Myeloma Canada
InfoGuide Series

Managing Pain and Fatigue

MYELOMA
CANADA
MAKING MYELOMA MATTER

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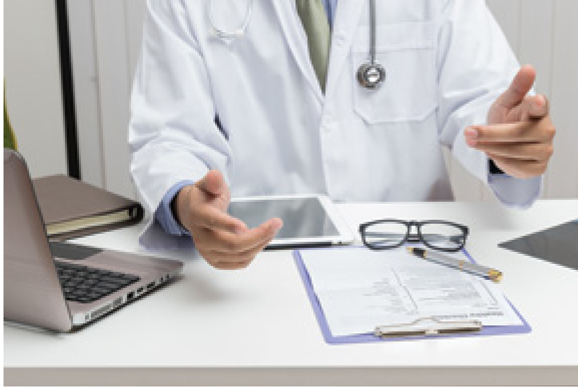

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The information in this InfoGuide is not meant to replace the advice of a medical professional.
They are the best people to ask if you have questions about your specific medical/social situation.

Introduction

If you've been diagnosed with myeloma, you know how challenging it can be to cope with pain and fatigue caused by the disease itself, side effects related to treatment, as well as medical tests or procedures. Pain and fatigue make day-to-day life more difficult. How and what you're feeling isn't always evident to the people around you; they can't understand exactly what you're going through.

This InfoGuide is written for people living with myeloma, their families and friends. It's intended to help you explain, manage and cope with your pain and fatigue.

Not all people living with myeloma experience the same symptoms and response to treatment. Pain and fatigue in myeloma may not be something you can fully control but understanding your symptoms and learning management strategies can be helpful and may have a significant impact on your overall well-being.

In this InfoGuide you'll find information on:

- causes of pain and fatigue in people living with myeloma;
- different types of pain;
- how to identify and describe pain and fatigue;
- ways to manage, treat and improve pain and fatigue symptoms.

Some of the more technical or unusual words appear in ***bold italics*** the first time they're used and are explained in the glossary on page 25. As you read through this InfoGuide, refer to the "More Information" and "Did You Know?" boxes to learn more about selected topics. Moreover, don't be afraid to ask members of your or your loved one's healthcare team to explain any terms you have trouble understanding.

Throughout your journey with myeloma, your healthcare team will provide you with a large amount of information, including how to best manage your pain and fatigue in order to improve your quality of life. Early identification, assessment and the treatment of symptoms is key. Write down your questions and share important information about your pain and fatigue with your healthcare team. They are the best people to help you understand and treat how you're feeling.

Be an informed and cautious information consumer

Be cautious of information that comes your way. While books and the internet offer a wealth of information, not all of it is correct, it may not apply to your unique situation, and it may be confusing or misleading. Well-intended people may also try to offer you health advice without knowing the details of your condition and its treatment. Certain online support groups may also be helpful, but again be wary of possible misinformation. It's important to know that your source is reputable and to discuss what you read with your healthcare team. Never make any change to your treatment plan without checking with them first, whether that be for pain, fatigue, or any other symptom you're experiencing.

Drug Access Navigator

Over the past 15 years, thanks to advances in research, new molecules and targeted therapies to treat myeloma are being developed at an impressive rate, with more options available than ever before. In Canada, access to, and coverage for, these new treatments varies across provinces and territories, making it often confusing and overwhelming to get the information you need.

About Myeloma Canada

Myeloma Canada is a registered non-profit organization created by, and for, people impacted by multiple myeloma. As the only national organization exclusively devoted to the Canadian myeloma community, Myeloma Canada has been making myeloma matter since its founding in 2005.

Working with leading myeloma researchers and clinicians as well as other cancer organizations and local support groups across Canada and internationally, Myeloma Canada seeks to strengthen the voice of the Canadian myeloma community and improve quality of life for those impacted by myeloma through awareness, education, advocacy, fostering an empowered community and supporting clinical research to find a cure.

Myeloma Canada's goals:

- **Increase awareness** of the disease and its effects on the lives of patients and their families
- **Educate** patients, families and caregivers
- **Advocate** for access to new therapies, treatment options and healthcare resources
- **Empower** patients and caregivers through community engagement
- **Advance** clinical research and promote access to new drug trials in Canada

Myeloma Canada educational publications

For more detailed information about myeloma and living with the disease, visit **myeloma.ca** and click on "Resources". From here, you can download Myeloma Canada's educational publications, watch educational videos, find a local support group and so much more.

Whether you're downloading a copy or requesting a printed version, all Myeloma Canada publications are free of charge. To order your printed copies of the materials below, email us at contact@myeloma.ca, or call us toll-free at 1-888-798-5771.

- *Multiple Myeloma Patient Handbook*
- *Multiple Myeloma Caregiver Handbook*
- *High-dose Therapy and Autologous Stem Cell Transplantation InfoGuide*
- *Myeloma Bone Disease InfoGuide*
- *Understanding Your Blood and Blood Tests InfoGuide*
- *Myeloma and the Kidney InfoGuide*
- *Clinical Trials as a Treatment Option InfoGuide*

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About Myeloma

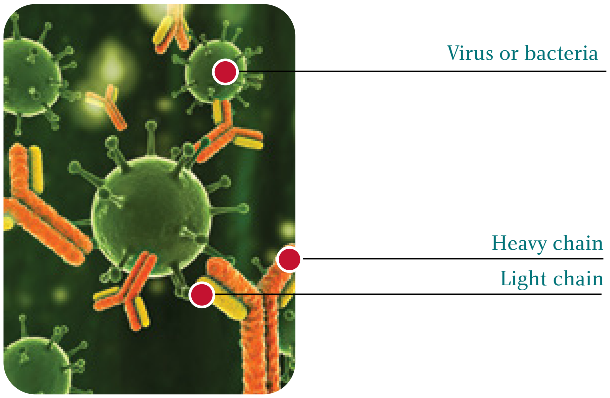
What is Multiple Myeloma?

Myeloma is a cancer that affects plasma cells, a type of ***white blood cell*** that is made in the ***bone marrow*** by "blood-forming" or hematopoietic ***stem cells***. Plasma cells produce ***antibodies (immunoglobulins)*** that fight infection (Figure #1). Plasma cells are therefore an important component of the body's immune system. The production of normal, healthy plasma cells is a controlled process. When plasma cells age or become damaged, they normally die and new plasma cells take their place.

Myeloma is a cancer associated with the abnormal behaviour of plasma cells. In someone with myeloma, this normal process "breaks down", resulting in the uncontrolled growth of abnormal plasma cells, also known as myeloma cells. Myeloma cells can have a negative effect on different parts of the body and interfere with the production of other types of blood cells by "crowding out" the bone marrow. Furthermore, myeloma cells overproduce one type of antibody, known as an ***M-protein*** (also referred to as ***monoclonal protein, paraprotein, myeloma protein or M-spike).*** Due to the overproduction of myeloma cells and M-protein, several related health problems can occur (among others):

- Elevated blood calcium (hypercalcemia)
- Kidney damage
- Low hemoglobin (anemia)
- Bone pain and/or fractures (lytic lesions)
- Frequent or recurring infections
- Fatigue/weakness

Figure #1: Antibodies fighting infection



Immunoglobulins (antibodies) are Y-shaped molecules. The heavy and light chains of the antibody contain specific binding sites that attach to bacteria or viruses, ultimately leading to their destruction thereby protecting against disease.

Pain and Myeloma

What is Pain?

Pain is a sensation that causes discomfort or distress and is often a warning sign that your body is dealing with an injury or illness. Most pain resolves when the cause or source of the pain is eliminated or when the body has healed. However, sometimes pain persists even after healing. Everybody experiences pain differently so response to pain also varies from person-to-person.

When left untreated, pain can lead to a cycle of increased pain, fatigue and anxiety. Chronic pain that persists for a long period of time can cause frustration, anxiety, anger, fear, poor concentration, sleep deprivation and fatigue. In turn, these can aggravate the pain itself, affect your overall well-being, how you cope with pain, as well as your ability to manage the disease.

Pain can be more than just physical hurting; it can play a significant role in how you deal with other symptoms and complications of myeloma, and in your overall quality of life. For some people living with myeloma, pain can be debilitating and impact them physically, emotionally and socially.

Most pain in myeloma can be managed, and you can play an active role in trying to control it. Understanding what type of pain you have, its patterns and its causes can help you reduce or prevent it. Communicating this information to your healthcare team will enable them to determine the most effective treatment for your specific myeloma-related pain.

More Information

How is pain sensed by the body? A pain stimulus is picked up by pain receptors on nerve endings at the affected area of the body and a signal is transmitted to the brain. The brain gathers the information and responds by telling your body to protect itself. While pain is most commonly linked to physical sensations caused by an illness, inflammation, injury or surgery, it can also be linked to psychological factors influenced by memories and emotions.

Did You Know?

Mild and acute pain is easier to control. Treating your pain before it gets worse (or unbearable) can help you avoid:

- waiting longer than necessary for your pain medication to take affect and for you to feel better;
- taking larger doses of medication to control your pain.

If your pain gets worse or returns before the next dose, speak to your doctor about potentially adjusting the dose of your pain medication(s).

Causes of Pain in Myeloma

Pain in myeloma can be due to the effects of the myeloma itself, side effects related to treatment, as well as medical tests or procedures. The most common causes of pain in someone with myeloma are usually due to weakened or fractured bones, ***peripheral neuropathy, plasmacytoma,*** and infection. Each may cause different degrees of pain.

Pain can also be a sign of other disease- and treatment-related side effects or even disease progression. It's very important to discuss any new or persistent pain with your healthcare team as quickly as possible.

Types of Pain

Pain can be categorized as either **acute, chronic** or **breakthrough:**

- **Acute pain** comes on quickly, can be mild to severe, lasts for a relatively short time, and is resolved after the injury heals. Examples of acute pain are a stubbed toe, a cut finger, pain from a needle or surgery.
- **Chronic pain** can be mild to severe and is either constant or repeatedly comes back over the course of months or years. Due to its long-term persistent nature, chronic pain can also be very difficult from a physical and emotional point of view. Examples of chronic pain are ***arthritis*** and back pain.
- **Breakthrough pain** is an abrupt, sharp spike of pain that "overrides" chronic pain and can last for a few minutes or hours. Breakthrough pain can be a sign that the body is developing a resistance to pain-relief medications or that the underlying cause of the pain may be getting worse. Breakthrough pain can also occur when someone does more (or different) physical activity than usual.

Pain can also be classified based on its location in the body:

- **Somatic, soft tissue, or musculoskeletal pain** is felt as a dull ache in your joints, muscles or bone.
- **Visceral pain** is felt in the organs, is often difficult to describe or pinpoint, and may feel like internal pressure or squeezing.
- **Neuropathic or nerve pain** is felt as sharp, burning, tingling or shooting, and is caused by damage to, or pressure on, your nerves. You may feel this pain after surgery, ***radiotherapy (radiation therapy)*** or ***chemotherapy.*** This type of pain can also be the result of the myeloma itself, chronic illness (e.g., diabetes) or, in some cases, without a known cause (know as **idiopathic neuropathy**). For information about ***peripheral neuropathy***, a type of neuropathic pain, see page 6.

Other non-specific symptoms that can be associated with pain include ***nausea,*** headaches, dizziness, shortness of breath, weakness, drowsiness, increased sweating, constipation and diarrhea. Be sure to discuss these symptoms with your healthcare team to see if they're related to your myeloma or its treatment.

More Information

Relieving constipation and diarrhea

The symptoms of constipation can be relieved by drinking plenty of fluids (i.e., 6-8 glasses of water per day) and eating foods that are high in fibre (fibre absorbs water and makes stools softer and easier to eliminate). Regular exercise can also help keep your bowels active. If constipation continues to be a problem, speak to your nurse or pharmacist about using a gentle laxative.

Conversely, diarrhea can become problematic for some myeloma patients but this is usually mild and manageable. If you're experiencing diarrhea, alert your healthcare team. Try to avoid dehydration by maintaining good fluid intake. Your healthcare team will determine if the diarrhea is being caused by medication or by an infection and will recommend the appropriate treatment (e.g., cholestyramine [Questran, Olestyr] for diarrhea caused by lenalidomide treatment).

Bone Pain

Bone pain is the most common cause of pain in people with myeloma. In a healthy person, cells called ***osteoclasts*** work to break down old bone, while cells called ***osteoblasts*** work to form new replacement bone. Together, these cells continually rebuild bones to keep them strong in a roughly equal rate of bone destruction and formation. This rate is skewed in myeloma because myeloma cells in the bone marrow cause the surrounding bone to be broken down faster than it can be formed or repaired. This can lead to bone thinning ***(osteopenia),*** disappearance of pockets of bone ***(lytic lesions)***, and higher than normal calcium levels in the blood ***(hypercalcemia)***.

Potential causes of bone pain in myeloma include:

- **Bone lesions** – soft spots that develop in locations where the bone has been damaged (most often on the spine, pelvis, or ribs). Bone lesions can lead to bone fractures and are the most common cause of pain in people with myeloma;
- **Bone fractures** – these occur when a weak bone cracks or breaks;
- ***Vertebral (spinal bone) fracture,* collapse, compression and/or thinning** – these are often the cause of persistent, severe pain;
- **Kyphosis (curve in the back)** – caused by vertebral collapse and frequently leads to chronic back pain and mobility problems;
- **Plasmacytoma** – depending on its location, can cause dull, aching pain as it grows. It may destroy bone and press on its surroundings (e.g., bones, nerves or organs). Removing or shrinking a plasmacytoma, usually with radiotherapy and/or chemotherapy, can help relieve this pain.

Listen to your body and call your doctor immediately if you have any worsening pain or severe new pain. Although not all pain may be necessarily related to myeloma (e.g., degenerative or chronic back problems), the goal is to find the cause of the pain and to treat it as quickly as possible. To learn more about bone complications, download or order Myeloma Canada's *Myeloma Bone Disease InfoGuide*.

What does pain caused by bone disease feel like?

- **Osteopenia and lytic lesions** can cause a dull pain that may spread over a generalized area or may be sharp and localized. Pain from bone lesions may be worse with movement. Some people may find this type of pain feels worse at night because it's more noticeable when trying to rest/sleep (but it's not actually worse). In contrast, some people will find the pain less noticeable when resting.
- **Bone fractures** often lead to persistent severe pain that may be localized or radiate around the injury. If you experience a new, severe pain, it may be a sign of a broken bone or fracture.
- **Vertebral fractures,** depending on their location, these can cause pressure on nerve roots and result in sharp shooting pain or numbness in the limbs. This may feel like a dull achy pain, an acute sharp localized pain that radiates to or around the ribs and abdomen, or a shooting pain that migrates up and down the leg. Vertebral fractures can also be associated with plasmacytomas (soft tissue) and may cause spinal cord compression. Depending on the location of the spinal cord compression, the related pain can be felt anywhere; pressure on the spinal cord can sometimes lead to ***incontinence.***
- **Kyphosis** may cause pain to radiate to other areas of the body (e.g., rib pressure leading to chest pain).

Peripheral Neuropathy

Peripheral neuropathy may be experienced as numbness, tingling, increased or decreased sensitivity or pain in your body's extremities (i.e., hands, feet, arms or legs). The symptoms of peripheral neuropathy can vary and will depend on which nerves are affected – the hands and feet are the areas most commonly affected in myeloma.

Potential causes of peripheral neuropathy in myeloma include:

- deposition of M-protein on the nerves causing nerve damage;
- myeloma treatments, such as thalidomide (Thalidomid - not routinely used in Canada) and bortezomib (Velcade) can be toxic to nerve cells even when given at standard doses and/or for a prolonged time;
- factors that aren't related to myeloma such as diabetes, vitamin deficiency and a history of high alcohol consumption.

The symptoms of peripheral neuropathy often start out mild but can increase and become more serious over time. They tend to travel up the arms and legs. If you develop any new pain or sensation, speak to your doctor or nurse immediately.

Did You Know?

Vitamin B12 deficiency can increase your risk of developing peripheral neuropathy. Speak to your doctor about whether you should have your vitamin B12 level tested.

What does pain caused by peripheral neuropathy feel like?

- Pain that varies in intensity and is often described as "sharp", "burning" or "jabbing";
- Tingling sensations that start in one place and travel through your limbs (e.g., pins and needles in the hands, arms, feet and legs);
- Increased sensitivity to touch (e.g., the slightest touch can cause extreme discomfort);
- Altered sensations (e.g., feeling of pain or cold when touching something hot);
- Loss of sensation or numbness (e.g., in the hands or feet);
- Muscle cramps, weakness and tremors.

Infection

Infection is a complication of myeloma that can lead to pain. People with myeloma have an increased risk of infection because the disease may cause a lower than normal number of white blood cells ***(leukopenia).*** Other potential causes of infection in myeloma include:

- **Neutropenia:** A low ***neutrophil*** blood count puts you at greater risk of infection because neutrophils help your body fight infections.
- ***Immunosuppression*** **due to myeloma treatments:** Drugs used to treat myeloma such as bortezomib (Velcade) and lenalidomide (Revlimid), etc. can reduce your neutrophils and also suppress your immune system.
- ***Central line (central venous catheter):*** Catheters can become infected and, if left untreated, lead to even more serious infections and complications. If you notice any redness or swelling around your catheter or are experiencing tenderness or pain, inform your doctor or nurse immediately.

Pain associated with infection may vary depending on the site of infection. Some commonly occurring infections, and the pain associated with them, are:

- **lung infections,** such as pneumonia can cause sharp chest pain, usually on one side, that's worse when you breathe or cough;
- **urinary tract infections** can cause a burning or stinging sensation while urinating and can sometimes be accompanied by lower back pain;
- **skin infections** such as shingles (caused by the chickenpox [varicella-zoster] virus) can cause a painful and sensitive rash. The pain may be intermittent, sharp or stabbing and, in the case of shingles, may continue up to a year or longer after the rash has disappeared ***(post-herpetic neuralgia).*** Early detection and treatment can minimize pain caused by shingles, which can cause nerve damage. People with myeloma are at an increased risk of shingles whether on treatment or not;
- **mouth infections** such as ***oral thrush*** can cause painful (i.e., burning) mouth ulcers and sores in the inner cheek, inner lip, tongue, gumline and floor of the mouth. Mouth infections may also cause difficulty swallowing;
- ***gastrointestinal*** **infections** caused by bacteria (e.g., E. coli, salmonella), viruses (e.g., rotavirus), and parasites (e.g., giardia) can cause abdominal pains and spasms, diarrhea and vomiting.

Note: It is also possible to have an infection without experiencing pain.

You may be prescribed ***prophylactic*** antibacterial and antiviral medications to prevent infections. Your doctor may also recommend the flu vaccine. Speak to your doctor before having "live" vaccines (i.e., measles, mumps, and rubella) because they may not be safe for you.

Thrombosis (Formation of blood clots)

Thrombosis, both arterial and venous thromboembolism (known as ATE and VTE, respectively), is a complication of myeloma and its treatment that can cause pain. VTE is the formation of a blood clot within a vein – most commonly in the veins of the legs – known as a deep vein thrombosis (DVT). Thrombosis can also be catheter-associated.

Several other factors can contribute to the risk of thrombosis in myeloma including older age, presence of other conditions (i.e., high amounts of lipids [fat] in the blood, high blood pressure, diabetes), and lack of mobility. The use of immunomodulatory drugs (thalidomide, lenalidomide, pomalidomide [Pomalyst]) in combination with dexamethasone also increases the risk of VTE. When on immunomodulatory drugs, you may be prescribed prophylactic medications (e.g., aspirin, warfarin or low molecular weight heparin).

The most common symptoms of a DVT include leg pain, swelling, cramps, redness and/or warmth and heaviness in the arms and/or legs. Part of a clot can sometimes break away and travel to the lungs – known as a pulmonary embolism (PE). The most common symptoms of PE include sudden breathlessness, chest pain, and anxiety. PE is a medical emergency that requires urgent medical treatment.

Myeloma Treatments and Procedures

People with myeloma undergo many treatments, tests, investigations and procedures to manage their disease. Some treatments that kill myeloma cells can also damage normal healthy cells, causing unpleasant side effects that are associated with pain. Additionally, some procedures that are carried out during diagnosis, monitoring and after treatment can also be painful. Most side effects are short-term, and if managed well, usually resolve once the procedures are finished.

Potential causes of pain from myeloma treatments and procedures may include:

- **Blood tests and injections** – This is felt as a momentary sharp sensation as a needle is placed into the vein. If it's difficult to find a vein, several attempts may be needed to obtain a blood sample, which may increase your chances of feeling discomfort, pain and/or bruising.
  - To learn more about your blood and blood tests, download or order Myeloma Canada's *Understanding Your Blood and Blood Tests InfoGuide*.
- **Central line** – The placement of a central line can cause discomfort or pain. The line is usually placed prior to ***high-dose therapy and autologous stem cell transplantation*** because it allows all treatment (i.e., ***intravenous*** infusions) to be given without the need for repeated needle insertions.
  - To learn more about high-dose therapy and autologous stem cell transplantation, download or order Myeloma Canada's *High-dose Therapy and Autologous Stem Cell Transplantation InfoGuide*.
- **Chemotherapy drugs** such as cyclophosphamide (Cytoxan) and melphalan (Alkeran) can cause dosing-related side effects such as nausea and vomiting, etc. High doses of melphalan, given as part of high-dose therapy and autologous stem cell transplantation, can also cause the inside of your mouth to blister ***(mucositis)*** and increase your risk of getting mouth infections. A sore mouth and throat may make eating, drinking and swallowing more difficult. You may need intravenous fluids and/or nutrition until you're able to resume eating and drinking normally.

- **Intravenous *infusion reactions* – *Immunotherapy*** treatments that are given intravenously (e.g., carfilzomib [Kyprolis], daratumumab [Darzalex], etc.) can cause infusion reactions. Prior to and immediately following immunotherapy infusions, you'll be given drugs to prevent or reduce infusion reactions.
- **Radiotherapy** is often used to kill myeloma cells and to relieve pain in localized areas where there is damage caused by myeloma bone disease. Although it's generally a painless procedure, it may cause some mild side effects, as well as pain and skin sensitivity depending on the area of the body that's treated. Some people will experience a temporary increase in pain due to local, treatment-related inflammation before feeling relief.
- **Bone marrow biopsy** tests can cause pain. The procedure may involve the removal of some liquid bone marrow by suction into a syringe (aspiration) and/or the removal of a piece/core of bone marrow tissue (biopsy). Bone marrow samples are usually taken from the back pelvic bone. Less commonly, other large bones such as the breastbone may be used.

Talking About and Assessing Pain

Assessing Pain

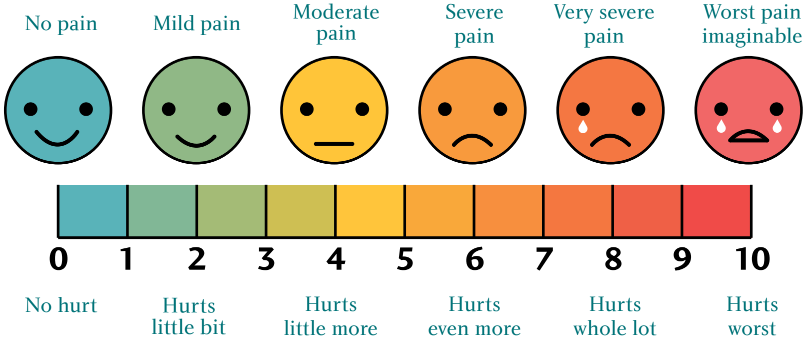
Your healthcare team will try to understand exactly where your pain is occurring, what could be causing it, and prescribe the most appropriate solution. That's why it's important to explain the pain you have in detail, and to be honest about your level of pain. Some doctors or nurses will ask you to use a pain rating scale (Figure #2) or body diagram to help them better understand and evaluate your pain.

The evaluation process may include:

- **Questions about your pain**
    - Where do you feel the pain and how long does it last?
    - When did the pain start, what were you doing and what might have caused it?
    - What does the pain feel like and is it better/worse during the day/night? Use descriptive words such as dull, sharp, aching, throbbing, shooting, burning, stabbing, pulling, or tingling.
    - How strong is the pain from 0 to 10 (0 = no pain) and is it constant?
    - Does anything make it better/worse (i.e., lying down, standing, heat/ice)?
    - How does the pain affect your daily life (i.e., trouble eating or sleeping)?
- **Physical exam** to check your body for signs of any changes:
    - Do you have other pain that may not be related to myeloma?
- **Neurological exam** to check brain, spine, nerves and muscle function;
- **Blood and urine tests**;
- **Imaging tests** such as X-rays, magnetic resonance imaging (MRI) scans, positron emission tomography (PET), or computed tomography (CT) scans of your bones to look for weaknesses, fractures, plasmacytoma or bone lesions that may be pinching nerves or compressing your spine;
- **Questions about your history with pain medications:**
    - What medications have you taken for pain and how well have they worked?
    - Does the pain come back before taking the next dose?
    - Did you experience side effects from the pain medication? If yes, how did you handle those side effects?

- **Questions about current medications, supplements and habits:**
  - Non-prescription medications, vitamins, minerals, and herbs;
  - Previous prescription drug use;
  - Recreational drugs, alcohol and tobacco;
- **Questions about the emotional and psychological impact of your pain:**
  - Do you feel anxious, scared or angry?
  - How often do you feel down or depressed?
  - Do you feel like you have enough support from family and friends?

Figure #2: Pain Rating Scale



Once the cause of your pain is determined, your healthcare team can work with you to find ways to manage it. Not all pain treatments will work the same for everyone and it's often only through a trial-and-error approach that your doctor will find the best pain relief for you. A solution can sometimes be found very quickly (days). Sometimes, it takes a bit longer (weeks or even months), but try to remain hopeful and continue working with your healthcare team until you get the relief you need.

Tracking Pain

Keeping track of your pain, medications and side effects in a journal or with electronic or online tools can help you better understand what makes the pain better and worse.

Treating and Managing Pain

Treating and managing your pain is an important part of your overall treatment plan. It can help you cope better with daily life, as well as with your myeloma treatments. In fact, just treating the myeloma itself can reduce your pain and improve your overall well-being and quality of life. If your myeloma shows a response to treatment but your pain doesn't go away, the goal of pain treatment is to achieve continuous relief, whenever possible, with minimal side effects. Pain control must be tailored specifically to each person and the treatment plan must be reviewed on a regular basis.

There are various pain relief treatment options available. Some people use pain medications, while others find relief with complementary therapies (e.g., acupuncture), or sometimes a combination of both. Your healthcare team will work with you to find the best combination of personalized care to help control your pain so you can return to your daily activities.

Below are some of the most commonly used treatments for myeloma pain management.

Pain Medication

Many types of pain medication are available to treat different types and levels of pain. Depending on the type of pain you're experiencing, you may be prescribed a number of different types or combinations of pain medications, usually starting with a low-dose first and increasing to an optimum dose before a different type of medication is given. When your doctor prescribes a new pain management plan, ask about timing and potential side effects so that you know what to expect. Your oncology pharmacist is also an excellent resource to help you better understand and manage side effects to medications.

Pain medications can treat mild, moderate, or severe pain, and may come in many forms: pills, capsules, liquids, patches, sprays or injections.

Examples of commonly used ***over-the-counter (OTC) medications*** for mild to moderate pain include:

- ***Non-steroidal anti-inflammatory drugs (NSAIDs)*** such as ibuprofen (e.g., Advil, Motrin), acetylsalicylic acid (e.g., Aspirin), naproxen (e.g., Aleve) and diclofenac (e.g., Voltaren). NSAIDs can reduce inflammation (swelling) but may also cause side effects:
  - can worsen kidney damage;
  - can affect the way your blood clots and cause complications during chemotherapy or surgery.

  Speak to your healthcare team before using NSAIDs.
- **Simple analgesics** such as acetaminophen (e.g., Tylenol, Atasol).

Examples of commonly used ***prescription medications / opioids (narcotics)*** for moderate to severe pain:

- **Weak opioids** such as codeine and low-dose buprenorphine;
- **Strong opioids** such as morphine, methadone, oxycodone, hydromorphone, fentanyl, and high-dose buprenorphine;
- **Combined opioids and non-opioids:**
  - Codeine and acetaminophen (e.g., Tylenol 1, 2 and 3)
  - Codeine and acetylsalicylic acid
  - Oxycodone and acetaminophen (e.g., Percocet)
  - Oxycodone and acetylsalicylic acid (e.g., Percodan)

Side effects of opioids

Some opioids can worsen kidney damage and thus are generally not prescribed to people with myeloma. Speak to your doctor if you have any concerns that your pain medications may have an adverse effect on your kidneys. Other possible side effects of opioids include:

- **drowsiness, confusion and sleepiness:**
    - may go away once you get used to the dose;
    - sleepiness may occur because your body is tired from being in pain and wants to rest once the pain is controlled.
- **nausea, vomiting and upset stomach:**
    - usually happens during the first week of opioids and can go away with time;
- **constipation:**
    - the amount of fluids you drink, your diet, and your level of physical activity can make a difference;
- **dry mouth:**
    - the amount of saliva your body produces can be reduced by opioids;
- **itching** all over the body or only the chest, neck and face;
- **muscle jerks or twitching:**
    - often happens with higher doses of opioids before falling asleep.

If the above side effects are affecting your quality of life, talk to your healthcare team about other possible medications (e.g., anti-nausea, laxatives) or tips and tricks that may help (e.g., humidifier for dry mouth). A reduced dose or a different opioid may work the same, or even better, with less side effects.

Bone Protectors

Treatment with bone protectors is recommended for most people with myeloma. These drugs help protect and strengthen bones in order to prevent or minimize hypercalcemia and bone damage, help reduce the likelihood of ***pathological fractures,*** and may help relieve bone pain and therefore reduce the need for pain medication.

Bone protectors that are most commonly used in myeloma:

- ***Bisphosphonates*** such as clodronate (Bonefos), pamidronate (Aredia), zoledronic acid (Aclasta, Zometa);
- ***RANK ligand inhibitors*** such as denosumab (Prolia, Xgeva).

More Information

Bisphosphonates and dental health

Osteonecrosis of the jaw (ONJ) is a rare side effect of long-term bisphosphonate use that causes the death (necrosis) of the jawbone. ONJ can occur spontaneously but appears to be more likely following particularly traumatic dental work such as extractions. The risk of ONJ appears to be higher among those taking zoledronic acid, compared to pamidronate.

Before starting any therapy, have a complete dental examination. Ask your dentist to speak with your doctor about any special precautions you may require, especially when receiving treatment. It's also a good idea to check if your cancer centre has a dental clinic.

Corticosteroids

Corticosteroids (e.g., dexamethasone, prednisone) can reduce bone pain by reducing inflammation.

Radiotherapy (Radiation Therapy)

Targeted radiotherapy can be helpful for treating localized bone pain and spinal cord compression. Your doctor may treat you with radiotherapy to shrink a plasmacytoma, reduce pain, and help you move more freely and comfortably. Early radiotherapy treatments can help prevent permanent damage to the spinal cord.

Surgery

Your doctor may recommend surgery to stabilize the bones in your back. ***Vertebroplasty*** and ***kyphoplasty*** are surgical procedures that treat vertebral fractures, relieve back pain, and strengthen the spine. These procedures are not suitable for all people and various factors must be considered: location of the pain, type of vertebral fracture, time elapsed since the fracture, as well as white blood cell and ***platelet*** counts.

Nerve Stabilizing Drugs

Nerves carry messages of pain to the brain. Nerve stabilizing drugs, antiepileptic drugs, or low-dose antidepressant drugs can alter or stop these messages. Examples of these types of medications may include gabapentin (Neurontin), amitriptyline (Elavil), pregabalin (Lyrica) and/or duloxetine (Cymbalta).

Non-medical Treatments

Some common non-medical strategies used to help treat or relieve pain:

- **Electrotherapy** with ***transcutaneous electrical nerve stimulator (TENS)*** machines deliver small electrical pulses that stimulate the release of the body's natural pain-killers (endorphins). Speak to your cancer centre's physiotherapist about treatment with a TENS machine.
- **Massage therapy** can ease muscle tension and help relax the body. It's very important to tell the massage therapist that a forceful massage could damage your bones or cause bruising.
- **Acupuncture** applies pressure to points along the body that are believed to restore balance, health, and relieve pain. People living with myeloma are at increased risk of infection and should consult their doctor before undergoing acupuncture.

You can also try some of the following at home to control your pain:

- Back or neck brace, heating pads, cold packs;
- Meditation, visualization, ***guided imagery*** and/or ***aromatherapy;***
- Distraction by talking to friends, laughing, listening to music/podcast or watching television;
- Stretching and relaxation exercises (i.e., tai chi, yoga, qigong);
- Muscle strengthening exercises;
- Correct postural positioning;
- Lifestyle changes regarding nutrition, exercise, and exercise habits.

Always ask your doctor, nurse or other members of your healthcare team about the possible risks and benefits of any non-medical therapies you are considering.

More Information

Exercising safely

Check with your cancer centre if there are exercise programs or classes offered for people living with cancer/myeloma. Exercise can provide many health benefits but it's important to stop exercising if you feel unwell or if your pain starts or gets worse while exercising.

Take special precautions if the following situations apply to you:

- **Neutropenia:** Your risk of infection is increased. Avoid activities such as swimming in a lake or heated public pool, gardening and large gym classes.
- **Low platelets:** Your risk of bruising and bleeding is increased.
- **Anemia:** Overexertion is not recommended because your body's capacity to carry oxygen is less and can lead to shortness of breath, increased heart rate and fatigue.
- **Peripheral neuropathy:** Can cause dizziness and affect balance and blood pressure. Start exercising slowly, avoid holding your breath, and stand, lie or sit slowly.
- **Blood clot(s):** Speak to your doctor before resuming or starting an exercise routine. Factors such as your physical condition before the clot(s), as well as the severity and location of the clot(s) must be taken into consideration.

Try to build up your exercise routine gradually by doing a little bit, often. Set realistic goals and don't be disheartened if you have a tough day – try to stay consistent.

Cannabinoids and/or Medical Cannabis (Marijuana)

It's important to talk to your healthcare team about the risks and benefits of using ***cannabinoids*** and/or medical cannabis products, before starting. Some people use cannabinoids in addition to traditional pain medications to help reduce or eliminate the amount of prescription pain medications they take. Cannabinoids and/or medical cannabis may not work for everyone.

Although recreational cannabis is legal in Canada, cannabis for medical purposes (i.e., nausea, vomiting, loss of appetite, sleep and chronic pain relief, etc.) should be prescribed and used under the direction of a healthcare provider, and obtained from a licensed producer. Self-medicating with recreational cannabis is not a safe alternative for medical cannabis. More research is needed to find out the risks and benefits of long-term medical cannabis use, as well as how it might interact with chemotherapy and other treatments for myeloma.

Cannabis is the flower that comes from the cannabis plant and contains hundreds of unique chemical components such as cannabinoids and ***terpenes.*** The two best-studied cannabinoids in cannabis are tetrahydrocannabinol (THC - causes ***psychoactive effects*** commonly known as a "high") and cannabidiol (CBD - does not cause a "high"). THC, CBD, other cannabinoids, and terpenes in the plant are thought to work together to create a therapeutic effect called the ***"entourage effect"***.

Cannabis can also cause side effects that affect memory, concentration and balance, as well as dry mouth, slow reaction times, rapid heartbeat and a rise in blood pressure. Cannabis may also negatively interact with other medications and/or alcohol and even cause additive sensations of ***euphoria*** or sedation.

Depending on where you live, cannabis and cannabinoid products (e.g., THC only, CBD only or THC/CBD combinations) may be available in various forms such as dried flower, oil, capsules, tinctures, edibles and sprays that can be either synthetic or plant-extracted:

- Nabiximols (Sativex) is a spray that combines plant-extracted THC and CBD (Epidiolex);
- Nabilone (Cesamet) is a synthetic version of THC that comes in capsule form.

Cannabis can be vaporized (dried flower), ingested orally (oil, capsules, tinctures, edibles, sprays), or burned/smoked (least preferable method of consumption).

- Vaporizing cannabis is a safer alternative to smoking because it reduces your exposure to harmful compounds created by burning the flower. Vaporizing is also more cost-effective (uses less flower) and provides the same therapeutic effects as smoking larger quantities.
- When cannabis is inhaled (vaporizing/smoking), the effects are generally felt within a few minutes and can last for several (2-4) hours.
- The effects of orally ingested cannabis can take 6-8 hours or longer to be felt however, the effects tend to be longer lasting compared to inhalation. Caution should be exercised prior to consuming a second dose.

The effects felt and dosing of cannabis varies. A "low and slow" medically supervised and guided ***titration*** approach (with dose logging) is recommended to establish an optimal dose that provides maximum benefit with minimal side effects. This approach to stabilizing your medical cannabis regimen can take 2 months or longer and in most cases, symptom relief can be achieved without feeling "high".

If your medical cannabis regimen is providing you with relief, you may feel eager to reduce/taper or stop taking your other pain medications; it's important to consult your healthcare team prior to doing so. Some medications must be reduced/stopped under medical supervision, one at a time, to ensure that any new side effects experienced can be attributed either to the cannabis or to the reduction of the other medications.

Common Concerns About Taking Pain Medications

You may be concerned about taking pain medications and/or about how much you're taking. Common worries may include:

- **Becoming addicted:** Addiction has a psychological component to it – it's more than just relieving physical pain – it's a craving/need or impulse for the drug. Your healthcare team will monitor you closely to make sure your pain is controlled.
- **Medications are "too strong" or will get me "high":** You may worry that you won't know "what's going on" when you're on medications for pain. When taken as prescribed, people don't get a "high" or lose control. You may feel confused or drowsy at first, but this usually goes away within a few days. Doctors commonly start you on low doses and weaker medications. Their goal is to control the pain with the fewest side effects. If your pain isn't being managed, your doctor will suggest higher doses or stronger medications. If you're not "feeling right" on the medication, let your healthcare team know they may be able to recommend or prescribe an alternative option.
- **Getting "used to" the medications or having withdrawal symptoms:** The body can build a tolerance for drugs taken for a long time and you may need higher doses to achieve pain relief. Your doctor can adjust your dose or prescribe a different type of pain medication. If you're ready to stop taking pain medications, your doctor will slowly lower the dose so that your body can adapt.

Living with Pain

Reducing and managing pain can involve a combination of pain medications, complementary therapies, support from your healthcare team, as well as emotional support from family, friends and members of a patient support group. Family, friends and support group members can also help out with practical tasks like house or yard work, chores such as cooking or taking care of children or pets, and keeping track of the medications you're taking and their doses.

Asking for help can feel awkward or uncomfortable, but you may be surprised to discover that many people are happy to pitch in. Start by asking for a small request, such as help preparing a meal or running a short errand, and build from there. If someone seems ready to make a bigger commitment, make a list of your current needs, discuss the list with the helper, and decide on what tasks they can take on.

If you're having trouble with your mobility, consider making small changes to your home. Your healthcare team may be able to recommend custom aids that can be fitted for you (e.g., bath or shower seat) and that will make everyday living easier. Government programs may also offer services that can help, free of charge. Check your hospital or cancer centre for information pamphlets or guides on these services.

Treatments for pain management work best when you follow your healthcare team's directions and keep them posted on how your pain responds. If the treatment is not controlling the pain, talk to your doctor or nurse about revising your pain management plan, and always remember:

- **Don't be afraid to ask** your healthcare team questions about anything that might not be clear to you (i.e., dosing schedule, what your pain means).
- **Prepare a list** of all the medications and supplements you're taking so that your healthcare team can evaluate if they're compatible with your pain medication.
- **Tell your healthcare team** about any and all side effects experienced before you stop taking medications, there might be ways to manage the side effects. Some of the medications you're on may cause even more side effects if they're not slowly reduced before stopping.
- **Never make any additions or changes** to your regimen (e.g., cannabis, herbal remedies and supplements), without discussing it first with your healthcare team.
- **Try to get enough sleep** and, if possible and with the consent of your doctor, continue your routine exercise or add some daily exercise.
- **Focus on the future.** Studies show that pain interferes less with the lives of people who have goals and who continue to do the activities they like.

For many people, accepting the "new normal" of living with myeloma takes time. Develop ways to cope with your new challenges. Remind yourself to take things one day at a time. Each day will bring new learnings, skills and strategies. Make the most out of your life – whether it's on your own or through the support of your family, friends or healthcare team. You don't have to go through this alone.

Fatigue and Myeloma

What is Fatigue?

Fatigue related to myeloma is not fully understood, however, it can be one of the most debilitating symptoms that may affect you physically, psychologically and emotionally. Fatigue is different than just feeling tired. It's described as a persistent sense of tiredness that isn't proportional to recent activity or that takes longer than expected to go away – even with extra sleep. In severe cases, you may feel too tired to eat, think or even move. Small amounts of activity can be exhausting, and your daily routine, work and social life can become disrupted.

You may find that your fatigue increases initially when you start treatment, but once you've been through a few ***treatment cycles*** and your myeloma is under control, your fatigue may improve. Like so much else, fatigue is experienced differently by everyone and may vary in its severity: it may be mild or it may be so severe that it substantially reduces your quality of life.

Some common signs of fatigue may include:

- reduced energy levels, weakness or lethargy;
- reduced concentration, poor memory and mood swings;
- difficulty sleeping or sleeping more than usual;
- dizziness, disorientation and shortness of breath;
- demotivation and lack of interest in regular daily activities;
- loss or reduction of appetite;
- loss or reduction of libido (sex drive).

If acknowledged and treated quickly and appropriately, you may be able to understand the cause(s) of your fatigue and adopt management strategies to improve how you feel and by extension, your quality of life. Don't simply assume that you're experiencing an unavoidable consequence of your diagnosis and treatment. Through it all, remember to keep an open dialogue and report any symptoms you experience to your healthcare team.

Causes of Fatigue in Myeloma

There are many possible causes of myeloma-related fatigue, including the emotional impact of living with the disease, symptoms and complications from the myeloma itself, side effects from your treatments (see below), and the changes these may bring to your lifestyle or routine. Any one of these factors alone, together or in combination with others, can certainly contribute to your overall level of fatigue.

Myeloma Treatments

Chemotherapy, high-dose therapy and autologous stem cell transplantation, radiotherapy, corticosteroids, and immunotherapy (i.e., bortezomib, lenalidomide, etc.) may cause side effects that can lead to increased fatigue.

- **Chemotherapy** kills both myeloma and healthy cells, and can lead to anemia and infection. If the chemotherapy causes nausea or mouth ulcers, you may find it difficult to maintain adequate nutrition; this can also affect your energy level.
- **High-dose therapy and autologous stem cell transplantation** involves high doses of chemotherapy. The fatigue usually improves with time and healing, however residual fatigue - up to one year after transplant - is common.
- **Radiotherapy-related** fatigue is felt because your body is repairing damaged cells. The fatigue can last anywhere from 3-4 weeks, or sometimes up to 3 months, after the procedure.
- **Corticosteroids** can cause insomnia and mood changes. Once the steroids have "worn off" it's common to "crash" and feel weak and fatigued.
- **Immunotherapy** can impair the production of new blood cells and lead to anemia and infection. Fatigue may be felt more at the start of treatment but it can improve as your myeloma gets treated.
    - Some immunotherapies can cause the immune system cells they affect to rapidly release chemicals called ***cytokines*** (i.e., interleukins, interferon) – changing their normal chemical balance in the blood. High levels of cytokines are known to cause fatigue similar to what's experienced when fighting a virus like the flu. Treating your myeloma can eventually lower your cytokine level and help improve your fatigue.

More Information

How does myeloma cause anemia?

Myeloma is associated with the abnormal, uncontrolled growth of plasma cells (know as myeloma cells) in the bone marrow – where red blood cells are also made. When too many myeloma cells are present, the bone marrow gets "crowded out" and fewer red blood cells are produced. Red blood cells carry oxygen to your body's tissues and so not having enough can make you feel weak, tired or fatigued.

Other Contributors to Fatigue

- **Anemia** – Anemia can develop in an acute (hours to days) or chronic (weeks to months) way. Although fatigue is the most common symptom of anemia, other symptoms can include shortness of breath, dizziness, tightness in the chest, and fast heartbeat. If you experience symptoms of anemia, talk to your doctor as soon as possible so that your red blood cell count and hemoglobin levels can be monitored.
- **Bone pain** – If left unaddressed, pain can make you less active, cause difficulty sleeping, make you feel depressed, and lead to even more fatigue. Through this cycle, fatigue can cause your pain to feel worse and harder to deal with.
- **Infection** – People with myeloma are more prone to infections from bacteria, viruses and fungi. Your body uses a lot of energy fighting infections, which can increase fatigue.
- **Kidney damage (renal impairment/insufficiency)** – Heathy kidneys control the balance of fluids and salts in your body. If your kidneys are affected and not working optimally, they may not be adequately clearing waste products from your urine. The buildup of these waste products increases fatigue.

- **Pain medications (see page 11)** – It's possible that some of the pain medications you're on can cause fatigue and/or enhance the effects of fatigue from other causes.
- **Poor nutrition** – Not eating a healthy balanced diet can contribute to fatigue. Moreover, some myeloma treatments can cause side effects that make eating and drinking difficult (i.e., nausea, vomiting, sore mouth, loss of appetite, taste changes).
- **Lifestyle/routine** – Living with myeloma has a huge emotional impact. Pain, anxiety, depression and prolonged stress can affect the duration and quality of your sleep, your relationships with others, and your self-esteem. In turn, you may find it harder to function in your daily life, concentrate, make decisions, and feel more irritable and isolated.

Assessing Fatigue

It can be difficult to diagnose fatigue so if you don't report it, it won't be detected. Your healthcare team can assess your fatigue by asking you questions about how you're feeling (some on a scale of 0 to 10):

- How well do you sleep at night?
- How often do you wake up feeling tired?
- How often do you need a nap during the day?
- Are there certain times of the day that you feel more tired?
- Does anything make your fatigue feel better or worse?
- Do you find activities/chores around the house more difficult than usual?
- What have you tried to help with your fatigue? How well has it worked?
- How would you describe the effect fatigue has on your day-to-day life?

It's critical that you remain open and honest with your healthcare team and keep them up-to-date on how you're feeling. Any input you provide will be helpful in determining the severity of your fatigue and for developing strategies to manage it.

Treatment and Management of Fatigue

Controlling your pain and stabilizing your myeloma with treatment can help relieve your fatigue. If you don't feel better, your doctor may adjust your medications so that their benefits outweigh their side effects.

Fatigue can also be managed through both, medical and non-medical complementary therapies.

Medical Treatments

Addressing/treating the underlying medical conditions that cause your fatigue could help improve your situation.

- **Anemia:** Depending on whether your anemia is acute or chronic, the treatment may vary. Blood transfusions can treat acute anemia by rapidly increasing the number of red blood cells and hemoglobin in your blood. Although this is a short-term solution, some people with myeloma may be given regular blood transfusions to boost their hemoglobin levels. Additionally, if you have chronic anemia and your kidneys are not producing a normal amount of ***erythropoietin (EPO),*** your doctor may prescribe a synthetic EPO injection to stimulate your body's production of red blood cells.
    - Your regular blood tests will show the level of both, your red blood cells and hemoglobin. This will help your doctor determine if the anemia treatments are working or if the doses need to be modified.

- **Kidney damage:** In most people with myeloma, kidney damage is reversible and the kidneys can recover. If your daily fluid intake is not sufficient and you're dehydrated, your kidneys may be working harder than they need to. In many cases, you can help your kidneys function better and potentially prevent or reduce kidney damage by maintaining a constant intake of fluids (i.e., 6-8 glasses per day). Water is the best fluid to drink; caffeinated or alcoholic beverages should be limited. You can also help your kidneys by avoiding drugs that are known to affect them (i.e., NSAIDs; see page 11).
  - Approximately 10% of people with myeloma have kidney problems that will require regular ***dialysis*** sessions. If you require dialysis, your healthcare team will ask you to restrict the amount of fluid you drink.
  - Kidney function can be monitored regularly through a blood test that measures ***creatinine.*** Your creatinine level is combined with your age, gender and ethnicity to provide a more accurate measurement of kidney function called an ***estimated glomerular filtration rate (eGFR).*** The eGFR assesses how well the kidneys are working by estimating how many millilitres (mL) of waste fluid your kidneys can filter from the blood in a minute (mL/min).
- **Infection:** Infections should be treated quickly and appropriately (i.e., with antibiotics, antifungal or antiviral medications) to help reduce the length of the infection and the amount of energy your body uses to fight it. The more energy you have, the less tired you will feel.
- **Emotional factors:** Anxiety, depression and stress can affect your quality of life and contribute to fatigue. ***Cognitive behavioural therapy (CBT)*** can help you positively manage your thoughts, behaviours, and emotions, and may also assist in you managing your fatigue. Speak to your cancer centre's psychologist or counsellor for more information on CBT.

To learn more about how myeloma can affect your kidneys, download Myeloma Canada's *Myeloma and the Kidneys InfoGuide*, available at **myeloma.ca**. Select "Resources", and then "Educational Publications". To order your free printed copy, email us at **contact@myeloma.ca,** or call us, toll-free, at **1-888-798-5771.**

More Information

Drinking lots of fluids can help flush toxins from your body, maintain normal blood volume and pressure, lubricate the joints, limit fatigue and help prevent kidney damage. The best single fluid to drink is water. Unless you're advised otherwise by your healthcare team, try to gradually increase your intake until you're drinking 6-8 glasses of water every day. Try to limit drinks that contain caffeine, such as coffee, tea and soft drinks. Caffeine and alcohol increase your urine output and can lead to dehydration and fatigue.

Non-medical Complementary Therapies

Complementary therapies can be used in conjunction with, but not instead of, the treatments prescribed by your doctor. If you're considering using a complementary therapy, look for a qualified, registered therapist who has experience and is familiar with myeloma.

Some examples of complementary therapies that could be helpful for reducing fatigue include aromatherapy, reflexology, relaxation techniques, spiritual practices, tai-chi, yoga and qigong (see page 13). Always tell your healthcare team about any complementary therapies you're using or planning to try.

Patient support groups can also help ease the burden of fatigue (see page 24). They provide a safe environment where you can discuss your feelings and symptoms with others who can relate to what you are experiencing.

Living with Fatigue

Fatigue can make even the simplest task seem daunting, but you can try to reduce your fatigue with a few small changes to your daily routine.

- **Get enough sleep at night** – Sleeping and maintaining a regular sleep pattern is crucial for anyone to feel their best.
  - Reduce noise and lighting, and keep the temperature of your bedroom cool and steady. Meditation or aromatherapy may also be useful.
  - Try to wake up and go to bed at the same time each day. Limit daytime naps to 30-60 minutes.
  - Avoid caffeine (i.e., tea, coffee or pop/soft drinks) in the afternoon or evening.
  - Try not to use electronic devices (screens) in bed.
  - If you can't sleep, get up and do something until you feel tired again. If your thoughts/concerns are preventing you from sleeping, try to set aside time during the day to deal with them.
- **Proper nutrition** – Eating well is key to maintaining your energy level. Your cancer centre's dietitian/nutritionist can fully assess your diet, offer advice and also prescribe food supplements, if necessary.
  - Cook when your energy levels are high and freeze extra food for low energy days. Consider hiring a food preparation service or ask others for help.
  - Nausea or loss of appetite: Try eating small amounts of food frequently throughout the day. If you feel hungry at certain times of the day and not at others, eat a larger meal when you are hungry. Drink plenty of fluids by keeping water nearby and sipping it frequently throughout the day.
- **Keep track of your fatigue** – Keep a daily log of how you feel and discuss it with your healthcare team. A few brief daily entries can help you identify the times you feel most tired, what makes you more tired and what helps you overcome your fatigue. You could also keep track of what you eat, how much activity you did, your sleeping habits and your general mood.
- **Rest and put your fatigue on a schedule** – Identify when you feel most fatigued and plan rest periods around those times. Another strategy may be to figure out if you feel more replenished after taking a long rest/nap or after several short rest periods.
  - Plan, pace yourself, and prioritize tasks throughout the day so that you do more demanding things (e.g., preparing meals) when you know you'll be less tired. Break big jobs into smaller ones throughout the day/week or ask someone to help by doing some tasks for you.
- **Get some exercise** – Although it may sound counter-intuitive, one of the best ways to combat fatigue is to get some exercise. It may be hard to even think about exercise when you're feeling exhausted, but even a bit of physical activity can do wonders to improve your health, well-being, self-esteem, stress, energy levels, and help you sleep better. Research shows that a gentle exercise program with stretching, aerobic and resistance exercises improves muscle strength and reduces fatigue.
  - Ask your healthcare team about the exercise you want to do and if it will put a lot of strain on your bones (i.e., high impact or contact sports). Gentle forms of exercise, such as walking, swimming, cycling, light weights, and yoga are recommended.
  - Your cancer centre's physiotherapist can help you create a personalized exercise plan, taking into account your current fitness level, fatigue, pain and any bone damage you may have.
- **Ask for help** – Tell your family and friends about your fatigue and explain to them how it's affecting you. You may also ask your doctor for a home assessment referral to see if anything can be done in your home to make everyday life easier for you. If you're having difficulty coping at home, speak to your nurse to see what additional support services might be available.

It's okay to take a "timeout" on days when you're feeling overly tired and have less energy. Be sure to also take advantage of the times you're feeling well to accomplish important tasks, socialize, and resume the activities/hobbies you enjoy.

Dealing with Pain and Fatigue

Challenging Situations

Pain and fatigue that significantly affect the quality of your life could be a sign that you may benefit from additional support. Some challenging situations that could arise:

- **Difficulty coping with work** - It's always best to inform your employer about your situation at an early stage. Discuss possible changes in your work schedule that could help reduce your fatigue, such as lowering the hours you work, adding breaks during the day or revising your role/workload. If possible, decrease the amount of time you spend travelling to/from work, or ask if you can work from home more often. If you do decide to stop work or reduce your hours, you might be worried about your finances. Ask your employer if your benefit plan allows for paid or unpaid leave. You may also be eligible to receive financial assistance through employment insurance offered by the Government of Canada. You can discuss this with your healthcare team/ social worker.
- **Anxiety and depression** - Dealing with the emotional ups and downs of living with myeloma may leave you spiraling through cycles of emotions, stress, depression, pain, insomnia and fatigue. If you feel overwhelmed, look for professional support (i.e., psychologist, psychiatrist, counsellor or social worker) at your cancer centre – they can help you explore your feelings and experiences, develop coping strategies, and help find solutions to the problems you're facing. Try talking to other people living with myeloma – they can help you feel less alone. Visit **myeloma.ca** to find a support group near you.
- **Strained relationships** - At times, you might feel frustrated or disappointed because you're "letting people down". Keep the lines of communication open and talk to the people around you. Explain the full impact of your pain and fatigue so they can better understand what you're going through – they will certainly understand, feel more involved and may even ask how they can better support you.
- **Caring for children** - If you have children, you may wonder what to tell them. While your first instinct may be to shield them from pain, they will surely sense that something is wrong. Saying nothing may leave them scared and confused. In general, children cope better with some information than with none at all. Keep it simple and age-appropriate, and always leave children with hope. Explain how you're feeling and let them know that you might not be able to play or "hang out" as much as usual. Talk to them and decide on activities you can do together that are less strenuous for you. For more complicated activities, ask your family and friends if they can step in for you. The hospital or cancer centre's social worker can also help by providing suggestions and strategies on how to speak with children about your myeloma, pain, and fatigue.

Talking to your healthcare team and support systems about your challenges can help you cope better. There is no stigma attached to seeking assistance to help you feel and function better.

For the caregiver: caring for a loved one with myeloma

Pain and fatigue can have a significant impact on those closest to the person living with myeloma. If you're caring for someone with myeloma, you may find it hard to know how to best help them and how to manage the changes this may bring to your lives.

It goes without saying that caregivers play an essential role in the lives of those for whom they're caring. Myeloma Canada's *Multiple Myeloma Caregiver Handbook* provides detailed information about helping your loved one while addressing the specific and unique concern of caregivers.

Like all Myeloma Canada publications, the Caregiver Handbook is free of charge. It can either be downloaded at **myeloma.ca**, or you can order printed copies by e-mailing us at **contact@myeloma.ca** or by calling, toll-free **1-888-798-5771.**



Beyond Family and Friends: Myeloma Patient Support Groups

Local Support Groups

Talking to people outside your immediate circle may be easier than talking to family and close friends. Meeting and speaking to others with shared experiences through support groups can truly provide you with invaluable information and support. Other patients may be, or have already been, in a similar situation to yours. They understand what you're going through and how to help from a different perspective. Sometimes relief can be found just by speaking to people that can personally identify and relate to you, your experiences and your feelings.

Visit **myeloma.ca** to find a support group near you. If a patient support group doesn't exist in your area, consider forming one yourself. Myeloma Canada can help you get started.

Virtual, Online Support Groups

You may also be able to meet and connect with other patients through an online support group. Myeloma Canada has created, and is the lead administrator of three online, virtual patient support groups on Facebook. These closed groups offer a safe environment for myeloma patients to connect and exchange experiences with others facing similar challenges. Thanks to the Facebook "translate" button, language barriers can be overcome, enabling you to communicate, in your mother tongue, with people nation-wide. Moreover, the information shared on the page is private and can't be viewed by the public. All members must request to join the group to gain access. To join, search for the **"Myeloma Canada Patient & Caregiver Support Group"**, **"Myeloma Canada Support Group for Young Patients and Caregivers"**, or **"Myeloma Canada Support Group for Caregivers"** on Facebook.

Glossary

Anemia: A decrease in the normal number of red blood cells, or in hemoglobin, causing shortness of breath, weakness and tiredness.

Antibodies (immunoglobulins): Protein produced by certain white blood cells (plasma cells) to fight infection and disease response to antigens (substance that causes the body to make a specific immune response) such as bacteria, viruses, toxins or tumours. Each antibody can bind only to a specific antigen. The purpose of this binding is to help destroy the antigen. Antibodies can work in several ways, depending on the nature of the antigen. Some antibodies disable antigens directly and others make the antigen more vulnerable to destruction by other white blood cells. Antibodies are Y-shaped molecules that have heavy and light chains (portions). These portions contain specific binding sites that attach to bacteria or viruses, ultimately leading to their destruction, thereby protecting against disease.

Aromatherapy: A holistic healing treatment that can be used as a complementary therapy. Aromatherapy uses aromatic plant extracts and essential oils to promote relaxation, well-being and healing.

Arthritis: A disease that causes inflammation and pain in the joints.

Bisphosphonates: Bisphosphonates are a group of drugs used to treat hypercalcemia (abnormally high blood calcium) and bone pain caused by myeloma. Bisphosphonates inhibit the overactivity of osteoclast cells that break down bone, reducing new bone damage and allow an opportunity for bone healing to occur. Bisphosphonate treatments for myeloma also have a direct anti-myeloma effect that improves overall survival.

Bone marrow: The spongy tissue found inside your bones that is soft, fatty and full of blood vessels. Your bone marrow is where most of the blood cells in your body (i.e., white blood cells, red blood cells, and platelets) are produced.

Bone marrow biopsy tests: Removal of bone marrow tissue for examination under a microscope.

Cannabinoids: A group of closely related chemicals found in the cannabis plant (or flower) that can provide certain therapeutic effects. Cannabinoids bind to cannabinoid receptors in the central nervous system.

Central line (central venous catheter): A thin, flexible tube that's placed in a blood vessel (usually in the upper chest) and can be kept there for the long-term administration of medications, fluids, or blood products, and from which blood samples can be taken.

Chemotherapy: Treatment with one or more drugs that kill all rapidly-dividing (cancer) cells. Chemotherapy can reduce the number of myeloma cells in the bone marrow and the M-protein they produce. Chemotherapy cannot "cure" myeloma but it may stop it from progressing or getting worse for a period of time.

Cognitive behavioural therapy (CBT): A type of psychotherapy that can help improve mental health by changing the way people think and feel.

Conscious sedation: A combination of medicines to help you relax (sedative) and block pain (anesthetic) during a medical or dental procedure.

Corticosteroids: A group of hormonal substances used to relieve swelling and inflammation. They are naturally produced by the body's adrenal glands, but can also be synthetically made. Corticosteroids (i.e., dexamethasone, prednisone) are part of almost every myeloma treatment regimen because they've been shown to kill myeloma cells and help increase the efficacy of other myeloma treatments.

Creatinine: A waste product that comes from the wear and tear of muscles and is excreted in the urine. Creatinine levels are measured to monitor kidney function.

Cytokines: Molecules secreted by cells of the immune system that send signals and stimulate the growth/activity in a particular type of cell. Can be toxic in high amounts.

Dialysis: A form of treatment that replicates many of the kidney's functions. It is often used to treat severe kidney disease, where the kidneys have lost most or all of their function.

Entourage effect: The synergistic therapeutic effects of the cannabis flower rather than specific isolated ingredients. Natural cannabis compounds interact together to produce a more meaningful effect compared to any one compound used alone.

Erythropoietin (EPO): Hormone produced by the kidneys that stimulates the bone marrow to make red blood cells. Synthetic EPO injections can be given to people with anemia.

Estimated glomerular filtration rate (eGFR): The volume of fluids filtered by the kidneys over a period of time. The eGFR is measured by a blood test. Also called **creatinine clearance**.

Euphoria: Feeling or state of intense excitement and happiness.

Gastrointestinal: Referring to the stomach and intestines.

Guided imagery: Technique that focuses a person's thoughts on positive images to help them reduce stress and reach a relaxed, focused state.

High-dose therapy and autologous stem cell transplantation: High-dose chemotherapy given intravenously before patients receive healthy stem cells as part of the transplantation procedure.

Hypercalcemia: A higher than normal level of calcium in the blood that may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.

Immunosuppression: Partial or complete reduction of a person's immune response.

Immunotherapy: Therapies that stimulate or enhance the immune system and help the body fight disease.

Incontinence: Inability to control the flow of urine from the bladder or stool from the rectum.

Infusion reactions: Type of hypersensitivity reaction that develops during or shortly after administration of a drug. Symptoms can include pruritus (itching of skin), urticaria (hives and itching), fever, rigors/chills, diaphoresis (sweating), bronchospasms (difficulty breathing), and cardiovascular collapse (low blood pressure, decreased blood flow to the brain).

Intravenous (IV): Into/within a vein. Medication (solution) is administered directly into the vein via an IV drip, syringe or catheter (central line).

Kyphoplasty: A procedure used to repair and stabilize a vertebral compression fracture that involves a balloon inserted into the vertebra and inflated to raise the collapsed section. The cavity is then filled with a bone cement.

Leukopenia: A reduced level of white blood cells. White blood cells are important for fighting bacterial infection.

Local anesthetic: Medication that causes loss of feeling or numbness in one small area of the body where it is injected.

Lytic lesions: A damaged area of a bone that shows up as a dark spot on an X-ray (looks like holes in the bone).

M-protein (monoclonal protein, paraprotein, or M-spike): Also known as myeloma protein. These are antibodies or parts of antibodies found in unusually large amounts in the blood or urine of myeloma patients. M-spike refers to the sharp pattern that occurs on protein electrophoresis (blood test) when an M-protein is present.

Mucositis: Complication in which the lining of the digestive system becomes inflamed. Often seen as mouth sores.

Nausea: Sensation of sickness or discomfort in the stomach that may come with an urge to vomit.

Neutrophil: A type of white blood cell important for fighting bacterial infections.

Non-steroidal anti-inflammatory drugs (NSAIDs): Drugs used to prevent or treat pain that do not contain steroids. NSAIDs decrease fever, swelling, pain, and redness.

Opioids (narcotics): Drugs that bind to opioid receptors in the central nervous system to treat moderate to severe pain. Opioids are like opiates, but are not made from opium.

Oral thrush: An infection that is caused by a fungus (Candida albicans) and is marked by white patches in the mouth.

Osteoblasts: Cells that work to form new replacement bone.

Osteoclasts: Cells that work to break down old bone.

Osteopenia: Thinning or weakening of the bone (lower than normal bone density). Osteopenia is a less severe form of bone loss than osteoporosis.

Over-the-counter (OTC) medications: Medications that can be purchased without a prescription.

Pathological fractures: Broken bone caused by disease, rather than injury.

Peripheral neuropathy: Damage to the nerves that make up the peripheral nervous system (i.e., hands, feet, arms or legs) causing pain, tingling and altered sensation.

Plasmacytoma: A collection of plasma cells found in a single location (i.e., tumour or mass) rather than diffusely throughout the bone marrow, soft tissue, or bone.

Platelet (thrombocyte): A major blood element that is involved in the defense against bleeding by the formation of blood clots. Low platelets can cause bleeding problems, while high levels may increase the risk of clotting (thrombosis).

Post-herpetic neuralgia: Nerve pain that persists in people who have had shingles after the shingles rash has disappeared.

Prescription medications: Medications ordered by a licensed healthcare professional that is legally allowed to write prescriptions.

Prophylactic: Something that prevents or protects.

Psychoactive effects: Temporary changes in how the brain works and in mood, awareness, thoughts, feelings, or behavior.

Radiotherapy (radiation therapy): Treatment with high energy radiation (i.e., X-rays, gamma rays, electrons, etc.) that shrinks, damages or kills malignant cells. The radiation may come from outside the body (external radiation) or from radioactive materials placed directly in the tumour (implant radiation). External radiation is used in myeloma.

RANK ligand inhibitors: Used for the management of osteoporosis in people at high risk for bone fractures. The interaction of RANK and its ligand regulates how bone is absorbed by the body.

Sedative: A drug used to calm a person down, relieve anxiety, or help them sleep.

Stem cells: Stem cells (also referred to as progenitor or master cells) are immature cells from which all blood cells develop. A normal stem cell can develop into normal blood components such as red cells, white cells and platelets. Stem cells are found in many of your body's organs, such as the bone marrow. When compared to other kinds of cells (e.g., muscle, nerve or blood), stem cells are unique because they are capable of long-term self-renewal.

Terpenes: Strong-smelling chemicals found in some plants (i.e., cannabis), especially trees that have cones. Terpenes are found in oils extracted from plants.

Titration: The process of adjusting the dose of a medication up or down until an optimal dose has been found.

Transcutaneous electrical nerve stimulator (TENS): Procedure that involves mild electric currents applied to some areas of the skin to help reduce pain and promote healing.

Treatment cycle: A course of treatment that is repeated on a regular schedule with periods of rest in between (i.e., three weeks of treatment followed by one week of rest is one cycle).

Vertebral (spinal bone) fracture: Fracture or break in one or more of the small bones surrounding the spinal column. Also referred to as a vertebral compression fracture.

Vertebroplasty: A procedure used to repair and stabilize a vertebral compression fracture that involves injecting bone cement into the vertebra to stabilize and strengthen it.

White blood cell or leukocyte: General term for a variety of cells responsible for fighting invading germs, infection and allergy-causing agents. These cells begin their development in the bone marrow and then travel to other parts of the body. Specific white blood cells include neutrophils, granulocytes, lymphocytes, and monocytes.

Make Myeloma Matter

Every year, Myeloma Canada provides information to thousands of people impacted by myeloma through programs and services such as the annual Myeloma Canada National Conference, InfoSessions, Meet & Greets, the Myeloma Matters online newsletter, webinars, videos, InfoGuides, and much more.

That's why we need your help. As the only national, charitable organization created by, and for, Canadians impacted by myeloma, we depend on your support and generous donations. Your contribution helps to improve the lives of those affected by myeloma by empowering the community through awareness, education and advocacy programs, and supporting research to find a cure. With your help, we've been making myeloma matter since we were founded in 2005.

Every donation is greatly appreciated and enables us to continue our vital work. There are many options for giving. Whether it's a one-time, a pre-arranged monthly, or a legacy gift, every donation brings us closer to finding a cure.

Ways You Can Help

Donate

We invite you to make your donation online at **myeloma.ca**, over the phone by calling toll-free at **1-888-798-5771**, or by mailing a cheque payable to Myeloma Canada to:

Myeloma Canada
1255 TransCanada, Suite 160
Dorval, QC H9P 2V4

Fundraise

There are many ways you can support Myeloma Canada, such as taking part in the annual Multiple Myeloma March held in cities across Canada, or by fundraising for Myeloma Canada in your local community. When so much about myeloma is beyond the control of the people that it affects - and those who care for them - fundraising can be a rewarding and fun way of doing something positive for yourself and for others affected by the disease.

Contact Myeloma Canada's fundraising team, toll-free, at 1-888-798-5771 for more information or visit www.myeloma.ca.

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Myeloma Canada publications are extensively reviewed by patients and healthcare professionals prior to publication.

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