much.

**Fact:** Most insurance prescription plans cover pain medications. If you are having trouble with your insurance, or do not have prescription coverage, tell your health-care provider. You may be able to use lower-cost medications or qualify for assistance from drug companies.

**Nerve blocks and spinal catheters**

While most cancer pain can be controlled using medications and other simple methods, 10–20 percent of patients also need special procedures to be more comfortable. Specially trained doctors, such as those at the Brigham and Women’s Pain Management Center, can perform these procedures.

Nerve blocks, for example, may help with certain types of local pain. In this procedure, the doctor injects special medication into the area of pain to numb or deaden the nerves.

Other procedures deliver pain medication directly into the spine. When you take pain medications by mouth, or through suppositories, opioid skin patches, injection, or IV, the medicine must go through your whole body before it reaches your spinal cord. If you do not have good pain relief from medications given in these ways – or if the medications produce uncontrolable side effects – you may receive pain medication through a tube in your spine. The tube is called an epidural or intrathecal catheter.

In these procedures, the medication blocks pain at the spinal cord. A pumping machine delivers small amounts of medication through the catheter all the time. The pain medication goes more directly to the spinal cord, so your pain can be controlled with a smaller dose. Because the doses are small, there are fewer side effects. This type of pain control can be used for a few days in the hospital through a temporary catheter. For a longer period of time, a permanent catheter is inserted during a short surgical procedure.
Eight tips for getting the most from your pain medication

1. Take your pain medications as directed by your doctor or nurse. Ask for a written schedule, if necessary.
2. Take sustained release or long-acting opioids, NSAIDs, and nerve pain medications on a regular schedule.
3. Keep a journal. Write down what works, what doesn’t, and why. Tell your doctor or nurse so that changes can be made, if needed.
4. Write down how much short-acting medication you take, and how often.
5. Take short-acting medication before your pain becomes really uncomfortable. Your pain will be easier to control.
6. If some activities cause pain, take short-acting medication 30–45 minutes before the activity.
7. Keep your pain medications in labeled containers so that you do not confuse them with other medications.
8. Keep your medications in a safe place that is out of the reach of children.

Do not stop taking pain medications without talking to your doctor or nurse. If you stop taking them suddenly, you could have side effects such as anxiety, sweating, runny nose, tears in your eyes, stomach pain, and diarrhea.

How to get good pain relief

• Tell your doctor or nurse about your pain at each visit.

• Make a list of all your medications and when to take them.

• Keep track of the medications you take and how much.

• Write down any side effects you have.

• Try different non-medication ways that may help you control your pain. (See “Other ways to manage pain,” page 7.)
Resources
Pain and Palliative Care Program (617) 632-6464
Pediatric Advanced Care Team (617) 632-5042
The Blum Resource Center (617) 632-5570
Zakim Center for Integrated Therapies (617) 632-3322
Brigham and Women’s Hospital Pain Management Center (617) 732-6708
Pain Treatment Clinic at Children’s Hospital Boston (617) 355-6995

Websites
American Cancer Society
www.cancer.org
(Visit the section on coping under Patients, Families, and Friends)

National Cancer Institute
www.cancer.gov
(Visit coping with cancer/complications of cancer.)

National Comprehensive Cancer Center Network
www.nccn.org

Pain Management in Children
http://pedspain.nursing.uiowa.edu

University of Pennsylvania OncoLink
www.oncolink.upenn.edu
(Search for “pain.”)
Reading materials

*Cancer does not have to hurt*, by Pamela Haylock and Carol Curtiss

Booklets from the National Cancer Institute and American Cancer Society:

- *Questions and Answers About Pain Control*: A guide for people with cancer and their families.
- *Pain Control*: A guide for people with cancer and their families
- *Getting Relief from Cancer Pain*
- *Understanding Cancer Pain*

Booklet from Network of Comprehensive Cancer Centers:

- Cancer Pain: Treatment guidelines for patients

Telephone contact

Cancer Information Service (a program of the National Cancer Institute)
(800) 4-CANCER
(800) 422-6237