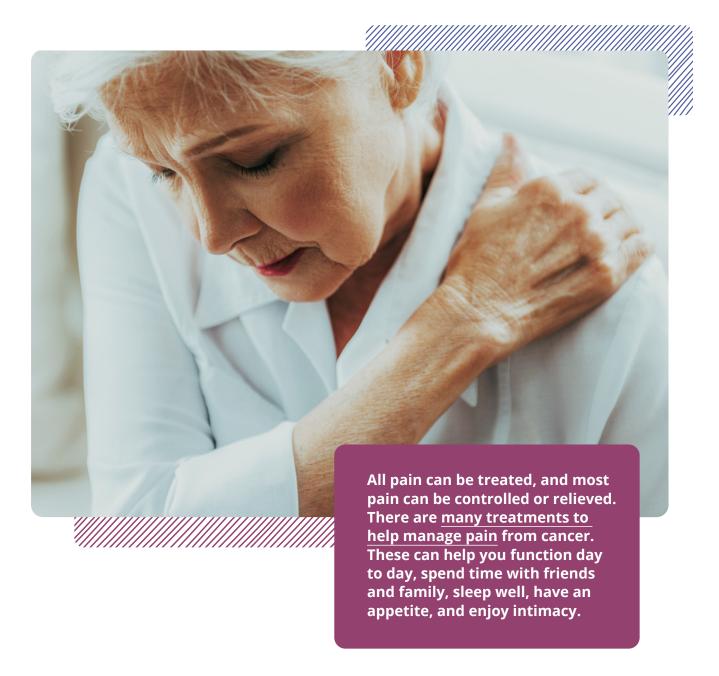


WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with a type of blood cancer. This does not mean you will experience pain, but some people with cancer do have pain at some point. What is pain management and how can it help you?

This fact sheet will help you:

- Learn about pain and blood cancers
- Get an overview of the impact and types of possible pain
- Understand what causes pain with blood cancers
- Find out how to assess and track pain
- Get an overview of treatment options



Pain and blood cancers

Pain is not always part of having cancer. When it is, many treatments are available to help manage the pain.

Pain can be a result of:

- Your cancer
- Your treatment
- Other conditions you have that are unrelated to cancer (such as arthritis)

Each person's pain is unique. It can come and go or be constant. It can vary from mild to severe. Talk to your healthcare provider right away so pain can be treated as soon as it starts, before it becomes severe. There are many options for pain management.

How can pain affect you?

Pain can impact many parts of your life. It can:

- Limit your ability to sleep, work, exercise, and perform regular daily tasks
- Reduce or increase your appetite
- Reduce your desire for intimacy with your partner
- · Slow your recovery from illness or surgery
- Interfere with your body's ability to fight infection
- · Alter your mood by making it easy to feel sad, frustrated, anxious, angry, or depressed

Together, pain and depression can create a cycle that makes both conditions worse. Talk to your healthcare provider if you feel depressed.

Types of pain

There are different types of pain. All have treatment options to help:

Acute pain

Comes on quickly and lasts a short time (up to three months). Acute pain can:

- · Be mild or severe
- Have a known cause (like surgery or an injury)
- Be treated with medication until the affected areas have healed

Chronic pain

Won't go away or comes back often. It often lasts beyond usual healing time or longer than three months. Chronic pain can:

- · Begin suddenly or happen over time
- · Be constant, come and go, or get worse over time
- Be treated with medications that are slowly released into your body over a long time. Taking medication on a schedule can give you a steady level of pain relief
- · Delay healing if left untreated

Breakthrough pain

Is pain that becomes more intense even when you are taking medication on a regular schedule. Breakthrough pain can:

- · Happen suddenly or for a short time, many times a day
- · Occur with chronic pain
- Break through the relief that your regular medications provide
- Be caused by end-of-dose failure (medication is wearing off), be spontaneous and have no known reason, or be triggered by an activity like doing laundry or climbing stairs
- Be treated with short-acting drugs that work quickly

If you experience any type of pain, talk to your healthcare provider right away.

Early treatment is more effective than waiting until the pain is more severe.



When you have cancer, you may experience pain from the cancer, the treatment, or both. You can also have pain caused by other health conditions unrelated to cancer.

How can blood cancers cause pain?

Pain can come from the cancer itself. For example, cancer cells can collect in the bone marrow and form a mass. The mass may press on your spinal cord or joints, causing pain.

Here are some examples from specific blood cancers:

Leukemia or myelodysplastic syndromes

- Can cause bone pain that is often felt in the arms, legs, ribs, and breast
- May cause swelling and joint pain that is often felt in the large joints like the hips and shoulders
- Can cause pain below the ribs on the left side due to an enlarged spleen in people with chronic lymphocytic leukemia (CLL), chronic myeloid leukemia (CML), and hairy cell leukemia (HCL)

Lymphoma

- Often causes swollen lymph nodes in people with Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL)
- Sometimes causes pain in different places in the body, depending on where the abnormal cells are (often in the chest, abdomen, or bones)
- May cause bone pain over time

Myeloma

- · Pain is common
- Back pain is often the first symptom
- Common areas of pain include the back, ribs, arms, legs, hips, and shoulders
- Myeloma cells can build up in the bone marrow and destroy normal bone tissue, causing bones to fracture or small bones in the spine (vertebrae) to collapse: this pain can be an emergency

Myeloproliferative neoplasms

This type of disease has three forms. Each involves a different kind of pain:

- Essential thrombocythemia (ET) often causes headaches, reduced blood flow, and pain in the hands and feet (numbness, tingling, throbbing or burning)
- Polycythemia vera (PV) can cause gout (painful swelling in the joints), ulcers in the stomach, small intestine, and esophagus, and burning or tingling pain on the skin of your arms, legs, hands, or feet
- Myelofibrosis (MF) may cause bone pain and an enlarged spleen may cause pain below the ribs on the left side



How can cancer treatment cause pain?

Some cancer treatments can cause side effects, including pain. Therapies can weaken your immune system, making you more susceptible to developing infections such as shingles. Talk to your healthcare provider right away if you experience pain or any side effects from your treatment. Many medications are available to manage the side effects.

Here are some common treatments that can result in pain:

Chemotherapy

Common side effects of chemotherapy that may cause pain include:

- Mouth sores (ulcers), headaches, and muscle and stomach pains
- Pain, tingling, and numbness in your feet, legs, and hands due to peripheral neuropathy (nerve damage)
- A weaker immune system that puts your body more at risk of viral infections and diseases, such as shingles (painful blisters on the skin when the chickenpox virus reactivates)

Radiation therapy

Common side effects of radiation that cause pain include:

- Dry skin or skin irritation on parts of the body that are exposed to radiation
- Pain, tingling, and numbness in your feet, legs, and hands due to peripheral neuropathy (nerve damage)
- A weaker immune system that puts your body more at risk of viral infections and diseases, such as shingles (painful blisters on the skin when the chickenpox virus reactivates)

Bone marrow biopsy and aspiration

These procedures can be uncomfortable and even painful. You will usually be given medication to reduce discomfort during the procedure. Some people have mild discomfort for a few days following the procedure.

High-dose chemotherapy for stem cell transplantation

A side effect of having a stem cell transplant includes pain from high-dose chemotherapy. It can cause stomach cramping, vomiting, diarrhea and mouth sores. A weaker immune system after a stem cell transplant puts your body more at risk of viral infections and diseases, such as shingles (painful blisters on the skin when the chickenpox virus reactivates).

Assessing and tracking your pain

It's important to let your healthcare provider assess your pain so they can make decisions on the dose and the type of medication that will work best for you. You play the most important role in assessing your pain: only you know how much you can handle. Be direct, honest, specific and as detailed as possible. Here are some tools that can help:

Description

Tool and example

Describing your pain

It can be difficult to find the right words to describe how the pain feels.

Words to help explain your pain:

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

To help your healthcare provider understand whether your pain control plan is working, they will ask you to rate your pain by choosing a number from 0 to 10.

Rate your pain from 0 to 10

0 1 2 3 4 5 6 7 8 9 10 No pain Moderate pain Unbearable

Tracking your pain

Keep a record of your pain on a daily/weekly basis to help your healthcare provider understand and know how to manage it. Keep a record of your medications in a journal or on your computer, noting how they are working and if there are any side effects.

Ask yourself: Where is the pain? What does it feel like? When does it happen? How long does it last? What prevents it?

Sample pain journal:

Date	Time	Describe the pain	Pain level 0 = no pain 10 = worst pai imaginable
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 lay down.	7

Treating pain

Many options are available to help manage pain effectively. The goal is to relieve pain, improve how you function day to day, and get you back to a good quality of life.

Medications and side effects

Almost everyone will find relief from pain by using a combination of medications. They can be taken by mouth or given intravenously (through a vein), rectally, by injection or infusion, or using a topical cream or skin patch.

Most oncologists (doctors who treat cancer) and primary care providers (family physicians or nurse practitioners) are experienced at managing pain. If they are unable to relieve your pain, ask to see a pain specialist.

Here are some examples of pain medication (talk to your healthcare provider for other options):

Acetaminophen and non- steroidal anti-inflammatory drugs (NSAIDs)	like over-the-counter (OTC) medications such as Tylenol, Aspirin, Aleve, and Advil can be effective for treating mild to moderate pain
Opioids	such as morphine are available only with a written prescription (due to the risk of overuse and addiction); they are effective for relieving moderate to severe pain
Antidepressants and antiepileptics	are traditionally used to treat depression and prevent seizures but are also very effective for managing pain in people with cancer
Steroids	like prednisone and dexamethasone can relieve pain caused by swelling

Clinical trials are research studies to investigate new treatments, including developing new and more effective treatments to manage pain. Talk to your healthcare provider to see if a clinical trial is right for you.

Common side effects

If you experience side effects, talk to your healthcare provider right away. They may be caused by your pain medication and there are ways to treat them. The most common side effects of pain medication are:

Fatigue and extreme tiredness	in the first three to four days after starting or increasing the medication; this often goes away when your body adjusts
Constipation	(a change in bowel habits when stools are hard to pass or infrequent) can be prevented by drinking plenty of fluids, exercising, eating fruits and vegetables, and using laxative medications
Nausea and vomiting	in the first three to four days after starting or increasing the medication; this often goes away on its own and can be helped with medication to settle your stomach, eating dry crackers with the medication, or lying still and doing deep breathing

Alternative treatments

Medications are the most common way to manage pain, but many people with cancer also use alternative therapies to find relief. When alternative therapies are used with pain medications, you can often find better pain relief with fewer side effects.

Here are some common examples of alternative therapies:

- Stress management, counselling, and coping mechanisms
- · Physiotherapy, exercise, and heat/cold therapy
- · Meditation, hypnosis, and guided imagery
- · Herbs, special diets, and vitamins
- Massage and chiropractic manipulation
- · Acupuncture, Reiki and therapeutic touch

Talk to your healthcare provider before starting anything new because alternative therapies can change the way your body reacts to medication and may damage your liver or kidneys.

Questions to ask your healthcare team

You are getting a lot of new information, and it can be hard to remember everything. Many of your concerns about pain can be addressed when you understand your diagnosis and learn about pain relief options.

Here are some things you can do to feel in control of your pain management plan and your health:

- Write a list of your questions and concerns. Bring the list with you to your appointment.
- Write down all instructions. If you can, bring a family member or friend with you to appointments (or have them join by phone) to take notes.
- Ask for printed information about your treatment and its side effects.
 If anything is unclear, ask the doctor or nurse to slow down or go over it with you again.
- Share your questions and concerns.

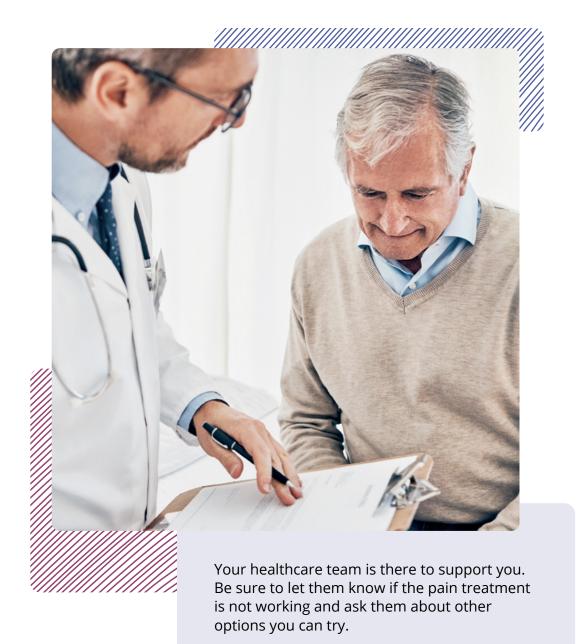
Here are some general questions you may want to ask:

- What could be causing my pain?
- Will certain activities be helpful or harmful?
- Should I see any other specialists to help with my pain, such as a nurse, physiotherapist, or nutritionist?
- Do you recommend any alternative therapies, like acupuncture or massage?
- How do I talk to my friends and family about my pain?

Here are some **questions** you may want to ask about treatment and medication:

- What options do you recommend for treatment (medications and non-drug therapies)?
- How long before the treatment starts to work? How much pain relief can I expect?
- How should I take my medication?
 With food? Do I need to avoid any foods or drinks? What if I miss a dose? What if I throw up after?
- Can I drink alcohol, drive, or operate machinery after I take the medication?

- Will the medication interfere with other supplements and medications I take?
- If it's not working, can I take more?
 Should I call you before increasing the dose?
- How should I store my medication?
- What can I do to prevent side effects?



This fact sheet was reviewed by:

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