

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

Highlights

- A cancer diagnosis does not mean that you will have pain. Still, many people with cancer do have pain at some point. Good pain control is part of proper cancer care.
- Pain may be caused by cancer, its treatment (certain drugs may cause bone or nerve pain, for example), or other health problems (like arthritis).
- Pain varies in its intensity and duration. It may be intense and short-lived (acute pain) or last for many months or even years after a disease or injury (persistent or chronic pain).
- There are many ways to manage pain. People with cancer who are having trouble getting their pain under control should ask to see a pain or palliative (supportive) care specialist.
- Managing pain may result in better treatment outcomes, so patients should talk to their healthcare team about their pain right away.
- Studies are being done to better understand pain linked to cancer and cancer treatments. Researchers are also looking to find more effective treatments to relieve pain. Some of these studies may lead to cancer treatments with fewer side effects.

Introduction

No matter when you have pain, it's 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 or myeloproliferative neoplasms), pain can be the result of the cancer itself, the cancer treatment, or both. Pain can also be caused by problems (such as arthritis or muscle aches) that are unrelated to cancer.

Pain can come and go, or be constant. It can be mild or severe. Each person's pain is different 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 a member of your healthcare team right away. Treating pain as soon as it starts, or even stopping pain before it begins, is key. Once pain becomes severe, it can be hard to treat.

Effects of Pain

Along with causing suffering, pain can have a negative impact on many parts of your life. The table below outlines the type of effects you may experience. It also lists the benefits of an effective pain management plan versus the risks of living with uncontrolled pain.

BENEFITS (when pain is under control)	RISKS (when pain is out of control)
You are able to do the things you want and need to do.	You are limited in your ability to do daily tasks, like taking a shower or doing light housework.
You sleep well.	Your sleep is disrupted and you may struggle through the day because you feel tired.
You have a healthy appetite.	You have a reduced or an excessive appetite leading to unhealthy weight loss or weight gain.
You are able to work.	You need to take time off from work, switch to a less demanding job, or retire early (impacting your finances).
Your recovery from an illness or surgery is within normal limits.	Your recovery from an illness or surgery takes longer than normal, which can be frustrating.
You are able to be physically active.	Your recovery from illness or surgery takes longer due to being sedentary and inactive.
Your body can effectively fight infection.	Your body struggles to fight infection, which may result in getting sick more often.
You are able to enjoy time with friends and family.	You have less interest in social activities and may become isolated and lonely.
You experience a positive mood.	Your mood is altered, including the possibility of being depressed.
You are able to enjoy intimacy with your partner.	You have less interest in intimacy with your partner.

Table 1. Pain Management Benefits and Risks

Pain can impact how you feel. When you're in pain, it's easy to feel sad, frustrated, anxious, angry or depressed (loss of interest, feeling hopeless). 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 team if you feel depressed. Treating depression has benefits for cancer patients. See *Resources* on page 13.

Types of Pain

There are distinct types of pain: acute, persistent, and breakthrough. No matter what kind of pain you have, there are treatments that can help.

Acute pain. This type of pain comes on quickly and lasts a brief time; it can range from mild to severe. This pain is nature's signal that causes you to change a harmful behavior or seek medical attention. Acute pain is due to a known cause, such as damage resulting from surgery or an injury (like a fall). You might need pain medicine to treat acute pain. But once the event is over or the injury has healed, the pain usually goes away.

Chronic or persistent pain. This type of pain doesn't go away, or comes back often. It lasts beyond the usual healing time or more than a few months. Chronic pain can begin suddenly, or slowly become a problem. It may be constant, come and go, or get worse over time. Left untreated, it can suppress your immune system and slow healing.

Chronic pain may be initially treated with short-acting medications to determine their safety and effectiveness. Chronic pain may be treated as needed, with pain medications that are slowly released into the body over a prolonged period of time (called sustained or extended release). You take these medicines at scheduled times even if you're not having pain at the time that the medicine should be taken. By taking these drugs on a schedule, you will have a steady level of pain medicine in your body and consistent pain control.

Breakthrough pain. This pain happens even though you're taking pain medicines on a regular schedule to control chronic pain. In other words, the pain "breaks through" your regular pain management schedule. Breakthrough pain often comes on suddenly and lasts a short time. It may happen several times a day. Many people with chronic pain also have breakthrough pain.

These are the main types of breakthrough pain:

• "End-of-dose failure" is pain you have when the current dose of your medicine is wearing off. It can occur

even when you're following the correct dosage and schedule for pain medication.

- "Idiopathic" or "spontaneous" pain just happens. The cause can be unknown, or it may be caused by something as simple as a sneeze or a cough.
- "Incident" pain occurs when something you do (such as riding in a car too long or climbing stairs) triggers the pain.

Breakthrough pain is treated with pain medicines that work quickly and for a brief period of time. These shortacting drugs are sometimes called "rescue medicines." They quickly get into your blood to relieve intense pain. If you have breakthrough pain, tell your healthcare team. If not treated, this pain can become chronic and harder to treat.

If you're taking medicine for breakthrough pain and still having more than 3 or 4 episodes a day, tell your healthcare team right away. Your scheduled, extendedrelease pain medicine may need to be adjusted.

Causes of Pain

People with cancer can have pain caused by the cancer itself, its treatment, or both. They may also have pain caused by other health problems that are unrelated to cancer (like arthritis or diabetes).

Studies are looking at genetic variations among people with cancer and pain response. Many genes are involved with inflammation and the release of certain chemicals, which impact a person's pain sensitivity and immune system functioning.

It's important to remember that no matter what the cause, pain can be treated.

Blood Cancer-Related Pain. Many people with blood cancers have pain caused by the cancer itself. For instance, cancer cells can build up in the bone marrow (the spongy tissue inside bones where blood cells are made) and form a mass. That mass may then press on nerves or joints and cause pain. Some of the ways in which specific blood cancers can cause pain are listed below.

Leukemia or Myelodysplastic Syndromes (MDS).

Leukemia occurs when a cell in the bone marrow undergoes a change. The leukemia cells multiply abnormally and crowd out the normal cells. MDS occurs when the bone marrow produces immature cells that grow too quickly and don't function properly. This prevents healthy cells from developing.

Some people with leukemia or myelodysplastic syndromes have bone or joint pain. This bone pain is most often felt in the long bones of the arms and legs, in the ribs and in the breastbone. Joint pain and swelling of the large joints, like the hips and shoulders, sometimes starts several weeks after bone pain begins.

People with chronic lymphocytic leukemia (CLL), chronic myeloid leukemia (CML) and hairy cell leukemia (HCL) sometimes have pain or feel full below the ribs on their left side. This happens when cancer cells build up in the spleen and cause it to swell (enlarge). The spleen is a small organ in the upper left part of the body under the ribcage. It acts primarily as a filter for your blood.

Lymphoma. Lymphoma is a type of cancer that develops in a white blood cell called a lymphocyte. The lymphocyte undergoes a change and becomes a cancerous lymphoma cell that multiplies abnormally. These lymphoma cells divide faster and live longer than normal cells. They form masses in the lymph nodes or other parts of the body.

People with Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL) often have swollen lymph nodes. This rarely causes pain at the time of diagnosis. Sometimes, depending on where a mass of abnormal cells forms, a person can have pain in one or more places in the body where the mass is—most commonly in the chest, abdomen (belly) or bones. For instance, a mass in the abdomen can cause back or belly pain. Over time, some people with lymphoma also develop bone pain.

Myeloma. Myeloma is a cancer of plasma cells, a type of white blood cell. The plasma cells multiply too fast and crowd out the healthy cells in the bone marrow.

Many people with multiple myeloma have pain. Back pain is often the first symptom, but because back pain is so common in our society, it might not be initially linked to myeloma.

When myeloma cells build up in the bone marrow, they release chemicals that cause an imbalance in the process called "bone remodeling" (reabsorption of old bone and formation of new bone). This imbalance causes greater bone destruction and less new bone formation, leading to bone thinning (osteoporosis) or holes in the bones (lytic lesions). Bones can fracture easily, or vertebrae (the small bones making up the spinal column) may collapse. This causes severe pain and could be an emergency. Common areas of pain in people with myeloma are the back, ribs, arms, legs, hips and shoulders.

Myeloproliferative Neoplasms (MPNs). Some people with myeloproliferative neoplasms have pain. Each MPN

disease is different, so people with different types of myeloproliferative neoplasms can have different kinds of pain. Three classic MPNs and the possibility of pain are described below.

- Essential Thrombocythemia (ET) is a type of blood cancer in which the bone marrow produces too many platelets, making it difficult for the blood to flow. Some people with ET have pain in their hands and feet caused by reduced blood flow. This pain is often described as "numbness," "tingling," "throbbing" or "burning." Some people get headaches or chest pain.
- **Polycythemia Vera (PV)** is a type of blood cancer in which the bone marrow produces too many red blood cells, increasing the chance of bleeding, bruising and blood clotting. Some people with PV develop gout, a kind of arthritis that causes painful joint swelling. PV is also linked to painful ulcers in the stomach, small intestine and esophagus. PV might cause burning or tingling pain of the skin, most often on the arms, legs, hands or feet.
- Myelofibrosis (MF) is a type of blood cancer in which abnormal blood cells and fibers build up in the bone marrow, making it difficult for the body to produce healthy blood cells. Some people with MF feel pain or have a sensation of fullness below the ribs on their left side, where the cancer causes the spleen to swell. MF may also cause bone or joint pain.

Please visit www.LLS.org/booklets to view the free disease-specific LLS booklets for more information.

Possible Side Effects of Common Blood Cancer Treatments

Chemotherapy or Radiation Therapy. Chemotherapy can cause painful mouth sores, headaches, muscle aches and stomach pains. There are treatments that help control these side effects.

Radiation therapy is linked to skin dryness and sunburnlike irritation in the parts of the body exposed to radiation. There are many ways that the side effects of radiation can be managed. Talk to your healthcare team to learn more.

According to the National Institute of Neurological Disorders and Stroke (part of the National Institutes of Health) an estimated 30 to 40 percent of people treated with certain forms of chemotherapy experience damage to the nerves. Radiation therapy can also cause nerve damage, though less commonly. This can lead to pain that tends to start in the hands or the feet and is often

described as "burning" or "tingling." This condition is called "peripheral neuropathy" (PN).

Both chemotherapy and radiation therapy weaken the immune system. This puts the body more at risk for viral infections and diseases. For instance, shingles, the painful blisters on the skin caused by a reactivation of the chickenpox virus, can develop. Shingles can also lead to post-herpetic neuralgia. This is nerve pain that lasts long after the rash and blisters from shingles have gone away. Talk to your doctor about the shingles vaccine if you have not already received the necessary two doses.

Bone Marrow Biopsy and Aspiration. Bone marrow biopsy and bone marrow aspiration can be uncomfortable and sometimes painful procedures. Talk to your healthcare team about getting medicine to help reduce any pain or discomfort during or following the procedure. Some people have mild pain for a few days at the place where the needle was inserted.

Stem Cell Transplantation. Most of the side effects of stem cell transplantation, including pain, are a result of the high-dose chemotherapy used. Common painful side effects include mouth and throat sores, stomach cramping, vomiting and diarrhea. There are ways to manage and even help prevent these effects.

Patients will have weakened immune systems for many months after a stem cell transplant. This puts the body at higher risk for viral infections like shingles, which causes painful rashes and nerve pain.

Stem cells for transplantation may be taken from the patient (autologous transplant) or a donor's bone marrow or blood (allogeneic transplant). People who donate stem cells from bone marrow may experience temporary soreness, bruising and aching in the hip and lower back following the procedure. People who donate stem cells from the blood receive an injection of growth factor to stimulate the movement of stem cells into the blood. For the donor, the growth factor injection may cause mild, flu-like symptoms, temporary joint pain, bone pain or headaches.

Visit www.LLS.org/booklets and click "Filter by Topic" (Side Effect Management) for more information or to view *Blood and Marrow Stem Cell Transplantation*.

Assessing Pain

Pain assessment is an important part of every medical appointment. Talk about any pain you have so your healthcare team can help manage it. If needed, your doctor may change the dose of your current pain medicine, give you a new one, or have you try a combination of medicines.

Describing Your Pain. You play the most important role in your pain assessment. Pain cannot be measured like your weight, blood pressure or temperature—only you can describe your pain. Accurately telling your healthcare team about your pain will help them work with you 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 hard to talk about their pain with their healthcare provider. You might have trouble finding the right words to describe how the pain feels. These words may help you explain:

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

Rating Your Pain. As part of your pain assessment, a member of your healthcare team will ask you to describe or "rate" your pain. This helps your provider understand how you are feeling and decide if your pain control plan is working. There are several tools your healthcare provider might use that can help you describe your pain.

One of the most common tools is a scale on which you rate your pain by choosing a number from 0 to 10. This is called the "numeric rating scale." A zero means you have no pain and a 10 means you have the worst pain you can imagine.

Numeric Pain Rating Scale



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 instance, a smiling face means no pain, and a face with crying eyes and a

furrowed brow mean the worst pain. The faces scale can also help 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 team understand your pain and better manage it. It can be hard to remember how pain has affected your everyday life, so it helps to write it down when it happens. Some ways to keep track of your pain include using a calendar, a journal or a computer spreadsheet. Find the way that works best for you and stick to it.

Start by keeping a record of any medicines you take to manage your pain. Also keep track of other prescription medicines, over-the-counter drugs, vitamins or supplements you take.

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 as-needed basis.

- Where is the pain? (Is it in one place or many?)
- What does the pain feel like? (Is it dull, burning or sharp?)
- How strong is the pain? (What's the score on a 0 to 10 scale?)
- How long does it last? (Does it come and go or is it nonstop?)
- When does the pain happen? (Is it mostly in the morning or at night? Is it worse when you're standing or sitting?)
- What activities does it keep you from doing? (For instance, does the pain make it hard to shower or dress, sit or stand? Does the pain make it difficult to enjoy spending time with friends and family?)
- Are there any other symptoms that go along with the pain? (Do you have trouble sleeping, have 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.	
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 your records with your healthcare team at every visit.

Visit www.LLS.org/HealthManager for more information about the LLS app that helps track side effects, medications, food and hydration.

Medicines to Treat Pain

There are many options to manage or control pain. The goals of pain management are to relieve pain, improve function and bring back a good quality of life (for instance, to allow you to return to work, get restful sleep, or be intimate with your partner). Most pain can be eased to help you be as comfortable as possible. In fact, almost all people find relief from pain by using a combination of medicines.

Most pain medicines are pills that are swallowed or dissolve quickly in the mouth. Some also come in liquid form. If you're unable to take medicine by mouth, pain medicines can also be given IV (intravenously, meaning through a small needle that's put in a vein), rectally (as a suppository), as a shot (injection), or through the skin as a cream or patch. Based on your pain and overall health, your healthcare team will consult with you and together you'll decide which medicine you need, how to take it, how much you need (the dose), and how often you should take it.

Here are some of the common pain medicines used today:

Acetaminophen and Nonsteroidal Anti-Inflammatory Drugs (NSAIDs). Over-the-counter (OTC) medicines like acetaminophen (Tylenol®) and NSAIDs (aspirin, Advil® and Aleve®) can work very well for treating mild to moderate pain. These drugs are good pain relievers, but they can be harmful if you take more than the recommended amount. If you're taking acetaminophen or an NSAID, be sure to follow the package instructions carefully. Some people should not take acetaminophen or NSAIDs, so talk to your healthcare team before using these medicines.

It is especially important for the parents of a child with cancer to check with the healthcare provider before

giving the child any of these pain relievers. Please note that children with cancer should not be given pain medicine rectally.

Many over-the-counter (OTC) and prescription products (especially pain medicines) contain acetaminophen. The upper limit for daily use is 4,000 mg of acetaminophen per day in a healthy adult. Those with medical conditions like cancer, diabetes and high blood pressure may be limited to lower daily limits (such as 2,000-3,000 mg per day). Taken in high doses, acetaminophen can damage your liver. Be sure you understand what dose is safe for you.

NSAIDs are commonly used in cancer pain treatment. Taken in high doses, NSAIDs can damage your stomach and kidneys. There are also many prescription NSAIDs that, when taken in higher-than-recommended doses, can cause high blood pressure, stroke and heart attack. Even drugs you can buy without a prescription can be dangerous if not taken correctly.

Opioids. Opioids are medicines that can work very well to treat moderate to severe pain. You need a written prescription to get these drugs. Refills cannot be "called in" to your pharmacy. It's best to receive opioids from a single healthcare provider, and to keep all members of your team informed about your use of opioids. If you are using an opioid, check your supply before each appointment so that you can ask your healthcare provider for any prescriptions you need. Be sure to follow the directions carefully.

There are many types of opioids. **Morphine (various brands)** is the opioid that's most often used to manage cancer pain. Others that are commonly used include:

- Hydromorphone (Dilaudid[®] or Exalgo[®])
- Oxycodone (various brands)
- Hydrocodone (Hysingla® or Zohydro ER®)
- Codeine (various brands)
- Fentanyl (various brands)
- Methadone (various brands)

Some opioids are combined with acetaminophen or an NSAID in one pill. For example:

- **Percocet**[®] (a combination of oxycodone and acetaminophen)
- Vicodin[®] or Norco[®] (a combination of hydrocodone and acetaminophen)
- **Vicoprofen**[®] (a combination of hydrocodone and ibuprofen).

The dose of combination medicines must be limited. This is due to the dangers of taking too much of the drug added to the opioid, most often acetaminophen or ibuprofen. Because of this, using single-agent opioids to treat severe pain may work better than combination medicines.

Some people worry about the risk of addiction when using opioids for pain control. People with chronic pain who need prolonged opioid therapy and take these medicines as directed have little-to-no risk of becoming addicted to these drugs. Make sure you understand the instructions for taking your medicine (such as proper dosage and timing) and take only the amount that is prescribed.

Still, there are people who might be at risk for addiction. These people tend to have a current or past history of substance misuse, a family history of addictive disease (alcohol, illegal drugs or prescription drugs) or a history of mental illness. Talk with your healthcare team about whether you're at risk for developing an addictive disease. This does not mean that you can't use opioids to treat your pain, but you may need an addiction specialist on your pain team, and your team may help you more closely monitor your pain medicine use.

Do not confuse tolerance and addiction. Addiction is the physical and/or psychological dependence on a drug. It's linked to cravings, loss of control, and use of a drug even when it's not needed or it's harmful. On the other hand, some people who take opioids for a long time develop tolerance to the drug. This means it stops relieving the pain. Higher doses or a different drug may be needed if your body stops responding to the same dose.

Antidepressants and Antiepileptics. Antidepressants are medicines most often used to treat depression. Antiepileptics are medicines used to help prevent seizures. Both antidepressants and antiepileptics can also be used to manage pain in people with cancer. They are very good for treating nerve or neuropathy-related pain. Taking an antidepressant such as **duloxetine (Cymbalta®)** or antiseizure medication such as **gabapentin (Neurontin®)** to help manage cancer pain does not mean that you are depressed or that you are going to have seizures.

These drugs can be used along with other pain medicines. They are often started at low doses and increased as needed.

Steroids. Steroids are a type of medicine that can relieve pain caused by swelling or inflammation. **Prednisone** and **dexamethasone (various brands)** are often used to manage pain in people with cancer.

Combinations of Medicine. Many times a combination of medicines is needed to control pain. A common combination is a short-acting opioid (one that starts relieving pain right away), along with a sustained-release opioid (one that relieves pain over a longer period of time), and a medicine for neuropathic pain. Your doctor and nurse will work with you to find the right combination of treatments to control your pain.

Other Options to Control Pain. Some other options doctors provide that can help control pain include:

- Nerve blocks—injections of anesthetic into the affected area
- Nerve ablation—destruction or removal of nerve tissue
- Epidural injections—medicine is injected into an area of the spinal cord
- Implanted devices, such as:
 - o Intrathecal pump—a device that delivers pain medication directly into the spinal fluid
 - o Spinal cord stimulation—a device that sends mild electrical currents to the spine
- Surgical procedures, such as:
 - Vertebroplasty—chemical cement is inserted into damaged bone or vertebra through a catheter to add strength and improve stability
 - o Kyphoplasty—a balloon is inserted and then inflated in the vertebra to get it into its normal position before stabilizing the area with chemical cement

Marijuana and Cannabinoids. Marijuana, made from the dried leaves and flowers of the cannabis plant, has been used in herbal remedies for centuries. The biologically active components in marijuana are called "cannabinoids." The two most-studied components are the chemicals delta-9- tetrahydrocannabinol (THC) and cannabidiol (CBD).

In cancer care, medical marijuana is sometimes used to manage side effects, such as nausea, appetite loss, pain or anxiety, if other medications or treatments are unsuccessful. There is limited evidence from studies trying to measure the effectiveness of various cannabisbased medicines for treating cancer pain. There is also concern about adverse side effects. More research is needed to better understand the benefits and risks of marijuana and its cannabinoids.

Under federal law, marijuana (specifically THC) cannot legally be prescribed, possessed or sold. However, under most state laws, the use of marijuana to treat some medical conditions is legal. To get medical marijuana, you will need a recommendation or certification from a licensed provider, verifying that you have a qualifying condition. Each state has its own list of qualifying conditions. You may then need to enroll in your state's medical marijuana program, which may include obtaining a medical marijuana ID card. Once enrolled, you will be able to buy medical marijuana at an approved dispensary. (Some state laws also allow the legal use of recreational marijuana by adults ages 21 and older; no states allow it for children and teens.)

Do not use marijuana or products made with cannabinoids without first talking to your healthcare team. Marijuana or related products (for example, CBD oils) could interfere with other medications. Do not obtain any kind of marijuana anywhere that is not a licensed dispensary. Marijuana products that are not obtained from licensed dispensaries carry additional risks as they may contain unknown ingredients, including infectious agents or more potent (sometimes illegal) drugs. Talk honestly with members of the healthcare team about your use of marijuana or related products.

Peripheral Neuropathy (PN). In addition to the medicines and treatment options listed above, people with PN may benefit from:

- Physical therapy—uses specially designed exercises and equipment to help patients regain or improve their physical condition and stability; this often relieves joint stiffness, strengthens muscles and relieves pain
- Occupational therapy—helps patients overcome challenges completing everyday tasks or activities
- Transcutaneous nerve stimulation ("TENS")—uses mild electric current to activate nerves in order to decrease pain
- Use of safety measures—protecting affected areas where sensation is decreased, such as wearing socks and shoes or using potholders when cooking
- Use of mobility aids—such as a cane, walker or wheelchair

Managing Your Pain Medicines

Your healthcare team should ask about your pain at each visit. You will work together to decide if you need to try a new medicine, change your dose or add other types of therapies to your pain management plan. It may take time for you to find the treatment plan that works best for you. Be sure to talk with your healthcare team about any problems or concerns you have with your pain management plan.

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 drugs, supplements and herbal remedies. Also tell them if you are using marijuana or CBD, or illegal drugs in any form. Sometimes there can be serious interactions. Your healthcare team can provide helpful guidance.

Alcohol is also considered a drug. Alcohol can increase the effects of certain prescription medicines. It can also increase serious side effects when used with certain medications. Cigarette smoking impairs the delivery of oxygen-rich blood to your bones and tissues, leading to increased healing time and fatigue. Cigarette smoke also causes the release of cytokines (proteins produced by certain cells) which increase inflammation and intensify pain. Talk with your healthcare team about these concerns.

If you're using medicines to manage your pain, it's your responsibility to keep all your drugs in a safe place. It's best if they're locked up. These drugs should not be within the reach of children, friends, pets or visitors. They could be stolen if left out in the open. They can be dangerous if taken incorrectly. **Naloxone nasal spray (Narcan®)** may be prescribed for emergency medical treatment to reverse the life-threatening effects of a known or suspected opiate overdose in adults and children.

If the cost of pain medicine is a concern for you, tell your healthcare team. They may be assuming that your health insurance is covering all the costs. If this is not the case, your provider may be able to prescribe less expensive medicines or refer you to sources for financial aid. Please call our Information Specialists for information about additional resources. See *We're Here to Help* on page 11.

Side Effects of Pain Medication

Many pain medicines have side effects. Talk with your healthcare provider right away about any side effects you notice. There are often things you can do to treat and even help prevent them.

Here are some common side effects:

Sleepiness or fatigue (extreme tiredness). Sleepiness or fatigue is most common in the first few days of starting a new medicine or increasing a dose. It usually goes away once your body adjusts to the medicine. If you feel sleepy, do not drive a car or do things that require you to be alert. Tell your healthcare provider if your sleepiness does not go away in about a week.

Constipation. Constipation is a very common side effect of opioids. Stools can be hard to pass and/or bowel

movements may be less frequent. You may feel bloated or gassy. If not treated, constipation can cause a bowel blockage. Drinking plenty of fluids, eating high-fiber foods like fruits and vegetables each day, and exercising or being physically active are all healthy practices. However, they are not sufficient to prevent or treat opioid-induced constipation. Talk to your healthcare provider about using stool softeners and mild laxatives. It's common to take a stool softener every day if you are using opioid pain medicines. Work with your healthcare team to find a plan that works for you. It's important to keep track of your bowel movements and let your healthcare provider know if you are constipated.

Nausea and vomiting. Nausea and vomiting most commonly occur within the first week of starting a new medicine or increasing a dose. These side effects often go away on their own, but medicines that settle your stomach can help. Tell your doctor or nurse if you have nausea or vomiting that keeps you from eating, drinking or taking your medicines. Other things that may help include taking your pain medicine with food or lying very still and doing some slow deep breathing for an hour or so after taking your pain medicine.

Side effects of opioids. Some other side effects of opioids to watch for include itchiness, dry mouth, sneezing, sweating, feeling irritable, dizziness, confusion, memory changes, vision changes and trouble passing urine.

Your healthcare provider will talk with you about the side effects linked to your pain management plan. Be sure you know what to expect, what to do to help with side effects, and when to call your provider.

Visit www.LLS.org/booklets and click on "Filter by Topic" (Side Effect Management) for more information.

Non-Drug Treatments for Pain

While medicines are most commonly used to manage pain, many people with cancer also use non-drug and integrative therapies to find relief. These therapies, especially when used along with pain medicines, can result in better pain relief with fewer side effects. Mind-body practices can help relieve anxiety, sleep disturbances and mood changes commonly associated with pain.

Here are some commonly used therapies:

- Psychosocial interventions, like stress management and counseling
- Physical therapy, exercise, heat/cold therapy

- Meditation, hypnosis, biofeedback, guided imagery, music therapy
- Herbs, special diets, vitamins
- Massage, chiropractic manipulation
- Acupressure—the application of pressure to specific sites on the body
- Acupuncture—very thin needles are placed at specific points in the body by a trained acupuncturist
- Reflexology—the application of pressure to specific points on the feet or hands
- Therapeutic touch and Reiki—types of energy medicine in which a practitioner places their hands just above the body or uses gentle touch to help with healing energy
- Yoga, tai chi and qigong (chi gong)—practices combining movement, stretching, balancing and controlled breathing

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

Visit www.LLS.org/booklets to view *Integrative Medicine and Complementary Therapies* for more information.

Pain Specialists

Most oncologists (specialist doctors who treat cancer) and hematologist-oncologists (specialist doctors who treat blood cancers) are experienced at managing pain. But if your healthcare provider is not able to relieve your pain, ask to see a pain specialist or palliative care specialist. These specialists are trained to manage pain for many different types of illness. They can help you find a pain management plan that works. Pain specialists include:

- Anesthesiologists—doctors who specialize in the use of medicines to prevent pain, often during surgery or a procedure
- Neurologists—doctors who specialize in treating disorders of the brain, spine and nervous system
- Palliative care specialists—doctors who work to improve a patient's quality of life by managing pain and other distressing symptoms of a serious illness
- Physiatrists—doctors who specialize in physical medicine and rehabilitation to help people with physical impairments restore functional ability and quality of life

Make sure the healthcare provider you see is boardcertified in pain management, interventional pain management (uses minimally invasive techniques, such as injections), and/or palliative care. Here are some resources that you can use to find pain specialists near you:

- The clinic or cancer center where you receive treatment and/or the doctor who treats you
- A local hospital or medical center
- A local palliative care team, hospice or pain clinic
- Your insurance company
- Your primary care provider
- People who belong to pain support groups in your area
- The Center to Advance Palliative Care. Visit www.getpalliativecare.org for a list of pain specialists near you

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing relief from the symptoms and stress of illness. It is appropriate at any point, including at the same time as treatment. The goal is to improve quality of life for both the patient and family.

Visit www.LLS.org/booklets to view Palliative Care.

Social Support

Social support helps patients cope with cancer, cancer treatment and side effects. Allowing others to provide encouragement and help with practical needs can be beneficial. Studies have shown that cancer patients with high levels of social support experience less distress and lower levels of pain intensity.

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 help you.

Questions to Ask Your Healthcare Team About Pain

Many concerns about pain can be relieved by understanding the facts about your diagnosis and learning about the help that's available for pain relief. Ask your healthcare team 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.

- Bring someone along to appointments for support and to help listen and take notes.
- Keep a written record of your pain and how well your pain management plan is working. Include a list of medicines you have tried and note why they were stopped and/or the side effects you experienced.

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

- What could be causing my pain?
- What options do you recommend for treating my pain (medicines 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 medicines?
- How should I take my medicine?
 - o Should I take it with food?
 - o Are there any foods or beverages I need to avoid?
 - o What if I miss a dose?
 - o What if I throw up after taking a dose?
- Is it safe to drink alcohol, drive, or operate machinery after I have taken pain medicine?
- Will my pain medicine interfere with other supplements and medicines I'm taking?
- If my pain is not relieved by the amount of pain medicine prescribed, can I take more?
 - o If I can take more, how much should I take?
 - o Should I call you before increasing the dose?
- What can I do to ease or prevent side effects from this medicine?
- Are there certain activities that will be helpful or harmful?
- Are there other specialists who should be part of my pain care team (nurses, physical therapists, social workers, dietitians)?
- Do you recommend any additional 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 team:

- If there are any special instructions, such as stopping a medication like a blood thinner temporarily
- 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 team

Visit http://www.LLS.org/WhatToAsk to view the free LLS printable question guide about pain.

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. Pain management is part of good cancer care.
- Early treatment of pain works better than waiting until it's severe.
- Let your healthcare team know if the pain treatment is working or if it's not working. Ask about other options you can try.
- Increased pain does not mean that the cancer is getting worse, but you should always tell your healthcare team if you have increased pain.
- Bring your pain journal or notebook to office visits to show the impact that pain is having on your quality of life.
- If your healthcare team is unable to treat your pain so you have relief and can function better, ask for a referral to a pain specialist. Be persistent in working with your healthcare team to set up a pain management plan that reduces your suffering and improves your function.
- 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're feeling and coping. Also let them know what they can do to help.
- Pursue activities that will help you relax and distract you from your pain.

Clinical Trials for Blood Cancer

Every new cancer drug goes through a series of carefully controlled research studies before it can become part of standard cancer care. These research studies are called "clinical trials" and they are used to find better ways to care for and treat people who have cancer. In the United States, the FDA requires that all new drugs and other treatments be tested in clinical trials before they can be used. At any given time, there are thousands of cancer clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat cancer.

Researchers use cancer clinical trials to study new ways to

- Treat cancer using
 - o A new drug
 - o A drug that has been approved, but to treat a different kind of cancer
 - o A new combination of drugs
 - o A new way of giving a drug—by mouth, intravenously (IV), etc.
- Manage cancer signs and/or symptoms and ease treatment side effects
- Find and diagnose cancer
- Keep cancer from coming back (recurring) after treatment
- Manage long-term side effects

By taking part in a clinical trial, patients can see doctors who are experts in their disease, gain access to new, cutting-edge therapies, and provide helpful information for future patients. The treatments and information we have today are due in large part to patients being willing to join clinical trials. Anyone interested in being part of a clinical trial should talk to their hematologist-oncologist about whether a clinical trial might be right for them. During this conversation it may help to:

- Have a list of questions to ask about the risks and benefits of each trial. (Visit www.LLS.org/WhatToAsk for lists of suggested questions)
- Ask a family member or friend to go with you when you see your doctor—both for support and to take notes

Clinical trials can be difficult to understand and to navigate, but The Leukemia & Lymphoma Society is here to help. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help find potential clinical trials, overcome the barriers to enrollment and provide support throughout the entire clinical-trial process. Our Clinical Trial Nurse Navigators are registered nurses who are experts in pediatric and adult blood cancers and clinical trials. Your Clinical Trial Nurse Navigator will:

- Talk with you about your treatment goals
- Help you understand the clinical-trial process, including your rights as a patient
- Ask you for details about your diagnosis (such as past treatments, treatment responses, and your cancer genetic profile), your current health, and your medical history, because these might impact whether you can take part in certain clinical trials
- Help you understand how your finances, insurance coverage, support network, and ability and willingness to travel might impact your choice of clinical trials
- Guide and help you in your efforts to find and enroll in a clinical trial, including connecting you with trial sites
- Help deal with any problems you might have as you enroll in a trial
- Support you throughout the clinical-trial process

Please call an LLS Information Specialist at (800) 955-4572 or visit www.LLS.org/CTSC for more information about clinical trials and the Clinical Trial Support Center at LLS.

Also, visit www.LLS.org/booklets to view Understanding Clinical Trials for Blood Cancers.

Feedback

Visit **www.LLS.org/PublicationFeedback** to make suggestions about this booklet.

Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by:

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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 regions throughout the United States and in Canada. To find the region nearest you, visit our website at www.LLS.org/LocalPrograms or contact an Information Specialist at (800) 955-4572.

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

For Help and Information

Consult with an Information Specialist. Information Specialists can assist you through cancer treatment and financial and social challenges, and provide accurate, upto-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: www.LLS.org/InformationSpecialists

Clinical Trials (Research Studies). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Nutrition Consultations. Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients of all cancer types and their caregivers. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit www.LLS.org/nutrition for more information.

Free Information Booklets. LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

Financial Assistance. LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

- Call: (877) 557-2672
- Visit: www.LLS.org/finances

Resources for Families. Blood cancer occurs in a small number of children. Families face new challenges, and the child, parents and siblings may all need support. LLS has many materials for families including a caregiver workbook, children's book series, an emotion flipbook, dry erase calendar, coloring books and a coloring app, a school re-entry program, and other resources. For more information, please

- Call: (800) 955-4572
- Visit: www.LLS.org/FamilyWorkbook

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

3D Models. LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs and lab and imaging tests. Visit www.LLS.org/3D for more information.

Free Mobile Apps.

- LLS Coloring For Kids[™] Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ColoringApp to download for free.
- LLS Health Manager[™] Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit www.LLS.org/SuggestedReading to find out more.

Connecting with Patients, Caregivers and Community Resources

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit www.LLS.org/chat for more information.

Local Programs. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection® Program* (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your region, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/LocalPrograms

Advocacy and Public Policy. Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit www.LLS.org/advocacy for more information.

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to view the directory.

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: www.publichealth.va.gov/exposures/AgentOrange

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program.

People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov and enter "depression" in the search box

Resources

American Chronic Pain Association (ACPA)

www.acpanow.com (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. ACPA also raises awareness among the healthcare community, policy makers and the public at large about issues of living with chronic pain. The ACPA and Stanford Resource Guide to Chronic Pain Management—An Integrated Guide to Medical, Interventional, Behavioral, Pharmacologic and Rehabilitation Therapies is a helpful resource.

CancerCare

www.cancercare.org (800) 813-4673

Cancer*Care* provides free, professional support services including case management, counseling, support groups, educational workshops, publications and financial assistance 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 is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC is a global community of 175 locations providing free, personalized cancer support. CSC administers a toll-free helpline, produces educational and digital resources, conducts research, and advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer.

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 includes the Palliative Care Provider Directory, 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 deciding whether palliative care might be right for you or a loved one.

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Information Specialist: 800.955.4572

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.