

## Highlights

- A cancer diagnosis does not mean that you will have pain. However, a number of people with cancer do have pain at some point.
- Pain may result from the cancer, from its treatment (for example, bone or nerve pain that can be a side effect of certain medications) or other coexisting diseases (for example, arthritis).
- Pain varies in its intensity. It may be short-lived (acute) or continue longer than it should after a disease or injury (persistent).
- There are many ways to manage pain effectively; patients whose pain is not controlled well enough should ask to be referred to a pain specialist.
- Pain treatment at the right time may result in better outcomes; therefore, pain should be discussed right away with healthcare providers.
- Studies are under way to help researchers better understand pain associated with various types of cancer and cancer treatments, and to find more effective treatments to relieve pain. Some of these studies may lead to therapy with fewer short- and long-term side effects, such as nerve pain (peripheral neuropathy).

## Introduction

No matter when you have pain over the course of your disease, it is important to remember that all pain can be treated and most pain can be controlled or relieved.

For people with blood cancers (leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative neoplasms) pain can be related to the cancer itself, to the treatment of cancer, or both. Pain can also be caused by problems unrelated to cancer.

Pain can come and go, or be constant. It can be mild or severe. Each person's pain is unique and may change over time.

You should never accept pain as a normal part of having cancer. If you (or someone you love) is in pain, tell your healthcare provider right away. Treating pain as soon as it begins or stopping pain before it starts is very important. Once pain becomes severe, it can be difficult to treat.

## Effects of Pain

Pain can have a negative impact on many parts of your life. In addition to causing suffering, pain can

- Limit your ability to function (sleep, work, exercise, or perform daily tasks such as taking a shower or doing light housework)
- Reduce or increase your appetite
- Reduce intimacy with your partner
- Slow your recovery from an illness or surgery
- Interfere with your body's ability to fight infection
- Alter your mood.

Pain can also impact how you feel. When you're in pain, it is easy to feel sad, frustrated, anxious, angry or depressed. Together, pain and depression can create a cycle in which pain worsens symptoms of depression, and then the depression worsens feelings of pain. Tell your healthcare provider if you feel depressed.

Pain is not always a part of having cancer, but when it is, there are many treatments available to help manage cancer pain. When pain is under control, you

- Are able to function
- Enjoy time with family and friends
- Sleep
- May have more of an appetite
- Enjoy intimacy with your partner.

## Types of Pain

There are different types of pain: acute, persistent and breakthrough. No matter what kind of pain you have, treatments are available to help.

**Acute pain.** This type of pain comes on quickly and lasts a short time (up to three months). Acute pain can be mild to severe. Acute pain is nature’s signal that causes you to change a harmful behavior or seek medical attention. It is due to a known cause, such as damage caused by an event (for example, a surgical procedure) or an injury (for example, a fall). During this time you might need to treat your pain with medication. But once the event is over or the injury has healed, the pain usually goes away. Usual healing time is four to six weeks.

**Persistent pain.** This type of pain won’t go away or comes back often (pain lasting beyond usual healing time or longer than three months). Persistent pain can begin suddenly or gradually. It can be constant, come and go, or worsen over time. Left untreated, it can suppress the immune system and delay healing. There is no purpose for persistent pain; it changes the nervous system and, therefore, it is considered a disease.

Persistent pain is most often treated with pain medications that are slowly released into the body over a long period of time. You take these pain medicines at scheduled times—even if you are not having pain at the time the medicine should be taken. By taking these drugs on a schedule, you can have a steady level of pain relief throughout the day and night.

**Breakthrough pain.** The intensity of pain rises despite a scheduled pain medication regimen. Breakthrough pain can occur suddenly or it can be felt for a short time. In other words, the pain “breaks through” the regular pain management schedule. Many people with persistent pain also have breakthrough pain. Breakthrough pain is not controlled by regular doses of pain medications and “breaks through” the relief that those medications usually provide. Breakthrough pain may happen several times a day.

There are three different types of breakthrough pain.

- “End-of-dose failure” is pain that occurs while the current dose of your medicine is wearing off. It can occur even when a person is following the correct dosage and schedule for pain medication.
- “Idiopathic” or “spontaneous” is pain that just happens; the cause can be unknown, or the pain may be from something as simple as a sneeze.
- “Incident” pain occurs when some specific action or occurrence (such as shopping, doing laundry, or climbing stairs) triggers the pain.

Breakthrough pain is treated with pain medications that work quickly and for a short period of time. These short-acting drugs (sometimes called “rescue medicines”) work faster than those used to manage constant pain.

If you experience any of these kinds of pain, don’t wait to tell your healthcare provider. Once pain builds up, it can be difficult to treat.

If you are already on medication for breakthrough pain, and you are having more than three or four episodes per day, tell your provider immediately. Your around-the-clock pain medication may need to be adjusted.

## Causes of Pain

People with cancer can have pain caused by the cancer itself, its treatment, or both. They can also have pain caused by other health conditions (for example, arthritis or diabetes) that are unrelated to cancer. No matter what the cause, it is important to remember that pain can be treated.

### Blood Cancer-Related Pain

Many people with blood cancers have pain caused by the cancer itself. For example, when cancer cells collect in the bone marrow (the spongy tissue inside bones where blood cells are made) and form a mass, that mass may press on the nerves of the spinal cord or joints. This can cause pain.

#### Ways Blood Cancers Can Cause Pain

##### Leukemia or Myelodysplastic Syndromes

Some people with leukemia or myelodysplastic syndromes have bone or joint pain. When bone pain does occur, pain is most often felt in the long bones of the arms and legs, in the ribs and in the breast bone. Joint pain and swelling of the large joints, such as the hips and shoulders, sometimes develop several weeks after bone pain begins.

In addition, people with chronic lymphocytic leukemia (CLL), chronic myeloid leukemia (CML) and hairy cell leukemia sometimes have pain or feel full below the ribs on their left side due to an enlarged spleen caused by the cancer.

##### Lymphoma

People with Hodgkin and non-Hodgkin lymphoma often have swollen lymph nodes but rarely experience pain at the time of their diagnosis. Sometimes, depending on the location of the mass of abnormal cells, a person can have pain in one or more places in the body—most commonly in the chest, abdomen or the bones. For example, a mass in the abdomen can cause back or abdominal pain. Over time, some people with lymphoma also develop bone pain.

## Myeloma

Many people with multiple myeloma experience pain. Back pain is often the first symptom, but because this is such a common condition, it might not be associated with myeloma.

In people with myeloma, myeloma cells may build up in the bone marrow. When this happens, the myeloma cells destroy normal bone tissue, sometimes causing bones to fracture or vertebrae (the small bones making up the spinal column) to collapse. This causes pain and could be an emergency. Common areas of pain in people with myeloma are the back, ribs, arms and legs, hips and shoulders.

## Myeloproliferative Neoplasms (Essential Thrombocythemia, Polycythemia Vera and Myelofibrosis)

Some people with myeloproliferative neoplasms have pain. Each disease is different, so people with different types of myeloproliferative neoplasms can have different kinds of pain.

- **Essential Thrombocythemia (ET)**  
Some people with ET have pain in the hands and feet caused by reduced blood flow. This pain is often described as “numbness,” “tingling,” “throbbing” or “burning.” Some people also get headaches.
- **Polycythemia Vera (PV)**  
Some people with PV develop gout, a kind of arthritis that causes painful joint swelling. Some people can also develop painful ulcers in the stomach, small intestine and esophagus. In addition, some people can have burning or tingling pain on their skin, particularly on the arms, legs, hands or feet.
- **Myelofibrosis (MF)**  
Some people with MF feel pain or have a sensation of fullness below the ribs on their left side due to an enlarged spleen caused by the cancer. Some people may also have bone pain.

## Cancer Treatment-Related Pain

Some cancer treatments cause side effects, including pain. Cancer therapies can also weaken the immune system, which is why shingles (the painful reemergence of the chickenpox virus, varicella zoster) is common among patients who are in active treatment. If you experience pain or any side effects from your treatment, tell your healthcare provider right away.

## Possible Side Effects of Common Treatments for Blood Cancers

### Chemotherapy or Radiation Therapy

Side effects of chemotherapy that cause pain include mouth sores, headaches, muscle pains and stomach pains. Medications are available to manage these effects.

Side effects of radiation therapy that cause pain are dry skin or skin irritation in parts of the body exposed to radiation. There are many ways side effects of radiation can be managed. Talk to your healthcare provider for more information.

Some forms of chemotherapy and radiation therapy can damage the nerves. This can result in pain—most often described as “burning” or “tingling”—that usually begins in the hands or the feet. This condition is called “peripheral neuropathy.”

Both chemotherapy and radiation therapy weaken the immune system. This puts the body more at risk for viral infections and diseases. For example, shingles, the painful blisters on the skin caused by a reactivation of the chickenpox virus, can develop. Shingles can also lead to postherpetic neuralgia (pain lasting long after the shingles rash and blisters have disappeared).

### Bone Marrow Biopsy and Aspiration

Bone marrow biopsy and bone marrow aspiration can be uncomfortable and sometimes painful procedures. Medication is usually given to reduce any pain or discomfort during the procedure. Some people have mild pain for a few days at the place where the needle was inserted.

### Stem Cell Transplantation and High-Dose Chemotherapy

Most of the potential side effects of stem cell transplantation, including pain, are a result of the high-dose chemotherapy. Common painful side effects include stomach cramping, vomiting and diarrhea. Another common painful side effect is the development of mouth sores. Medications are available to manage these effects.

Patients will have weakened immune systems for several months after a stem cell transplant. This makes the body more at risk for viral conditions such as shingles, which causes painful rashes.

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

## Assessing Pain

Pain assessment is an important part of every medical appointment. It provides information that will help your healthcare provider to manage any pain you may be experiencing. If indicated, your doctor may change the dose of your current pain medication, prescribe a new one or have you try a combination of pain medications.

## Describing Your Pain

You play the most important role in pain assessment. Pain cannot be measured like your weight, blood pressure, or temperature—only you know how much pain you can stand. Telling your healthcare providers about your pain will help them to develop a pain management plan.

Honest and direct communication with your healthcare provider is important. Be as specific and detailed as you can about your pain.

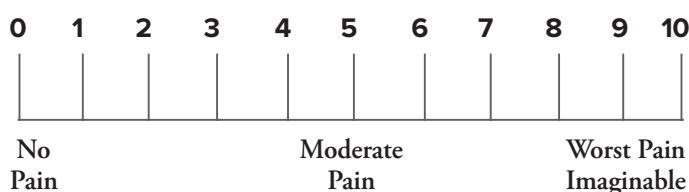
Some people find it difficult to talk about their pain with their healthcare provider. You might have trouble finding the right words to describe how the pain feels. The words below may help you explain.

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

## Rating Your Pain

As part of your pain assessment, your healthcare provider might ask you to describe or rate your pain. He or she wants to understand how you are feeling and see whether your pain control plan, if already in place, is working. There are several tools your healthcare provider might use that can help you to describe your pain.

One of the most common tools is a scale that asks people to rate their pain by choosing a number from 0 to 10. This is referred to as the “visual analog scale” or “VAS.” As the numbers get higher, they stand for pain that is getting worse. A zero means you have no pain and a 10 means you have the worst pain you can imagine.



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.

Some healthcare providers also use a chart with a series of faces and you are asked to point to the face that best describes how you feel. For example, a smiling face means no pain and a tearful face means the worst pain. The faces scale helps children rate pain.

## Wong-Baker FACES Pain Rating Scale



From: Hockenberry MJ, Wilson D: *Wong's Essentials of Pediatric Nursing*, ed. 8, St. Louis, 2009, Mosby. Used with permission. Copyright Mosby.

## Keeping Track of Pain

Keeping a record of your pain on a daily or weekly basis can help you and your healthcare provider understand your pain and how to manage it. It can be hard to remember how pain affects your everyday life. Some ways to keep track of your pain include using a notebook, a journal or a computer spreadsheet. Find the way that works best for you and stick to it.

Begin by keeping a record of any medications you take to manage your pain, as well as other prescription medications, over-the-counter drugs, vitamins or supplements.

Date	Medicine	Dose	Is it Working?	Side Effect?
3/1	hydromorphone	8 mg	yes	none

Try recording the answers to these questions on a daily or weekly basis.

- Where is the pain? (For example, is it in one location or many?)
- What does the pain feel like? (For example, is it dull or sharp?)
- How strong is the pain? (For example, is it a 5 or an 8 on the numeric scale?)
- How long does it last? (For example, does it come and go or is it nonstop?)
- When does the pain happen? (For example, is the pain mostly in the morning or at night? Does the pain occur more often standing or sitting?)
- What activities does it prevent? (For example, does the pain make it hard to shower or dress? Does the pain make it hard to enjoy spending time with friends and family?)
- Are there any other symptoms that go along with the pain? (For example, depression or anxiety?)

Date	Time	Description of Pain	Pain Level
3/1	6 a.m. – 7 a.m.	Sharp, shooting pains in lower back and legs that woke me from sleep.	9
3/2	2 p.m. – 4 p.m.	Constant gnawing pain in lower back while sitting at desk. Had to leave work early. Felt better once I was able to lie down.	7

Review these records with your healthcare provider at your next appointment.

## Medications to Treat Pain

There are many options available to manage pain effectively. The goals of pain management are to relieve pain, improve function and bring back a good quality of life (for example, to allow patients to return to work, get restful sleep, be intimate with their partners). Most pain can be reduced so that you are as comfortable as possible. In fact, almost all people will find relief from pain by using a combination of medications.

Most pain medications come in tablet form to be swallowed or dissolve quickly in the mouth. Several also come in liquid form. If you're unable to take medications by mouth, pain medications can also be administered intravenously (through a small needle inserted into a vein), rectally, by injection or infusion, or through the skin by using a topical cream or skin patch. Based on your pain and condition, you and your healthcare provider will decide which medication you need, how you should take it, how much you should take and how often.

Here are some examples of pain medications.

**Acetaminophen and Nonsteroidal Anti-Inflammatory Drugs (NSAIDs).** Over-the-counter medications (OTCs) like acetaminophen (Tylenol®) and NSAIDs (aspirin, Advil® and Aleve®) can be very effective in treating mild to moderate pain. Although acetaminophen and NSAIDs are valuable pain relievers, they can also be harmful to the body if taken in doses over the recommended amount. If you are taking acetaminophen or a NSAID, be sure to follow the package instructions carefully. Some people should not take acetaminophen or NSAIDs, so tell your healthcare provider if you are using these medications. It is important for all your healthcare providers to know about every medication you are taking during your treatment. Provide them with a list of your prescription and OTC medications as well as herbs, vitamins and dietary supplements.

Many OTC and prescription products (especially pain medications) contain acetaminophen. The upper limit for daily use is 4,000 mg of acetaminophen per day in a healthy adult. Those with medical conditions such as cancer, diabetes and high blood pressure should limit their intake to 2,500 mg per day. Taken in high doses, acetaminophen can damage your liver.

NSAIDs are frequently used in cancer pain treatment. Taken in high doses, NSAIDs can damage the stomach and the kidneys. There are also many prescription NSAIDs that, when taken in higher than recommended doses, can cause high blood pressure, stroke and heart attack.

**Opioids.** Opioids are a type of medication that can be very effective for the relief of moderate to severe pain. Opioids are available only with a written prescription. If you are using an opioid, check your supply before your appointment so that you can ask your healthcare provider for any prescriptions you need.

There are several types of opioids. Morphine is the opioid that is most often used to manage pain in people with cancer. Other commonly used opioids include hydromorphone (Dilaudid®), oxycodone, hydrocodone, codeine, fentanyl and methadone. Oxycodone and fentanyl 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 as a single agent, 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 to treat severe pain may be more effective than using other medications.

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 doctor 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.

**Antidepressants and Antiepileptics.** Antidepressants are a type of medication most often used to treat depression. Antiepileptics are a type of medication used to prevent seizures. Both antidepressants and antiepileptics are also used to manage pain in people with cancer. They are especially effective at treating neuropathy-related pain. Taking an antidepressant or antiseizure medication to help manage cancer pain does not mean that you are depressed or that you are going to have seizures.

**Steroids.** Steroids are a type of medication that can relieve pain caused by swelling. Prednisone and dexamethasone are often used to manage pain in people with cancer.

**Combinations of Medication.** Sometimes a combination of pain medications is needed to control pain. A common combination is a short-acting opioid (one that starts relieving pain instantly), a sustained-release opioid (one that relieves pain over a longer period of time), and a medication for neuropathic pain. Your doctor and nurse will help find the right combination for you.

**Other Options to Control Pain.** Additional options for controlling pain include nerve blocks or nerve ablation, anesthetics, medical devices or surgical procedures or implanted devices like an intrathecal pump and spinal cord stimulation.

Your healthcare provider 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. It may take time for your treatment to be effective. Keep the lines of communication open and work together with your healthcare team. It is important to find the right balance between giving the treatment a chance to work and trying another treatment.

Remember to tell your healthcare provider and other members of your treatment team about all of the medicines you are taking, including over-the-counter medications, supplements and herbal remedies. Sometimes there can be serious interactions. Your medical team can help direct you on how to take them safely.

If the cost of pain medication is a concern for you, discuss this with your healthcare provider. He or she may be assuming that your medical insurance will cover all the costs. If this is not the case, your healthcare provider may be able to prescribe less expensive medications or refer you to sources for financial aid. Please call our Information Specialists (See *We're Here to Help* on page 9) for information about additional resources.

If medication management is a chosen therapy for your pain, it is your responsibility to keep all the drugs in a safe place, preferably locked up. These medications should not be within the reach of children, and could be stolen from you if left out in the open.

## Alternative Treatments for Pain

Although the use of medications is the most common way to manage pain, many people with cancer use alternative therapies to find relief. Alternative therapies, especially when used in combination with pain medications, can result in better pain relief and fewer side effects.

Here are some commonly used alternative therapies:

- Psychosocial interventions—stress management, counseling, coping mechanisms
- Physical therapy, exercise and heat/cold therapy
- Meditation, hypnosis and guided imagery
- Herbs, special diets and vitamins
- Massage and chiropractic manipulation
- Acupuncture, Reiki and therapeutic touch.

You may be interested in learning more about alternative therapies. Talk to your healthcare provider before starting anything new. Some alternative therapies—including those involving vitamins, herbs and certain diets—can change the way your body reacts to medications and may cause damage to your liver or kidneys. It is a good idea to have a clinical pharmacist review any supplements you are thinking of adding to your prescribed and over-the-counter medications.

See the free LLS publication *Integrative Medicine & Complementary and Alternative Therapies as Part of Blood Cancer Care* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or call our Information Specialists for a copy.

## Side Effects of Pain Medication

Some pain medications have side effects. Talk with your healthcare provider right away about side effects as they may be caused by your pain medication. If you do have side effects, there are ways to treat them.

Here are some common side effects:

**Sleepiness or fatigue (extreme tiredness).** Sleepiness or fatigue can be caused by pain medications. This side effect is most common in the first three to four days after starting a new medication or increasing a dose. Sleepiness or fatigue usually goes away once your body adjusts to the medication. If you feel sleepy, do not drive a car or operate other equipment. Tell your healthcare provider if your sleepiness does not go away. There are sleep clinic specialists who can help with insomnia issues and sleep hygiene.

**Constipation.** Constipation can be caused by pain medications. Constipation is a change in bowel habits. Even though a person feels the need to empty the bowels, stools can be hard to pass and/or movements infrequent. 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 healthcare provider to come up with a plan that works for you. If you are on medications for persistent pain, a bowel prep (cleaning of the intestines of all solid matter) should already be set up by your primary team. It is important to let your healthcare provider know if you are constipated.

**Nausea and vomiting.** Nausea and vomiting can be caused by pain medication. These side effects most commonly occur in the first three to four days after starting a new medication or increasing a 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 if you are vomiting. Other approaches that may help include eating some dry crackers prior to taking the medications, briefly holding an alcohol swab under your nose, or lying very still and doing some slow deep breathing for a couple of minutes until the nausea subsides.

## Pain Specialists

Most oncologists (doctors who treat cancer) are experienced at managing pain. But if your healthcare provider is not able to relieve your pain, ask to see a pain specialist. Pain specialists are trained to manage pain for many different types of illness and can help you set up a pain management plan that works. Pain specialists include anesthesiologists, neurologists, and physical medicine and rehabilitation doctors. Make sure the healthcare provider you see is board certified in pain management and/or interventional pain management. Here are some resources that you can use to find pain specialists near you:

- The clinic or cancer center where you receive treatment
- Your local hospital or medical center
- Your insurance company
- Your primary care provider
- People who belong to pain support groups in your area
- The Center to Advance Palliative Care, [www.getpalliativecare.org](http://www.getpalliativecare.org) (for lists of pain specialists in each state).

## Questions to Ask Your Healthcare Provider About Pain

Many concerns about pain can be relieved by understanding the facts about your diagnosis and learning about the help that is available for pain relief. Ask your healthcare provider any questions you may have. 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 recording the conversation.
- Bring someone along for support and to help listen and take notes.

Here are sample questions you can ask your healthcare provider to start a conversation about pain:

- What could be causing my pain?
- What options do you recommend for treating my pain (medications and non-drug therapies)?
- How long will it take for the treatment to start working?
- How much pain relief can I expect from this treatment?
- How should I store my medication?
- How should I take my medication?
  - Should I take my medicine with food?
  - Are there any foods or beverages I need to avoid?
  - What if I miss a dose?
  - What if I throw up after taking a dose?
- Is it safe to drink alcoholic beverages, drive or operate machinery after I have taken pain medication?
- 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 prescribed, can I take more?
  - If I can take more, how much should I take?
  - Should I call you before increasing the dose?
- What can I do to ease or prevent side effects from this medication?
- Are there certain activities that will be helpful or harmful?
- Are there additional specialists who should be part of my pain care team (nurses, physical therapists, social workers, nutritionists)?
- Do you recommend any alternative therapies, such as acupuncture or massage?
- Do you have suggestions for how I can talk to friends and family about my pain?

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

- If the test/procedure will be painful
- How much pain to expect
- How long the pain may last
- How the pain will be managed before, during and after the test/procedure
- If there are any signs or symptoms that you need to report to your healthcare provider.

To view the free LLS printable question guide about pain, please visit [www.LLS.org/whattoask](http://www.LLS.org/whattoask).

## Remember

- Pain can be managed. No pain should go untreated or ignored.
- You are not bothering members of your healthcare team if you tell them 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 healthcare provider 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 healthcare provider 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 healthcare provider 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. 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.



## Treatments Under Investigation

Clinical trials are carefully controlled research studies, conducted under rigorous guidelines, to help researchers determine the beneficial effects and possible adverse side effects of new treatments. Studies are also conducted to evaluate new indications for therapies that are already approved for other cancers or types of diseases. Patient participation in clinical trials is important in the development of new and more effective treatments for pain management and may provide patients with additional treatment options. Patients interested in participating in clinical trials are encouraged to talk to their healthcare providers about whether a clinical trial would be appropriate for them. For more information about clinical trials, see the free LLS publication *Understanding Clinical Trials for Blood Cancers* or visit [www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials).

Some research approaches under investigation include studies examining interventions aimed at influencing emotions, attitudes and behavior to help reduce persistent pain and associated distress. For example, studies are uncovering a biological link between the brain systems involved in depression and pain regulation. Other approaches include examining a link between hormonal balance and persistent pain and research on neuropathy.

We encourage you to contact our Information Specialists and visit [www.LLS.org](http://www.LLS.org) for more information about specific approaches under study in clinical trials.

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## We're Here to Help

LLS is the world's largest voluntary health 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, enter your ZIP code into "Find your Chapter" at [www.LLS.org](http://www.LLS.org) or contact

### **The Leukemia & Lymphoma Society**

1311 Mamaroneck Avenue  
White Plains, NY 10605  
Information Specialists: (800) 955-4572  
Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)

Callers may speak directly with an Information Specialist Monday through Friday, from 9 a.m. to 6 p.m. ET. You may also contact an Information Specialist between 10 a.m. and 5 p.m. ET by clicking on "Live Chat" at [www.LLS.org](http://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 neoplasms. The LLS website has information about how to find a clinical trial, including a link to our free online clinical-trial search service at [www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials).

LLS also provides free publications that can be ordered via the 800 number or through the "Free Education Materials" option at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter).

## Resources

### American Chronic Pain Association (ACPA)

www.theacpa.org  
(800) 533-3231

ACPA facilitates peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain. They also raise awareness among the health care community, policy makers and the public at large about issues of living with chronic pain.

### CancerCare

www.cancercare.org  
(800) 813-4673

CancerCare provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved.

### Cancer Support Community (CSC)

www.cancersupportcommunity.org  
(888) 793-9355

CSC strives to optimize patient care by providing essential, but often overlooked services including support groups, counseling, education and healthy lifestyle programs. CSC provides emotional and social support through a network of more than 50 local affiliates, 100 satellite locations and online.

### Center to Advance Palliative Care (CAPC)

www.getpalliativecare.org

CAPC provides a website for patients, families and caregivers that includes clear, comprehensive palliative care information. The site, www.getpalliativecare.org, includes the Palliative Care Provider Directory of Hospitals, a definition of palliative care, detailed descriptions of what palliative care does and how to get it and an interactive questionnaire to assist you in determining whether palliative care might be appropriate for you or a loved one.

### National Coalition for Cancer Survivorship (NCCS)

www.canceradvocacy.org  
(877) NCCS-YES (877-622-7937)

NCCS advocates for quality cancer care for all people touched by cancer and provides tools that empower people to advocate for themselves. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.

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