



Pain Management

No. 19 in a series providing the latest information on blood cancers

Patients living with leukemia, lymphoma, myeloma and other blood cancers might experience pain at some time due to either the cancer, complications of the cancer, or cancer treatment. It is common for myeloma patients to have bone pain at the time of diagnosis; most leukemia and lymphoma patients do not describe pain as a symptom at diagnosis.

If you do have pain, it is very important to tell your doctor about it and describe what makes it worse or better. This will help your doctor understand the cause of the pain, the quality and the intensity of the pain and determine the best way to manage it. When describing your pain, give examples from your daily life to help your doctor understand how your pain is affecting you. For example, tell your doctor about any everyday activities you can no longer do because of your pain.

Many people think that pain is an unavoidable part of cancer. Your disease or its treatment may cause pain, but there are many options available to manage pain effectively. Most cancer pain can be relieved and usually, by relatively simple means, such as with medicines taken by mouth. Other treatments are available for the small number of people who may not respond to standard pain medicines. You may be given a few medications one at a time or in combination. You may have to communicate with your doctor frequently at first until you achieve an acceptable level of pain relief. If your doctor is unable to treat your pain so that you have satisfactory relief and can function better, request a referral to a pain specialist. These doctors are trained to manage pain for many different types of illness.

This fact sheet provides important and practical information you can use to get the help you need to manage your pain.

Why Is Managing Pain Important?

Some people with cancer actually do not experience pain. For those who do, pain management is an essential part of cancer treatment. Unrelieved pain can have a negative effect on your life and also changes your quality of life. It can make it hard to sleep, to work, to perform daily activities such as housework, and to socialize. Relationships with friends and relatives may become strained. Ongoing pain can leave you with no appetite, which can lead to weakness. Pain that is not treated can also cause depression and feelings of hopelessness.

Pain and Blood Cancers

Leukemia

People with leukemia often don't feel much pain related to their illness. At times, leukemic cells may form a mass near nerves including spinal cord or in the joints. In acute lymphocytic leukemia, bone pain occurs in approximately 25% of patients at the onset of the disease. This is less common with acute myelogenous leukemia. When bone pain does occur, the pain is most often felt in the long bones of the arms and legs, and in the ribs and the sternum of the rib cage. Joint pain and swelling in the large joints, such as hips and shoulders, may not begin for several weeks after bone pain begins.

Lymphoma

Hodgkin and non-Hodgkin lymphoma usually begin with painless swelling of lymph nodes – often in the neck, armpit or groin. During the course of the disease, complications of the lymphoma and its treatment may cause pain, for example, chest, abdominal or bone pain.

Myeloma

Bone pain, most notably in the back or chest and occasionally in the arms and legs, is present in more than two-thirds of patients when they are first diagnosed with myeloma. Bone pain caused by myeloma may be severe, but when successfully treated with chemotherapy, there is usually a marked improvement.

What are acute, chronic and breakthrough pain?

There are two main types of pain: acute and chronic. The difference between the two is how long they last. Acute pain tends to be severe and lasts a relatively short time. It is a signal that the body is being injured and, most of the time, the pain goes away when the injury

heals. Examples of acute pain are pain after surgery or breaking a bone. People with blood cancers often require procedures, such as bone marrow biopsies, that might cause acute pain. If you are going to have any kind of procedure related to your illness, ask your doctor ahead of time:

- How much pain to expect
- How long it may last
- How the pain will be managed before, during and after the procedure.

Chronic pain is usually defined as pain that continues from three to six months or beyond. It can last for long periods of time, even years; it can always be present (constant) or come and go for periods of time (fluctuating or periodic). Chronic pain is also called persistent pain. Some people with cancer experience chronic pain due to their illness, from their cancer treatment or from new medical conditions that develop while ill, such as arthritis. Pain treatment may include both pain medications and non-drug methods to provide relief. These may be needed for long periods of time.

Breakthrough pain is the term used when a person who is taking pain medication regularly experiences a brief, perhaps severe, flare of pain (it “breaks through” the regular pain medication schedule). It can occur even when a person is taking the correct dose of pain medicine, on a regular schedule, for their persistent pain. It can occur as the pain medication is wearing off before the next dose is due, or can emerge from a pain-producing activity or event. If you have episodes of breakthrough pain, tell your doctor. He or she may want to prescribe pain medicines that work quickly and for a short period of time. Medications for breakthrough pain are usually taken as needed, which means that they should be used as soon as breakthrough pain begins. These medications work faster than those used to manage persistent pain. They also stay in your body for a shorter time, and therefore cause fewer side effects.

What if my cancer treatment causes pain?

Sometimes the toxic effects of standard drug therapies or radiation therapy used to treat blood cancers can result in, or lead to, uncomfortable symptoms, including pain. All side effects from treatment, including pain, should be reported to the doctor. Information on managing the side effects of drug therapy is available in The Leukemia & Lymphoma Society’s booklet, *Understanding Drug Therapy and Managing Side Effects*, 2004. Radiation treatment damages cancer cells, but it can also affect normal cells, causing pain

and discomfort. Dry skin, difficulty swallowing and mouth sores are some of the common side effects of chemotherapy and radiation therapy.

What role do I play in managing my pain?

If you do experience pain or discomfort during treatment for your illness, tell your doctor, nurse, radiation therapist or other caregivers right away. They can give you medication that will relieve your pain, add other methods that relieve pain, or may consider adjusting your treatment, to help reduce painful side effects. Remember, your caregivers won't know you are having pain unless you tell them.

You are the expert and the role you play is one of the most important parts of good pain control. Remember that nobody understands your pain the way you do. Only you know how much pain you feel, and where it hurts. The information you provide will help your doctors, nurses, friends and family understand your pain. And, you or a caregiver may have to ask for the help you need and report pain control and side effects of pain medications back to your doctor. Learning to communicate with your doctors, nurses, friends and family will help you be an active participant in your care.

Remember:

- You are not a “bad” patient if you tell your doctor you have pain. You are not bothering him or her. Doctors want to make you feel as comfortable as possible and improve the quality of your life.
- Coping with unrelieved pain can be exhausting and can keep you from enjoying friends, relatives and activities.
- Asking for pain relief is not a weakness. It is an important part of maintaining the best quality of life possible for yourself and your family while living with cancer.
- Pain does not necessarily mean your cancer is getting worse. Most side effects from pain medicine can be managed as long as you tell your doctor about them.
- If you feel you are not getting adequate pain relief, your doctor will reassess your pain carefully and might adjust the dosage, prescribe a different medication or use a combination of drugs to relieve your pain.
- If the cost of medication is of concern to you, discuss this with your doctor. He or she may assume your medical insurance will cover all the costs. Your doctor may be able to prescribe less expensive medications or refer you to sources for financial aid.

- Taking your pain medications as instructed does not mean you will become addicted to those medications.
- Taking strong pain medications now does not mean that they will not work when/if your illness should become worse at a later time.

The American Pain Foundation Pain Care Bill of Rights

As a person with pain, you have:

- The right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists and other healthcare professionals.
- The right to have your pain thoroughly assessed and promptly treated.
- The right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks and costs of each.
- The right to participate actively in decisions about how to manage your pain.
- The right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- The right to be referred to a pain specialist if your pain persists.
- The right to get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are rights you should expect, and if necessary demand, for your pain care.

Provided by the American Pain Foundation www.painfoundation.org.

How should I talk to my doctor about pain?

Talk openly about your pain with your doctor and any other professionals treating you for pain. Your doctor in particular needs to know the type and intensity of pain you are feeling so that he or she can prescribe the most effective medicine and dose for you.

Some people find it difficult to talk about their pain; they might have trouble finding the right words to describe how the pain feels or knowing what questions to ask about their pain. Your doctor may ask you some of the following questions. However, reading them here and thinking about how you would answer them may help prepare you to speak with your doctor.

- Where is the pain? Your pain may be in more than one place; list all the painful areas. You may even want to draw a simple picture of your body and mark or color the areas where you feel your pain.
- What does the pain feel like? Is it aching? Throbbing? Burning? Sharp? Dull? The list below includes some of the words frequently used to describe pain. If you don't find a word that describes what you feel, use the most descriptive words you can find.

Aching	Sharp	Dull	Burning
Crushing	Pins & Needles	Sore	Stabbing
Prickling	Pounding	Throbbing	Shooting
Crampy	Knot-like	Deep	On-the-surface
Pressing	Stretching	Tight	Pinching
Tender	Electric	Pulsing	Gnawing

Tell your doctor or nurse if you tend to use words like “discomfort” or “being uncomfortable” or “I hurt” rather than “pain.” Just be aware that those words alone may not communicate all the information he or she might need to understand your pain.

Descriptive words tell the doctor what the pain feels like. However, the doctor also needs to know how much pain you are feeling. There is no blood test, visual test or fool-proof way to measure pain, like we use a thermometer to measure body temperature. The doctor will rely on you to tell him or her how much you hurt. He or she may be able to help you, though, by asking you to use a pain rating scale to “measure” your pain.

A numeric pain rating scale asks you to rate your pain by picking a number from 0 (no pain) to 10 (worst pain imaginable) that best indicates how bad the pain feels to you.

The doctor will write down the number in your chart and compare it to the number you select next time; this way you will both be able to see how your pain level is changing.

“Faces” pain rating scales are helpful for children, and for people who have trouble speaking or understanding how to respond to the 0 to 10 scale. There are several different scales that use a series of faces with expressions from smiling (0 = no hurt) to tearful (5 = hurts worst). At each appointment, your doctor should ask you to rate your pain using the same kind of scale

How can I get the most from a doctor's appointment?

Feeling nervous or anxious before going to the doctor is very common. It can make it hard to remember what happened during the visit. Even though you think you are listening carefully, you may not hear everything the doctor says. Remember that you are an active participant in your care. The following suggestions may help you prepare for a trip to the doctor and get the most out of your time there.

Prepare before you go:

- Write out your questions ahead of time and bring them with you.
- Consider using a tape recorder (make sure to ask permission before turning it on).
- Bring someone along to help listen and take notes.

Speak openly and honestly with the doctor or nurse: Let them know how much information you want to have. Work toward mutual trust and respect. Report what is really going on and don't leave anything out.

Don't leave until all your questions have been answered or there is a clear plan on how they will be answered when more information becomes available.

Remember:

- There is no such thing as a silly or dumb question.
- Ask for explanations of words or concepts you don't understand.
- Keep asking questions until what you want to know is clear.
- Repeat back to the doctor what you think you have heard.
- Make sure you've had time to share all the information you wish.
- Do not let anyone make you feel rushed. It's your appointment.
- Ask whom you can call to clarify things or to ask new questions.
- Insist on privacy. Important discussions should take place in a private place, not in the hallway or at a reception desk.

Treating Pain

Your doctor should determine the best approach to manage pain based on its cause and description. At times, treating the cause, as in using chemotherapy to treat myeloma, will relieve or decrease your pain and reduce the need for pain medications. Your doctor will recommend and prescribe specific medication for pain relief most of the time.

What are the different types of pain medication?

For mild pain your doctor may recommend acetaminophen (Tylenol[®]). Other medications, like nonsteroidal Anti-inflammatory (NSAID's) medications, including aspirin and ibuprofen may be recommended for mild to moderate pain. Most of these are available without a doctor's prescription. Acetaminophen and NSAID's used alone have an upper limit to their pain relieving effect — that is, at a certain point, taking more of the medicine will not have a greater effect on your pain. Though acetaminophen and NSAID's are valuable pain relievers, your doctor may advise against taking them during chemotherapy or radiation therapy. When you are being treated for cancer your doctor should always know what medicines you are taking. If you are taking pain medications without a prescription (over-the-counter), your medical team needs to know this and help direct you on whether you need them and how to best take them.

For moderate to severe pain, your doctor may prescribe stronger pain relievers also known as opioid pain medication, such as morphine, fentanyl, hydromorphone, oxycodone and codeine. These medications require a prescription. Opioids can be taken by mouth (pill or liquid), as a suppository, by injection or absorbed through a patch on the body. Opioids can be prescribed as pure medications or as combination agents. Examples of pure opioids are: Oxycodone[®], Roxinol[®], Durgesic[®], Dilaudid[®]. Examples of combination opioids are: Percocet[®], Vicoden[®], Vicoprofen[®]. Opioid pain relievers don't have an upper limit on their ability to relieve pain when used in its pure form. The dose can be gradually increased as pain levels rise, therefore, pure opioids can be better used to treat severe pain. Your doctor will be careful, of course, to ensure your dose is appropriate to manage your level of pain. And, as with any treatment for pain, if one of these medications aren't helping you, your healthcare team may try another until they find the drug that works best for you. Sometimes your doctor may also prescribe non-opioids along with these opioids to treat specific types of pain, such as using NSAIDs along with opioids to treat bone pain or anti-seizure medications to treat nerve-related pain problems. Non-drug treatments can be added as a compliment to your medication therapy.

When opioid medications are used, there is an underlying worry about the risk for addiction. Patients with persistent pain who require prolonged opioid therapy have little to no risk of developing addictive disease just because they are taking pain medications every day. Those at risk for developing addictive disease are ones who have a current or past history of substance abuse, a family history of addictive disease (alcohol, illegal drugs or prescription drugs) or a history of mental illness. If you are at risk for developing addictive

disease, it is important to report this to your healthcare provider. This does not mean that using opioids to treat your pain will not be required. Working with an addiction specialist as a new member of your pain team, as well as an increased monitoring plan, may be recommended.

In 2002, the U.S. Drug Enforcement Administration (DEA) made a commitment to work closely with many of the country's leading health organizations — such as the American Medical Association, the Oncology Nursing Society, the American Pharmaceutical Association, the American Cancer Society as well as top pain organizations and others — to make sure that laws enacted to curb the abuse and diversion of controlled substances, like opioids, do not prevent access to those in need of these powerful pain-relieving drugs. Our federal and state governments in partnership with many committed healthcare professionals are working together to make sure that laws to protect public safety and those to safeguard access to proper pain relief treatments are kept “in balance.”

What questions should you ask your doctor about taking your pain medicine?

- How much medicine should I take? How often should I take it?
- If my pain is not relieved, can I take more? If I can take more, how much should I take?
- Should I call you before increasing the dose?
- What if I forget to take the medicine or take it too late?
- Should I take my medicine with food?
- How much liquid should I drink with the medicine?
- How long does it take the medicine to start working? (called “onset of action”)
- Is it safe to drink alcoholic beverages, drive or operate machinery after I have taken pain medicine?
- What other medicines can I take with this pain medicine?
- What side effects from the medicine are possible and how can I prevent them?

What are some non-drug therapies for pain?

Nondrug therapies are often helpful in relieving pain when used alone or in combination with your pain medication. It is important to discuss with your physician what type(s) of nondrug approaches may be most appropriate for your specific condition. Here is a list of some of the most common additional therapies.

- Acupuncture
- Biofeedback
- Exercise: Walking, Pool Therapy, Tai Chi, Yoga
- Distraction
- Guided Imagery
- Hot or cold packs
- Hypnotherapy
- Massage, pressure, vibration
- Music therapy
- Relaxation and Breathing Techniques
- Touch Therapies: Healing Touch, Reiki, Therapeutic Touch
- Transcutaneous electrical nerve stimulation (TENS)

What can I do if my pain is not being managed?

If you've done all your homework, asked all your questions, shared your own information honestly and your pain is still not being adequately managed:

- First speak to your healthcare professional or a case manager to express your concerns.
- Always bring your pain diary or notebook to doctors' visits to show the impact that pain is having on your quality of life.
- Ask what other options are available for you to try to help find relief.
- Request a referral to a pain specialist.

You are not alone. There are many resources in your community that can provide guidance and support. Local hospital libraries often have patient education materials, and many offer videos to be viewed there, on a variety of topics. Hospital social workers or nurses can be valuable sources of information and will listen if you need to talk. Many hospitals also have patient advocates who can assist you.

The Leukemia & Lymphoma Society is Always Here to Assist You

The Society offers accurate, current disease-related and coping information on blood cancers. Information Specialists (social workers and health advocates) are available to speak to patients and family members in the Information Resource Center Monday through Friday from 9 a.m. to 6 p.m. Eastern Time at (800) 955-4572, or to respond to email requests at the Society's Web site, www.LLS.org, Contact Us. They will also help you to locate the chapter nearest to you, or you can find your chapter by typing in your zip code in the upper right hand corner of the Society's Web site. Support programs, patient financial aid and education programs are offered through the Society's local chapters.

There are also many organizations devoted to the effective management of pain (see list below). Many of these have local chapters you can contact. All of the Web sites (phone numbers are listed where available) have information to help you and your loved ones learn to effectively manage pain and live life to its fullest.

American Pain Foundation

<http://www.painfoundation.org>
Pain Notebook
<http://www.painfoundation.org/downloads/Notebook.pdf>
1-888-615-PAIN (7246)

**American Society for Pain
Management Nursing**

<http://www.aspmn.org>
888.342.7766

**American Academy of Pain
Management**

<http://www.aapainmanage.org>
(209) 533-9744

American Pain Society

<http://www.ampainsoc.org>
(847) 375-4715

Cancer Care, Inc.

<http://www.cancercare.org>
(800) 813-4673

**City of Hope National Medical Center
(Comprehensive Cancer Center)**

<http://www.cityofhope.org>
(800) 826-4673

**International Association
for the Study of Pain**

<http://www.iasp-pain.org>
(206) 547-6409

The Mayday Pain Project

<http://www.painandhealth.org>

National Cancer Institute

<http://www.cancer.gov>
(800) 4-CANCER

**The National Foundation
for the Treatment of Pain**

<http://www.paincare.org>
(713) 862-9332

National Institutes of Health

<http://www.nih.gov>
(301) 496-4000

National Library of Medicine

<http://www.nlm.nih.gov>
(888) 346-3656

National Pain Foundation

<http://www.painconnection.org/>

Oncology Nursing Society

<http://www.cancersymptoms.org>
(866) 257-4667

OncoLink

<http://www.oncolink.com>

Pain.com

<http://www.pain.com>

PainNet

<http://www.painnet.com>
(614) 481-5960

Partners Against Pain

<http://www.partnersagainstpain.com>
(888)726-7535 ext. 5

Pain and Policy Studies Group

(University of Wisconsin
Comprehensive Cancer Center)
<http://www.medsch.wisc.edu/painpolicy> (608) 263-7662

StopPain

(Department of Pain Medicine
and Palliative Care Beth Israel
Medical Center)
<http://www.stoppain.org>
(877) 620-9999

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