

Pain Management

No. 19 in a series providing the latest information for patients, caregivers and healthcare professionals

Introduction

Some patients with leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative diseases (blood cancers) may experience pain related to the cancer or its treatment. Pain assessment is an important part of any medical evaluation, and pain management is an important part of care. Left untreated, pain can suppress the immune system, delay healing and often leads to depression. Accordingly, pain should be properly assessed and effectively managed throughout treatment and recovery. When pain is accompanied by persistent depression, for example, if a person feels depressed every day for a two-week period, it is also important to seek medical advice. Depression is an illness that needs to be treated even when a person is undergoing treatment for other conditions.

Pain management often includes a combination of medications and non-drug options to provide relief. This fact sheet provides information about pain management including

- Different types of pain (acute, chronic and breakthrough pain)
- Assessing pain and communicating about pain
- Pain related to blood cancers
- Treatments for pain
- Additional resources for support.

Highlights

- Pain may result from the cancer, from its treatment (for example, bone or nerve pain as a side effect of certain medications) or other coexisting diseases (for example, arthritis).
- Pain varies in its intensity and may be short-lived (acute) or persist beyond the normal course of healing from a disease or injury (chronic).
- There are many ways to manage pain effectively; patients whose pain is not adequately controlled should ask to be referred to a pain specialist.
- Studies are under way to better understand pain associated with various types of cancer and cancer treatments, and to find more effective treatments to relieve pain.

Acute and Chronic Pain

There are two main types of pain: acute and chronic. It is important to talk with your physician about any pain you experience.

Acute pain is nature’s signal that causes you to change a harmful behavior or seek medical attention; for example, if a person steps on a piece of glass or leans against a hot surface, he or she would experience acute pain. Acute pain is not long lasting and ends once an injury has healed.

Chronic pain can last for months or longer. There is no useful purpose for chronic pain; it changes the nervous system and, therefore, it is considered a disease. Left untreated, it can suppress the immune system and delay healing. Chronic pain places an emotional and physical burden on patients and caregivers.

Acute Pain	Chronic Pain
<ul style="list-style-type: none"> • Sudden onset • Temporary (up to 3 months) • Pain lessens over time • Stress response may be present (increased heart rate, blood pressure, breathing rate) • Nature’s “red flag” warning signal 	<ul style="list-style-type: none"> • Sudden or gradual onset • Persistent (beyond usual healing time or longer than 3 months) • Pain can be constant or come and go • Pain worsens over time • Stress response often absent • Considered a disease state—serves no useful purpose

Breakthrough Pain

The term “breakthrough pain” describes a brief, sometimes severe, flare of pain that a person who is taking pain medication may experience. In other words, the pain “breaks through” the regular pain medication schedule. Breakthrough pain can start as the pain medication is wearing off, before the next dose is due, or from a pain-producing activity or event (for example, remaining in the same position for too long, or from certain sudden movements). It can occur even when a person is following the correct dosage and schedule for pain medicine. Be sure to tell your physician if you have episodes of breakthrough pain.

Assessing and Managing Pain is Important

Pain assessment is an important part of any medical evaluation. It is as important as measuring blood pressure, pulse, breathing rate and body temperature. Unrelieved pain may cause needless suffering and

- Limit the ability to work, exercise, sleep, perform everyday tasks (for example, going to the grocery store, dressing)
- Make it harder to heal or fight infection by weakening the immune system
- Reduce appetite
- Lead to anxiety and depression, which can worsen pain sensation
- Place a strain on relationships with family and friends
- Reduce intimacy with a partner.

Don't Delay Seeking Pain Care

A person who has pain should seek pain treatment early to avoid additional health problems later on. Some people find it difficult to talk about their pain. They might have trouble finding the right words to describe how the pain feels. According to the American Pain Foundation and other experts, studies show that people with cancer may delay seeking the pain relief they deserve because they fear that addressing the pain may distract the physician from treating the cancer and that they

- Falsely believe relief is not possible and that pain is an inevitable part of cancer
- May not want to acknowledge the pain in case it is a sign of disease progression or a recurrence
- Worry about becoming addicted to pain medicine
- Mistakenly believe that early pain relief may mean the medication will not work in the future
- Want to appear strong and brave.

Blood Cancer-Related Pain

Pain may result from your disease or its treatment. However, having pain does not necessarily mean your cancer is getting worse. Here are some possible ways in which blood cancers may result in pain.

Blood Cancer Type	Examples of Possible Pain Experience
Leukemia or Myelodysplastic syndromes	Some patients have bone or joint pain. This pain usually results from the bone marrow being overcrowded with cancer cells. At times, these cells may form a mass near the nerves of the spinal cord or in the joints. In acute lymphocytic leukemia, bone pain occurs in approximately 25 percent of patients at the onset of the disease. This is less common with acute myelogenous leukemia or myelodysplastic syndromes. 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 develop 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.

Blood Cancer Type	Examples of Possible Pain Experience
Myeloma	Bone pain, generally 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. Masses of cancer cells build up, especially in the marrow, destroying normal bone tissue, and possibly causing fractures of long bones and collapse of vertebrae, resulting in pain. Bone pain caused by myeloma may be severe, but when myeloma is successfully treated with chemotherapy, there is usually a noticeable relief of bone pain.
Myeloproliferative diseases (Essential thrombocythemia, Polycythemia vera, Idiopathic myelofibrosis)	These diseases can result in different types of pain. Patients with essential thrombocythemia may experience headaches and/or a burning or throbbing pain in the feet, which is sometimes made worse by heat or exercise and is also likely to be worse when the legs are hanging down for long periods. This is because of reduced blood flow to the feet and toes. Those with polycythemia vera may have gout, a painful inflammation of the joints caused by increased levels of uric acid associated with the disease. Patients with idiopathic myelofibrosis experience severe upper left shoulder pain (reflecting the referred pain from the spleen, sometimes as the result of impaired blood flow to part of the spleen). In rare cases, there is bone pain, especially in the lower extremities.

Pain Related to Side Effects of Treatment

Sometimes the toxic side effects of standard drug therapies or radiation therapy used to treat blood cancers can result in, or lead to, uncomfortable symptoms, including pain. Here are some examples.

Treatment	Examples of Possible Pain-Related Problems
Radiation or chemotherapy	Radiation and chemotherapy damage cancer cells, but these treatments also affect normal cells, causing pain and discomfort. Dry skin, difficulty swallowing and mouth sores are some other common side effects of chemotherapy and radiation therapy. Some drug therapies and radiation therapy may cause damage to the peripheral nerves that is called “peripheral neuropathy.”
Bone marrow biopsy and aspiration	These procedures may be painful, so medication may be used to reduce the pain. Some patients will experience slight bone pain and/or discomfort where the needle was inserted for a few days after the procedure.
Stem cell transplantation	Painful oral ulcers, called oral “mucositis,” may develop as a consequence of harsh conditioning therapy (high-dose chemotherapy and/or radiation therapy) given prior to stem cell infusion for some types of stem cell transplants.

Cancer therapies can also weaken the immune system, which is why shingles (a painful reemergence of the chickenpox virus, varicella zoster) is common among patients who are in active treatment.

All side effects from treatment, including pain, should be reported to the physician. Most side effects from pain medicine (for example, fatigue, gastrointestinal problems) can be managed as long as you tell your physician about them.

See the free LLS booklets *Understanding Drug Therapy and Managing Side Effects* and *Blood and Marrow Stem Cell Transplantation* for more information about treatment side effects.

Talking to Your Physician About Pain

We can use a thermometer to measure temperature, but there is no test or foolproof way to measure pain. Because there is no objective measure, the person experiencing the pain plays an important role in achieving good pain control.

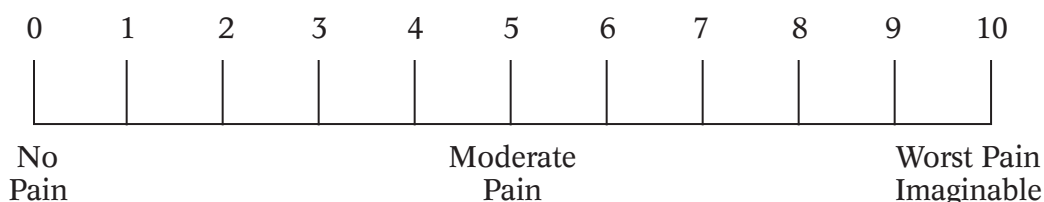
Good communication will help your physician to understand and treat your pain. The American Pain Foundation recommends addressing these questions:

- Where is your pain located? (Does it occur in one or multiple areas?)
- When does the pain occur and how long does it last? (Are there certain times of the day that are worse than others, and is the pain constant, or does it come and go?)
- What makes the pain better or worse? (Have you found ways to ease the pain by applying heat or cold, or sitting or lying in certain positions?)
- Are there any other related symptoms? (For example, numbness, depression or nausea?)
- What are examples of pain you experience during your daily life that can help your physician understand how your pain is affecting you? (For example, are there any activities you can no longer perform because of your pain?)
- How does the pain feel? (Is it dull, aching, sharp or burning?)

Your physician might use pain assessment tools to help evaluate your pain. For example, looking at a list of the following words may help you to describe your pain:

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

Another tool, the standard *numeric pain scale* asks patients to rate their pain by picking a number from 0 (no pain) to 10 (worst pain imaginable). Keeping a written record of the number you choose on a daily or weekly basis will enable you and your physician to see if your pain management treatment is effective or if it needs to be changed.



From: Acute Pain Management: Operative or Medical Procedures and Trauma, Clinical Practice Guideline No. 1. AHCPR Publication No. 92-0032: February 1992; Agency for Healthcare Research & Quality. Rockville, MD; pages 116-117.

Certain *visual scales* can help patients explain the intensity of their pain or pinpoint where they feel pain. For example, by drawing a simple picture of your body you can mark or color the areas where you feel pain. The “faces” pain rating scale is helpful for children or people who have trouble with the numeric 0 to 10 scale. There are several different scales that use a series of faces with expressions from smiling (0 = no hurt) to tearful (10 = hurts worst).



From: Wong DL, Hockenberry-Eaton M, Wilson D, Windelstein MI, Schwartz P. Wong’s Essentials of Pediatric Nursing, 6th Edition, St. Louis, 2001; page 1301. Copyright by Mosby, Inc. Reprinted by permission.

Using a daily pain diary or pain notebook, such as the American Pain Foundation’s *TARGET Chronic Pain Notebook* (see www.painfoundation.org/Publications/TargetNotebook.pdf) to track your pain over several days or weeks may help you identify what makes it better or worse, whether certain medications or non-drug therapies are effective in controlling your pain, as well as how your pain episodes impact your daily activities and emotional well-being. You may want to use the scales provided above to rate your pain. Be sure to share this information with your healthcare provider so he or she can evaluate your pain and treatment plan.

Questions to Ask Your Physician About Pain

- What could cause my pain?
- What options would you recommend for treating my pain (medications and non-drug therapies)?
- How long does it take the medicine to start working? (Called “onset of action.”) How much relief should I expect from this treatment?
- What if I forget to take the medicine?
- Should I take my medicine with food? Are there any foods or beverages I need to avoid? Will my pain medication interfere with other supplements and medications I’m taking?
- If my pain is not relieved by the amount of pain medication you prescribed, can I take more? If I can take more, how much should I take? Should I call you before increasing the dose?
- Is it safe to drink alcoholic beverages, drive or operate machinery after I have taken pain medicine?
- What can I do to ease or prevent side effects from this medication, such as constipation or fatigue?
- How should I store these medications in my home?
- Are there certain activities I should avoid? Will certain exercises help?
- What other pain treatment options should be considered? Are there additional specialists who should be part of my pain care team (nurses, physical therapists, counselors, nutritionists)? Can you recommend any qualified practitioners who offer complementary therapies, such as acupuncture, massage, yoga or hypnosis?
- Do you have suggestions for how I can talk to friends and family members about my pain?

For a printable list of these questions please go to www.LLS.org, click on **Treatment and Clinical Trials** and then click on **Pain Management**.

If you are scheduled for a medical or surgical test or procedure, ask your physician

- How much pain to expect
- How long it may last
- How the pain will be managed before, during and after the procedure
- If there are any signs or symptoms that you need to report to your physician right away.

It may help to

- Write out your questions ahead of time and bring them with you
- Share your concerns; there are no silly or dumb questions
- Consider using a tape recorder (make sure to ask permission before turning it on)
- Bring someone along for support and to help listen and take notes.

Remember

- Pain can be managed. No pain should go untreated or ignored.
- You are not bothering your physician if you tell him or her you are having pain. Your healthcare providers want to improve the quality of your life.
- Early treatment of pain is more effective than waiting until it is more severe.
- Let your physician know if the pain treatment is working or if it is not working. Ask about other options you can try.
- Increased pain does not necessarily mean that the cancer is getting worse, but you should always inform your physician if you have pain.
- Bring your pain diary or notebook to office visits to show the impact that pain is having on your quality of life.
- If your physician is unable to treat your pain so that you have satisfactory relief and can function better, request a referral to a pain specialist. These physicians are trained to manage pain for many different types of illness. Be persistent in working with your healthcare team to set up a pain management plan that reduces suffering and improves function. Hospital social workers and nurses can also be valuable sources of information and are available to listen if you need to talk. There are also patient advocates, sometimes called “patient navigators,” who can assist you.
- Lean on your loved ones for support. Coping with unrelieved pain can be exhausting and can keep you from enjoying friends, relatives and activities. Pain is invisible; so let them know how you are feeling and coping, and what they can do to help.
- Pursue activities that will help to relax and distract you.

Pain Treatment

There are many options available to manage pain effectively. The goals of pain management are to relieve pain, improve function and restore quality of life (for example, to allow patients to return to work, get restful sleep, be intimate with their partners). Your physician will work with you to set goals that are right for you.

The approach used to manage your pain will depend on the cause and type of your pain. Treatments may include

- Medication—non-steroidal anti-inflammatory drugs (NSAIDs), acetaminophen, opioid analgesics, antidepressant and anticonvulsant drugs; nerve blocks, corticosteroids, anesthetics; specialized injections, infusions, medical devices or surgical procedures; topical creams and skin patches
- Psychosocial interventions—stress management, counseling, coping mechanisms
- Rehabilitation techniques—exercise therapy, application of heat or cold, myofascial therapy
- Complementary and alternative medicine (CAM)—meditation, acupuncture, hypnosis, yoga, aromatherapy, therapeutic massage, supplements (see the free LLS Fact Sheet, *Integrative Medicine & Complementary and Alternative Therapies as Part of Blood Cancer Care*, for more information).

At times, treating the cause, as in using drug therapy to treat the underlying cancer, may relieve or decrease your pain and reduce the need for pain medication.

About Pain Medications

Often, medication will be recommended or prescribed for pain relief. Some of these medicines are available at a pharmacy or grocery store without a prescription, while others require a prescription and close follow-up care.

For mild pain your physician may recommend acetaminophen. Other medications, like NSAIDs, including aspirin and ibuprofen, may be recommended for mild to moderate pain. Although acetaminophen and NSAIDs are valuable pain relievers, there is a point at which they reach an upper limit for providing relief. In addition, your physician may advise against taking them during chemotherapy or radiation therapy.

For moderate to severe pain, your physician may prescribe stronger pain relievers known as opioid analgesics—for example, codeine and morphine, hydrocodone, oxycodone, hydromorphone, oxymorphone, methadone, and fentanyl. These medications may require treatment agreements to ensure they are taken and stored safely and appropriately by the patient. As part of this agreement, your provider may establish very clear guidelines to ensure that you take the opioid as prescribed.

Opioid pain medicines differ in how well they control pain, how much you have to take, how long they last and in the ways that they can be given. Opioids can be taken by mouth (pill or liquid), as a suppository, by injection or absorbed through a patch on the body.

Oxycodone and fentanyl (Dilaudid®) are examples of single-agent opioids. Percocet® (a combination of oxycodone and acetaminophen), Vicodin® (a combination of hydrocodone and acetaminophen), and Vicoprofen® (a combination of hydrocodone and ibuprofen) are examples of combination medications. When opioids are used in their pure forms, there is no upper limit on their ability to relieve pain. The dose can be gradually increased as pain levels rise. Therefore, using pure opioids may be more effective than other medications to treat severe pain. Your physician will be careful to ensure your dose is appropriate to manage your level of pain. Also, your physician may try different medications to find the one(s) that work(s) best for you. Sometimes your physician may also prescribe non-opioids along with opioids to treat specific types of pain—using NSAIDs along with opioids to treat bone pain or antiseizure medications to treat nerve-related pain problems, for example. Other medications include certain antidepressants, anticonvulsants and corticosteroids. Non-drug treatments are often recommended in addition to medication therapy.

Your physician should reassess your pain at each visit and may opt to prescribe a new medication, alter the dosage or recommend a combination of pain medicines with psychological and rehabilitative therapies. Remember to tell your physician and other members of your treatment team about all of the medicines you are taking, including over-the-counter medications, supplements and herbal remedies as these can result in serious interactions. Your medical team can help direct you on whether you need to be taking certain medications and how to use them safely.

When opioid medications are used, there is an underlying concern about the risk for addiction. Patients with persistent pain who require prolonged opioid therapy and take these medicines as directed have little-to-no-risk of developing addictive disease. Persons at risk for addiction 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. Tell your physician if you are at risk for developing addictive disease. This does not necessarily mean that using opioids to treat your pain will not be an option. However, you may need to work with an addiction specialist as a member of your pain team, and increased monitoring may be necessary.

If the cost of medication is a concern for you, discuss this with your physician. He or she may be assuming that your medical insurance will cover all the costs. Your physician may be able to prescribe less expensive medications or refer you to sources for financial aid. LLS offers a *Patient Financial Aid Program* to help with the cost of some medications, transportation and procedures for those in need. LLS also has a *Co-Pay Assistance Program* to help with the cost of insurance co-payments and/or insurance premium costs for prescription drugs for some blood cancers. Patients must qualify both medically and financially for this program. Please see *We're Here to Help* near the end of this fact sheet for contact information.

About Non-Drug Options

Increasingly, people living with cancer are turning to non-drug therapies to help alleviate pain and enhance their sense of well-being. It is important for you and your physician to discuss what type(s) of non-drug approaches may be most appropriate for your specific condition. The addition of these therapies often results in better pain relief and fewer side effects.

Some of the more common non-drug therapies include

- Physical therapy and rehabilitation
- Complementary and alternative medicine (CAM) techniques
 - Mind-body medicine (for example, meditation, hypnosis, distraction, guided imagery)
 - Biologically based practices (for example, herbs, special diets or vitamins)
 - Manipulative and body-based practices (for example, massage or chiropractic manipulation)
 - Energy medicine (for example, acupuncture, Reiki and therapeutic touch)
- Exercise (for example, walking or pool therapy)
- Hot or cold packs
- Relaxation and breathing techniques
- Transcutaneous electrical nerve stimulation (TENS).

There is a growing body of research showing that interventions aimed at influencing emotions, attitudes and behavior can aid in the reduction of chronic pain and associated distress. For example, studies are uncovering a biological link between the brain systems involved in depression and pain regulation. People with pain often suffer from depression, which can increase pain sensitivity and intensity. It is important to tell your physician if you are using any complementary or alternative treatments. Some natural products can change the way your body reacts to prescribed medications.

We're Here to Help

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary healthcare organization dedicated to funding blood cancer research, education and patient services. LLS has chapters throughout the country and in Canada. To find the chapter nearest you, visit our Web site, www.LLS.org, or contact

The Leukemia & Lymphoma Society

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Information Resource Center (800) 955-4572

Email: infocenter@LLS.org

Callers to the Information Resource Center may speak directly with an information specialist, Monday to Friday, 9 a.m. to 6 p.m., ET. You may also contact an information specialist by clicking on Live Help (10 a.m. to 5 p.m.) at www.LLS.org or by sending an email. Information specialists can answer general questions about diagnosis and treatment options, offer guidance and support, and assist with clinical trial searches for leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative diseases. The Web site, www.LLS.org, has information about how to find a clinical trial, including a link to TrialCheck®, a clinical trials search service provided by LLS. For questions about the *Co-Pay Assistance Program*, please contact us at (877) 557-2672 or via copay@LLS.org. LLS also provides fact sheets and booklets that can be ordered via (800) 955 4572 or through the Free Materials on the Web site.

Resources

American Chronic Pain Association

www.theacpa.org

(800) 533-3231

American Pain Foundation

www.painfoundation.org

(888) 615-PAIN (615-7246)

CancerCare, Inc.

www.cancercare.org

(800) 813-4673

National Cancer Institute

www.cancer.gov

(800) 4-CANCER (422-6237)

National Institute of Mental Health (NIMH)

www.nimh.nih.gov

(866) 615-6464

Several publications about depression that may be helpful; go to the NIMH Web site and enter “depression” in the search box at the top of the Web page, or call the NIMH.

National Pain Foundation

www.painconnection.org

Pain Care Bill of Rights

www.painfoundation.org/Publications/BOREnglish.pdf

Pain Resource Guide: Getting the Help You Need

www.painfoundation.org/Publications/PainResourceGuide2007.pdf

TARGET Chronic Pain Notebook

www.painfoundation.org/Publications/TargetNotebook.pdf

Treatment Options: A Guide for People Living with Pain

www.painfoundation.org/Publications/TreatmentOptions2006.pdf

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Acknowledgement

LLS gratefully acknowledges Micke A. Brown BSN, RN, Director of Advocacy, American Pain Foundation, for her review of *Pain Management* and her important contributions to the material presented in this fact sheet.

This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services.

FS-19 September 2008