Myeloma Canada
InfoGuide Series
A web-based resource

Financial Implications of Living with Myeloma



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The information in this web-based InfoGuide is not meant to replace the advice of a professional.

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Overview

Over the last 15 years, the addition of novel and targeted treatment options for myeloma have significantly increased the prognosis for people living with the disease. People are living longer than ever and as such, are experiencing some unique challenges.

Whether at diagnosis, disease relapse or times in between, symptoms of the disease and side effects from treatment can affect a person's ability to work, remain independent, and be socially involved. Over time, this can have long-lasting effects on quality of life and emotional wellbeing, leading to stress, anxiety, and/or depression.

To help ease the mental burden of living with myeloma, some patients and caregivers find it helpful to share common experiences with others who understand their situation; this is where local and virtual myeloma patient support groups can truly be invaluable. For more information on Myeloma Canada's Support Groups, click here.

If you or your loved one has been diagnosed with myeloma, you know how challenging it can be to find information that can help you manage your finances. With this in mind, the sections that follow have been written specifically to address the financial concerns of people living with myeloma and their caregivers.

Financial Implications of Living with Myeloma is intended to help you better manage your financial situation and help you optimize your finances to get the most out of what's available to you.

Given the nature of how quickly information related to the topics covered in this guide change, we've created *Financial Implications of Living with Myeloma* as a web-based document only. You may of course print out any sections you'd like.

Financial Implications of Living with Myeloma is divided into clearly defined sections, with a list of resources by province and/or territory where applicable. We've made it easy for you to navigate through the WebGuide. From within the Guide's Table of Contents, you'll see that sections appear in bold, teal. To jump to the section you'd like to read, simply click on the section title. Or of course, you can also choose to read through the document as a whole.

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Resources that can help you understand, manage and navigate your diagnosis

There is a vast array of educational videos and publications from Myeloma Canada that can help demystify your diagnosis. Please visit the Resources section on our website at myeloma.ca to learn more. All publications are offered to you free-of-charge. **You can download them at myeloma.ca, or order printed copies by e-mailing us at contact@myeloma.ca or by calling, toll-free 1-888-798-5771.**

The Multiple Myeloma Patient Handbook is an excellent resource for those who are newly diagnosed, as well as their family and loved ones. Designed to provide educational support to patients, caregivers, families and friends, this Handbook gives accurate, reliable, and clear information on myeloma. Some of the topics covered include the causes and effects of myeloma, how it's diagnosed, and treatment options available in Canada.

Be sure to visit Myeloma Canada's YouTube channel that features over 100 educational videos, webinars, and inspiring patient journey videos that you can watch at your own pace and leisure.

Our website features materials and tools to help you track and manage your myeloma, stay confident and informed about your treatment options. Among helpful tools you'll find:

- Myeloma Canada's Discussion Guide for Newly Diagnosed Patients and Discussion Guide for Patients Experiencing a Relapse:
  Important questions to spark important conversations with your healthcare team, such as your treatment plan, goals, sequences and options that are best suited for you and your specific needs and situation;
- Myeloma Canada's Multiple Myeloma Treatment Decision-Making Guide:
  Map out your thoughts, emotions and other relevant information to help you think about – and understand – what's important to you. This guide helps you identify what you may need to know more about in order to make a decision that you're comfortable with.

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Introduction

Although those with limited incomes are the most affected, the financial burden can affect the quality of life and mental health of anyone living with myeloma and their loved ones.

At various stages of your journey with myeloma, important financial considerations may include:

- ability to work full- or part-time during and after treatment;
- insurance coverage status and quality/extent of coverage;
- access to caregiver(s) in general and when undergoing a stem cell transplant;
- need for prescription drugs and over-the counter vitamins, dietary supplements or medications;
- travel and lodging expenses, especially for people living in remote areas, to:
    - undergo one or more stem cell transplant;
    - access standard myeloma treatment;
    - receive supportive care treatment (i.e., bone protector infusions);
    - attend follow-up appointments;
    - undergo testing (e.g., blood, urine, imaging);
    - participate in clinical trials.
- frequency of travel for treatment, follow-up appointments and tests;
- ability to recover or adjust to treatment;
- need for additional support:
    - Medical equipment, supplies, devices and mobility aids
    - Complementary therapies (e.g., yoga, meditation, tai-chi, acupuncture, massage, etc.)
    - Physiotherapy or occupational therapy
    - Dental and vision care
    - Counseling / mental health therapy
    - Housekeeping, child care, respite care, pet care, etc.;
- financial and employment status of spouse, caregiver, and/or family.

We know the process of finding information that can help with your finances can be confusing and overwhelming. So, to simplify the process for you, Myeloma Canada has consolidated the information you need here in one, easy-to-find place.

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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, place an online order, or call us toll-free at 1-888-798-5771.

- *Multiple Myeloma Patient Handbook*
- *Multiple Myeloma Caregiver Handbook*
- *Managing Pain & Fatigue InfoGuide*
- *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: Are They an Option for Me? InfoGuide*
- *Myeloma Immunotherapy InfoGuide*
- *MGUS and Smouldering Multiple Myeloma InfoGuide*

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Myeloma Treatment & Treatment-related Costs

Overview

Myeloma treatment and healthcare costs can be classified in two ways:

- Drug costs
- Treatment-related costs

Drug costs

In Canada, myeloma drug costs may be covered by:

- provincial and territorial government public drug benefit programs;
- group insurance and benefit plans offered by an employer, union, or school;
- the drug manufacturer (all or partially covered; must meet certain financial eligibility criteria);
- paying for the drug out-of-pocket or through a private health insurance plan.

Access to treatment options and treatment coverage, however, varies from province-to-province.

Learn more by visiting these pages on the Myeloma Canada website (myeloma.ca):

- **Myeloma Drug Coverage & Access in Canada**
- **Myeloma Drug Access Navigator**

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Treatment-related costs

You are responsible for covering treatment-related costs that aren't paid for by your provincial or territorial government health insurance plan. Among these costs are:

- prescription drugs, vitamins, and dietary supplements;
- travel (e.g., parking) and lodging expenses for treatment, follow-up appointments, and tests;
- medical equipment, supplies, devices and mobility aids;
- dental and vision care;
- physiotherapy, occupational therapy, osteopathy and massage therapy;
- counseling / mental health therapy;
- home nursing care;
- complementary therapies;
- ambulance services;
- hospital room upgrade.

Some of these costs may be fully or partially covered by either a group insurance and benefit plans offered by an employer, union, or school, or a private health insurance plan.

Cancer centre or hospital resources

Dealing with financial issues, processes and responsibilities can be complicated and difficult. Rest assured, you're not alone…there are people who can help you. Most major Canadian cancer centres have social workers, supportive care counsellors, medication reimbursement specialists and drug access navigators that can guide and help you access financial assistance for myeloma drugs that aren't covered by your provincial or territorial government's health insurance plan. They can often assist with completing paperwork needed by insurance providers and drug manufacturers so that you pay little or no out-of-pocket costs. That's not all. They may also be able to provide helpful strategies regarding your routine responsibilities (e.g., paying bills, cooking) while you undergo treatment. This is particularly challenging for those patients who may not have a caregiver to assist them.

Ask your doctor, nurse or other members of your healthcare team about the resources available at your cancer centre or hospital. Some of the services listed above may not be available at smaller centres, so it's important to ask what services are available, where to find them, and how to access them.

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Group Insurance & Benefit Plans

Overview

Group insurance and benefit plans can help cover myeloma drug costs and offset out-of-pocket, treatment-related costs. Some employers or unions offer group insurance and benefit plans to employees, who in turn, are usually required to cover a portion of the plan's cost. That portion is usually automatically deducted off your pay.

If you're no longer able to work and would like to keep your plan active while off work, you may need to also cover the employer's portion of the payment (premium) until you return to work. After you return to work, you might be offered the same insurance package or be re-assessed based on your medical condition.

It's important to recognize that group insurance doesn't cover everything and all plans have some exclusions (i.e., coverage of pre-existing conditions, payout maximums, and limits). Plans might limit coverage on a per year and/or per lifetime basis. Some plans might even place limits on medical equipment, supplies or devices.

Group insurance

Group insurance offered by employers/unions may include:

- **Short-term disability (sick leave):** Income-replacement benefit that pays you a portion of your income for a short, specific period of time while unwell and unable to work.
- **Long-term disability:** Income-replacement benefit you receive after your short-term disability and/or federal government employment insurance sickness benefits are finished. Long-term disability (percentage of your regular income) is received for the first two years if you're deemed unable to perform your specific job. After two years, it's paid out based on your inability to perform any job.

  Both, myeloma patients and caregivers may be eligible for short- and long-term disability benefits if their symptoms are affecting their ability to do their job. These symptoms may include:
  - fatigue, weakness, higher risk of infection (patients only), and other problems that limit physical ability;
  - emotional (i.e., mood) and mental health problems (i.e., anxiety, depression);
  - problems with attention, concentration, memory and other cognitive functions.

  As always, the first step is to speak with your healthcare team about the type of symptoms or problems you're experiencing.
- **Travel insurance:** Covers unexpected medical expenses during travel outside your province or country.
- **Accidental death & dismemberment:** Covers unintentional death or loss of use of body parts or functions.
- **Life insurance:** Set amount paid after a person dies.

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Health-related benefits

Health-related benefits can help cover some expenses not covered by your province's healthcare insurance plan. Plans vary widely among different employers/unions and may include:

- **Supplementary health:** Covers some hospital and medical expenses
- **Drug coverage:** Covers all or part of prescription drug costs
- **Health spending account:** Credit that can be used towards health, dental and vision costs not covered by health-related benefits or insurance plans.

Know the details of your plan(s)

Speak to your employer's human resources department, manager or union representative, and/or your insurance company to better understand your group insurance and benefit plan(s). This will allow you to take full advantage of your benefits as well as carefully weigh all your options if you find yourself in a situation where you have to decide whether to change, continue or suspend your plan. Be sure to also carefully read your policies and understand what's covered, excluded, amounts paid, payment start dates, payment maximums, and limits. It's also a good idea to find out which forms you and your doctors must complete in order for you to access and take full advantage of your benefits.

Conversion plan

You may find yourself in a situation where your group insurance and benefit plan is about to, or has recently, ended due to:

- retirement;
- change from full-time to part-time employment;
- being laid-off or becoming self-employed;
- a pre-existing condition.

If this is your case, and you would like the option of keeping all or some of your coverage and benefits, speak to the insurance provider about options available to you, including converting your current group insurance and benefit plan to an individual policy.

Please note: The option to convert your group plan to an individual policy may only be available within a certain number of days following the termination of your plan coverage (i.e., 60 days). For many people living with myeloma, or a loved one whose plan covers someone with myeloma, it's often very important to keep as much coverage as possible, for as long as possible.

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Private Health Insurance Plans

You may already have one or more private health insurance plans (policies) purchased through an insurance broker, bank, financial advisor, and/or credit card. Although many different types of health insurance exist, the most common types include:

- **Benefits similar to group insurance and benefit plans** offered by employers/unions.
- **Critical illness:** A one-time lump-sum payment when a specific life-threatening diagnosis is confirmed (e.g., cancer, heart attack, stroke). The types of illnesses covered depend on the specific policy.
- **Disability:** Tax-free monthly payment if an illness or injury keeps you from working.
- **Credit and mortgage payment:** Covers credit and mortgage payments in the event of sudden illness or job loss.
- **Hospital cash:** Pays a small flat daily amount for out-of-pocket expenses while you're in the hospital or receiving outpatient treatment (treatment without being admitted to a hospital).
- **Travel insurance:** Covers unexpected medical expenses during travel outside your province or country.
- **Life insurance:** Set amount paid after a person dies.

Similar to group insurance and benefit plans, it's important to recognize that private health insurance plans don't cover everything and most have exclusions (i.e., coverage of pre-existing conditions, payout maximums, and limits).

Be sure to read your insurance policy information booklets carefully and speak to your policy issuers to better understand your policy's coverage, exclusions, payout maximums, and limits.

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Leaving & Returning to Work & School

Overview

At some point following a diagnosis, it's not uncommon for people living with myeloma, and their caregivers, to take time off of work or school. The amount of time you can take off will depend on your specific situation – so before doing anything, it's important to ask questions and weigh all your options and then decide what's right for you.

As a first step, speak to your hematologist/oncologist to find out how your treatment will impact your ability to work or go to school. Important considerations include:

- Start date of your treatment and length of each treatment;
- Number of cycles for a full treatment regimen;
- Frequency of travel for treatment/testing/monitoring;
- Periods of recuperation (e.g., following a stem cell transplant) and/or additional therapies;
- Common side effects of treatment and their impact on daily activities, work and/or school;
- Workplace/school risks (e.g., risk of infection, physical labour).

Disclosing your diagnosis

Discrimination based on illness is illegal in Canada and you are under no obligation to disclose the exact nature/details of your diagnosis to your employer, union, or school – it is entirely your decision!

If you'll still be able to work as you normally would, there may not be a benefit to disclosing your situation. However, you should consider disclosing your situation if you will have to take time off or in order to ask for more work/school flexibility. In that case, your obligation is to provide fundamental information (e.g., doctor's note confirming your inability to perform your regular work duties due to medical reasons; estimated length of the absence). Your doctor is not obliged to disclose the exact nature of your diagnosis. For more information on disclosing your diagnosis to your employer, visit www.cancerandwork.ca.

Your legal rights

To learn about the various laws that can protect employees here in Canada, visit www.cancerandwork.ca. There you'll find information on legal resources, human rights, employment standards laws, union help, workers' compensation, frequently asked legal questions, and employment termination. Regarding employment termination, in short, employers cannot legally lay you off because you have myeloma or any cancer diagnosis.

Leaving work

Depending on your specific situation and the type of work you do, you may take a short- or long-term leave of absence, or stop working entirely. If you have a flexible job arrangement, you may be able to work reduced hours or even from home.

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Some important consideration to discuss with your employer/union, if you need to stop working, include:

- Date of leave and potential return date;
- Job position and accumulation of credits/seniority;
- Available use of accumulated sick days, credits, and vacation days;
- Need to pay Group insurance and benefit plan premiums during the medical leave of absence to maintain extended healthcare coverage;
- Additional benefits that may be available (e.g., counselling, rehabilitation).

Important note: Quitting your job relieves your employer from its obligation to take you back and makes you ineligible for Employment insurance.

For more information on taking time off work, visit www.cancerandwork.ca.

Unpaid medical leave

Provincial and territorial governments run medical leave programs that protect you from the risk of losing your job. Eligible employees may also qualify for Employment Insurance benefits offered by the Canadian government.

Provincial governments

Please click on the program name to access the website.

- **Alberta**
  - Compassionate care leave
- **British Columbia**
  - Critical illness or injury leave
  - Compassionate care leave
- **Manitoba**
  - Compassionate care leave
- **Nova Brunswick**
  - Compassionate care leave
- **Newfoundland & Labrador**
  - Compassionate care leave
- **Nova Scotia**
  - Compassionate care leave
  - Critically ill adult care leave
- **Ontario**
  - Family medical leave
- **Prince Edward Island**
  - Compassionate care leave
- **Quebec**
  - Accidents and illnesses
  - Family or parental obligations
- **Saskatchewan**
  - Compassionate care

Territorial governments

Please click on the program name to access the website.

- **Northwest Territories**
  - Short-term sick leave
  - Special leave
- **Nunavut**
  - Sick leave
  - Medical travel leave
  - Compassionate care leave
  - Special leave
- **Yukon**
  - Current and proposed leave options in Yukon
  - Family caregiver benefit for adults
  - Compassionate care benefits

Leaving school

Speak with your school's human resources department and your student union representative to better understand all of your rights. If you're a full-time student, you may have access to a student group insurance and benefit plan. By law, your school is required to provide you with reasonable accommodations such as a slow or gradual part-time return to school. You may also be able to request specific, flexible accommodations though a human resources or student services representative, or directly with your professor(s).

Returning to work & school

Returning to work or school can feel both exciting and overwhelming. Once you have a better idea of when you'll be returning, be sure to notify your employer, union or school in advance, to discuss the details of your return to work or school. Workplaces and schools can often slowly ease you back to work (graduated return to work or modified duties) or allow you to take a reduced course load. A doctor's note may be needed.

If you're planning on returning to work and you're currently benefitting from a long-term disability plan, your case manager or counsellor might be able to help you negotiate your return with your employer. Worksite representatives (e.g., return to work coordinators, disability managers, occupational health specialists, human resources personnel, union representatives) may also be helpful with your return to work.

Some practical things to consider before you make your final decision include:

- Who do you have to inform about your return and how do you have to inform them?
- Will you be returning gradually or on a part-time basis?
  - What will the impact of paycheque contributions (i.e., pension contributions) be?
  - What is the impact on number of vacation days?
  - Who pays the employer's share of insurance and benefit premiums?
  - Will you be able to live on the reduced income?
- What happens if you must leave again due to illness? Is there a recurrence period?

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For more information on returning to work, visit www.cancerandwork.ca, specifically these two sections:

- 11 steps to return to work (video)
- Return to work – communication & teamwork

If you're planning on returning to school, speak with a member of your school's human resources department or a student services representative. They may be able to provide you with more information regarding the process and help with a return plan.

Recurrence/relapse of myeloma

If your myeloma relapses and you require treatment, you may not qualify for government benefits unless you've worked a certain number of hours since your last claim. For example, the Canadian federal government requires you to have worked 600 hours (or approximately 16 weeks full-time).

This page is updated periodically. Government programs listed are not exhaustive. Additional federal programs can be found through the Government of Canada's Benefits Finder.

Federal Government Programs

The Canadian government administers programs that offer short- or long-term financial aid that could help if you or a loved one becomes sick and/or disabled. For provincial or territorial government programs, see the Provincial Government Programs and Territorial Government Programs sections in this document.

Employment insurance (EI)

Federal EI programs provide temporary financial assistance (taxable) to patients and caregivers who can't work due to sickness or injury. In order to be eligible, you must have worked at least 600 hours in the last 52 weeks. The EI benefit can provide up to 55% of your average weekly earnings (up to a maximum) for a maximum of 15 weeks. If approved, you'll receive your first payment within 4-6 weeks. There is also a 1-week unpaid waiting period. To keep the payments going for the full 15 weeks, you must submit an online or phone report every 2 weeks.

EI benefits include (click on the program name to access the website):

- Sickness benefit for employed people
- Sickness benefit for self-employed people
- Caregiver benefits and leave

To apply for EI, you must submit one or more the following documents for your application (click on the document name for more information):

- Record of employment
  - Submitted by your employer directly to Service Canada (electronic or mail).
- Medical certificate for EI sickness benefits
  - Ask your doctor to complete this form. You must also complete and sign the consent section of the form prior to submitting it.
- Authorization to release a medical certificate for EI compassionate care or family caregiver benefits
  - Signed by the patient.
- Medical certificate for EI family caregiver benefits
  - Completed by the patient's doctor.
- Medical certificate for EI compassionate care benefits
  - Completed by the patient's doctor.

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Canada pension plan (CPP)

Click on the program name to access the website.

- CPP retirement pension
    - The CCP retirement pension is a monthly (taxable) benefit that replaces part of your income for the rest of your life. You must be at least 60 years old to qualify.
- CPP disability benefits (all provinces/territories excluding Quebec)
    - CPP disability benefits provide long-term monthly income replacement (taxable) to people who are unable to work due to a mental or physical disability. To be eligible, you must be under 65 years of age and have made enough contributions into the CPP. Please see the link below for full information, including other eligibility criteria.
    - Since multiple myeloma is considered to be a grave condition, application processing may be completed within 30 calendar days. Processing for terminal illness patients may be completed within 5 business days. Payment amounts depend on the amount of your past CPP contributions (up to a maximum).
    - Quebec pension plan disability pension (for Quebec residents)
- CPP post-retirement disability benefits
    - You must be between 60 and 64 years of age, have been receiving the CPP retirement pension for more than 15 months, or have become disabled after starting to receive the CPP retirement pension (other eligibility criteria apply). A fixed amount is received ($505.79 in 2020). This payment stops at 65 years of age and is continued by the CPP retirement pension plan.

The same application is used for both the CPP disability benefits & CPP post-retirement disability benefits programs. To apply you must submit the following documents (click on the document name for more information):

- Application for CPP disability benefit
    - Must be completed by the applicant (online or paper). It's a good idea to keep copies
- Medical report for a CPP disability benefit
    - Must be completed and signed by the applicant and their doctor. The completed consent form must by submitted in paper format.

Programs & services for seniors

The Federal government administers various programs and services for seniors. These include:

- CPP retirement pension
- Old age security
- Guaranteed income supplement
- Guaranteed annual income system

Certain eligibility criteria apply. Information on these programs and services can be found on the Canadian government's easy-to-use website.

- Programs & services for seniors

Tax credits

- See the Tax Credits & Additional Help with Health-related Costs section in this document.

Other programs/benefits

Click on the program name to access the website.

- Workers' compensation benefits for federal workers inside or outside of Canada
  - Protects employees from the financial hardships associated with work-related injuries and occupational diseases (e.g., if you have reason to believe that your myeloma was caused by occupational exposure to certain substances).
- **Workers' compensation benefits for non-federal workers**
  - Please see the Provincial workers' compensation benefits section in this document
- **Veterans registered with Veterans Affairs**
  - Financial programs and services
  - Mental and physical health support
  - Housing and home life
  - Veterans Affairs drug formulary. Some drugs require that the prescriber contacts the Veterans Affairs Special Authorization Unit directly at 1-888-VAC-AUTH.
- **Military, RCMP, and federal civil servants**
  - Public service healthcare plan
- **Refugees or federal detainees**
  - Interim federal health
- **Individuals under correctional services**
  - Correctional Services of Canada (CSC)
  - Coverage is managed by CSC pharmacies located on-site in federal institutions.

This page is updated periodically. Government programs listed are not exhaustive.

Provincial Government Programs

Provincial governments administer financial aid programs that may be of help if you or a loved one becomes disabled or if you don't have the means and income to pay for basic living costs such as food, clothing, and shelter (social assistance). For federal or territorial government programs, see the Federal Government Programs and Territorial Government Programs sections in this document.

Disability benefits

The Canadian government administers pension plan disability benefits for all provinces and territories other than Quebec; the province of Quebec administers their own plan.

- CPP disability benefits (all provinces/territories excluding Quebec)
- Quebec pension plan disability pension

You may be eligible for additional disability benefits:

- Alberta aids to daily living
- British Columbia disability assistance
- Manitoba: Information for Manitobans with disabilities
- New Brunswick disability support program
- Newfoundland & Labrador disability benefits
- Nova Scotia disability support program
- Ontario disability support program
- Prince Edward Island AccessAbility supports
- Quebec programs for people with disabilities
- Saskatchewan assured income for disability

Workers' compensation benefit (WCB)

The workers' compensation benefit protects employees from the financial hardships associated with work-related injuries and occupational diseases (e.g., if you have reason to believe that your myeloma was caused by occupational exposure to certain substances).

- **More Information:** Association of Workers' Compensation Boards of Canada

Each province administers their own WCB program:

- Alberta
- British Columbia
- Manitoba

- New Brunswick
- Newfoundland & Labrador
- Nova Scotia
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan

Drug and healthcare programs

In Canada, myeloma drug costs may be covered by provincial and territorial government public drug benefit programs. Click on the program name for more information.

- **Alberta**
  - Health care insurance plan
  - Drug coverage & health benefits
  - Specialized drug benefits
  - Non-group coverage
  - Adult health benefit
  - Palliative care health benefits
- **British Columbia**
  - Medical services plan
  - PharmaCare for BC residents
  - BC Cancer drug funding
  - Fair PharmaCare plan
- **Manitoba**
  - Pharmacare program
  - Home cancer drug program
  - Exception drug status program
- **New Brunswick**
  - Drug plan
  - Prescription drug program
- **Newfoundland & Labrador**
  - Medical care plan
  - Prescription drug program
  - Special authorization drug products

- **Nova Scotia**
  - Pharmacare
  - Drug assistance for cancer patients
  - Exception status drugs
  - Seniors' Pharmacare program
  - Palliative care drug program
- **Ontario**
  - Ontario health insurance plan (OHIP)
  - Ontario drug benefit program (Trillium drug program & Senior's co-payment program)
  - Exceptional access program
- **Prince Edward Island**
  - Pharmacare
  - Seniors' drug program
  - Drug cost assistance
  - High cost drug program
  - Generic drug program
  - Catastrophic drug program
  - Financial assistance drug program
- **Quebec**
  - Public prescription drug insurance plan
  - Exceptional medications
- **Saskatchewan**
  - Drug plan
  - Exception drug status
  - Palliative care drug coverage
  - Drug cost assistance
  - Emergency assistance for prescription drugs

Income, social assistance, and other programs

Income and social assistance programs can provide a basic level of support to those who are not benefitting from other government programs. Each Canadian province administers their own social assistance programs, and benefits and procedures differ widely.

- **Alberta**
  - Income support
  - Financial assistance for seniors
- **British Columbia**
  - Income assistance
  - Support for seniors
  - Family & social supports

- **Manitoba**
  - Employment & income assistance
  - Financial benefits & assistance
- **New Brunswick**
  - Social assistance program
  - Health services
- **Newfoundland & Labrador**
  - Medical transportation assistance program
  - Income support
- **Nova Scotia**
  - Income assistance & employment support
  - Cancer care program
- **Ontario**
  - Ontario Works
  - Home and community care
  - Tax credits and benefits
- **Prince Edward Island**
  - Social assistance
  - Federal & provincial benefits
- **Quebec**
  - Social assistance & social solidarity
  - Basic income program
  - Finding a job program
  - Aid programs
- **Saskatchewan**
  - Income assistance programs
  - Extended benefits
  - Transitional employment allowance

This page is updated periodically. Government programs listed are not exhaustive.

Territorial Government Programs

Territorial governments manage programs that may help if you or a loved one becomes sick and/or disabled. For federal or provincial government programs, see the Federal Government Programs and Provincial Government Programs sections in this document.

Disability benefits

The federal government administers pension plan disability benefits for all Canadian territories.

- Canada Pension Plan disability benefits

You may be eligible for additional disability benefits:

- Northwest Territories income assistance
- Northwest Territories disability services
- Nunavut income assistance program
- Yukon disability services

Workers' compensation benefit (WCB)

The workers' compensation benefit protects employees from the financial hardships associated with work-related injuries and occupational diseases (e.g., if you have reason to believe that your myeloma was caused by occupational exposure to certain substances).

- Association of Workers' Compensation Boards of Canada
- Northwest Territories & Nunavut
- Yukon

Drug and healthcare programs

In Canada, myeloma drug costs may be covered by provincial and territorial government public drug benefit programs. Click on the program name for more information.

- **Northwest Territories**
  - Health care plan
  - Extended health benefits
- **Nunavut**
  - Health care plan
  - Extended health benefits

- **Yukon**
  - Health care insurance plan
  - Drug coverage information
  - Extended heath care benefits and Pharmacare for seniors
  - Chronic disease program

Income, social assistance, and other programs

Income and social assistance programs can provide a basic level of support to those who are not benefitting from other government programs. Each Canadian territory administers their own social assistance programs – benefits and procedures differ widely.

- **Northwest Territories**
  - Income assistance
  - Seniors supplementary benefit
  - All income security programs
  - Medical travel
- **Nunavut**
  - Income assistance
  - Seniors supplementary benefit
  - Medical travel
- **Yukon**
  - Social assistance
  - Travel for medical treatment

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Government Programs for First Nations & Inuit Peoples

Federal, provincial, and territorial governments manage programs that may help if you or a loved one becomes sick and/or disabled. For federal, provincial, or territorial government programs, see the Federal Government Programs, Provincial Government Programs, and Territorial Government Programs sections in this document.

First Nations & Inuit benefits

- Non-insured health benefits
    - Coverage for a range of medically necessary health services (prescription drugs, over-the-counter medications, dental and vision care, medical supplies and equipment, mental health counselling and transportation) that are not available on the reserve or in the community of residence.
- British Columbia First Nations health benefits (Plan W)
    - The First Nations Health Authority is responsible for the design, management, delivery and funding of the delivery of health services to First Nations residing in British Columbia.
- Additional Indigenous health care services

Making Claims

Group insurance & benefit plans

Your group insurance and benefits plan booklet will outline your coverage for most services; however, coverage of prescription drugs, devices, or equipment may not be listed. Call your insurer or check your portal on their website to verify the details of your coverage. Your pharmacy may also be able to check your coverage for certain items.

Benefit packages may vary so it's a good idea to know your coverage and the difference you will be responsible for paying. Items for which you may be covered include:

- prescription drugs, vitamins and dietary supplements;
- travel and lodging expenses for treatment, follow-up appointments, and tests;
- medical equipment, supplies, devices and mobility aids;
- dental and vision care;
- complementary therapies;
- physiotherapy, occupational therapy, osteopathy and massage therapy;
- counseling / mental health therapy;
- home nursing care, ambulance services, hospital room upgrade.

Drugs, products, or devices

Depending on the details of your specific plan, drugs, products, or devices may be partially or fully covered:

- directly by your insurer (give the pharmacy or healthcare provider your policy and identification numbers located on the card issued by the insurer);
- through a reimbursement claim after you pay the full cost. You must submit your receipt for the claim.

Most plans allow electronic claims to be submitted through a mobile application or portal on their website. If you're set up for direct deposit, the reimbursement can be deposited directly into your account within a few days.

Aside from the cost of the drug, product, or device in question, you may be responsible for covering other fees:

- **Deductible:** A fixed amount that you're required to pay before the insurer provides the benefit.
- **Co-payment:** A percentage or fixed amount paid each time you pick up a drug or product.
- **Dispensing fee:** Service fee paid to a pharmacy or healthcare provider for preparing and dispensing a drug or product. There is a vast range for fees but they are typically less than $15 CND.
- **Brand vs generic:** Some drugs or products are available in both branded and generic versions; some plans may only cover the lower priced version – usually the generic. This means you can either choose the generic, or cover the difference in cost between the branded or generic option and opt for the branded product. Ask your pharmacist about this before filling your prescription(s).

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Understanding the fees you'll have to pay can help you evaluate if you'll need extra help covering your future drug, product or device costs.

Special authorization

Some drugs, products, or devices must be approved before they can be covered. There are two ways this can be done:

1. The prescriber must complete a special form that is usually available on the insurer's website or can be emailed/mailed to you. It is your responsibility to ensure the prescriber receives and completes the form.
2. The pharmacist or provider uses a "billing authorization code" to replace the form. Check with your insurer if a code can be used instead of a form.

Special authorization approval can take 10 business days or more to be processed. It's a good idea to contact your insurer to verify that the form was received and completed properly since any errors or omissions by the prescriber can result in further delays.

Private health insurance plans

Check your insurance information booklet for details on how to submit a claim. The claim process can sometimes only be started after a specialist (hematologist/oncologist) has confirmed your diagnosis. Your doctor will need to complete a portion of the claim and your insurer may ask for copies of your results and reports. It may take several weeks for your insurer to review your claim.

Credit/mortgage payment insurance

Contact your lender(s) for instructions on how to make a claim. They should be able to guide you through the process and tell you what documents you are required to submit. Your claim may take several weeks to process, and in the interim, you might still be responsible for payments; your lender should be able to provide you with any information you may need. If approved, insurers may also periodically review your claim and request updates of your condition.

Verifying your coverage

When calling insurers to verify your coverage, you will need the following:

- Your policy/contract number and identification/certificate number located in your policy booklet or card;
- Drug identification number (DIN) if you're inquiring about a drug: Search for DIN
- Product/device name or number if you're inquiring about a product/device

Sample questions you may want to ask:

- Is the drug/product/device listed on my plan?
- Does the drug/product/device require special/prior authorization? What are the next steps?
- How much of the cost is covered by my plan?
- Are there any exclusions, payout maximums, or limits that I should know about?

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If you're told that the drug/product/device is not listed on your plan:

- The insurer may have already reviewed the drug/product/device and decided against covering it (known as a "non-benefit");
- The drug/product/device might be new to Canada and the insurer hasn't reviewed it yet. If a review isn't in progress, you might be able to appeal for coverage.
- The drug/product/device requires special/prior authorization.

Appealing Decisions

Self-advocacy & documenting communications

During your journey with myeloma, you may need to advocate for yourself or your loved one to obtain the services you need or the benefits that you're entitled to. One form of self-advocacy is appealing decisions you disagree with. It's important to document all communications with the government agency or insurance company related to the appeal – it can help you build a winning case. Staying educated and informed helps make self-advocacy easier and much more effective.

Appealing government income support program decisions

If you disagree with a decision, government income support programs have appeal processes in place. Appeal processes for provincial and territorial government programs will vary. The federal government has the following process in place:

- Request for reconsideration
  - Requests are made in writing and are submitted in person or by mail within 30 days after the date the decision was communicated to you.
- Social Security Tribunal of Canada
  - If you disagree with the decision made on your request for reconsideration, you can file an appeal with the Social Security Tribunal (SST) General Division within 30 days after the day the decision is communicated to you by letter or by phone.

Appealing drug, product or device coverage decisions

If you disagree with a drug/product/device decision, government programs have appeal processes in place; however, they will vary between provinces and territories.

For group/private insurance, if a drug/product/device is not included in your plan and it's not listed as a "non-benefit", you may:

- Ask your prescriber to submit an appeal letter that explains your need for the drug/product/device. The letter should include:
  - Patient name, insurance policy (contract) number and identification (certificate) number;
  - Diagnosis and prior treatments (if any);
  - Drug/product/device required with DIN or product name/number;
  - Reasons for recommendation, reasons why other options are not appropriate, recent study results, and estimate of how long the drug/product/device will be used;
  - Process for monitoring and assessing the impact of the drug/product/device.
- Inform your employer/union that the drug/product/device is not covered in the group plan, if you're comfortable doing so. Some plans allow employers to modify coverage.

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Tax Credits & Additional Help with Health-related Costs

Federal government tax credits

- **Medical expense tax credit**
  - Various medical expenses can be claimed on your annual income tax return as non-refundable credits that reduce your taxable income. Among medical expenses that can be claimed are travel for medical services, walking aids, wheelchairs, cancer treatment in or outside Canada, dental, medical cannabis, and laboratory procedures or services fees.
    - Medical expense tax credit
    - Complete list of eligible medical expenses
    - Claiming medical expenses on your tax return
    - Meal and vehicle rates
    - Other deductions, credits, and expenses
- Disability tax credit
  - This is a non-refundable tax credit that helps persons with disabilities, or their supporting persons, reduce the amount of income tax they may have to pay each year. To qualify, you must have a severe and prolonged mental or physical impairment.
  - Registered disability savings plan: Savings plan intended to help others save for the long-term financial security of a person (under the age of 60) who is eligible for the disability tax credit.
- GST/HST credit
  - Non-taxable amount paid four times a year to individuals and families with low and modest incomes to help offset all, or part of, the GST/HST they pay.
- Canada caregiver credit
  - Non-refundable tax credit to help support a spouse, common-law partner or dependant with a physical or mental impairment.

Medical equipment, supplies, and devices

Provincial government programs

- **Alberta**
  - Aids to daily living
- **British Columbia**
  - Medical equipment & devices
- **Manitoba**
  - Assistive technology
  - Information for Manitobans with disabilities

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- **New Brunswick**
  - Health services medical supplies/services
  - Disability support program
- **Newfoundland & Labrador**
  - Special assistance – Medical equipment and supplies
- **Nova Scotia**
  - Wheelchair loan program
  - Health equipment loan program
- **Ontario**
  - Assistive devices program
- **Prince Edward Island**
  - AccessAbility supports
- **Quebec**
  - Assistive devices, disabilities and handicaps
- **Saskatchewan**
  - Aids to independent living

Territorial government programs

- **Northwest Territories**
  - Extended health benefits
- **Nunavut**
  - Extended health benefits
- **Yukon**
  - Extended heath care benefits and Pharmacare for seniors

Additional Support, Counselling and Caring for Yourself

Overview

Everyone reacts to their diagnosis in different ways. You may feel sad, angry, afraid, alone, stressed, and even depressed at times. Or you may feel "mentally numb" or separated from your emotions...you may even feel that you're coping well and aren't experiencing any changes in your mental health. Whatever your situation, the emotions you experience are not right or wrong; they're yours, and they can come and go.

It's important to remember that feelings tend to gain power when they're bottled up or when we pretend they don't exist. Try to recognize, acknowledge, accept and express how you're feeling. Over time, not addressing or handling the emotional ups and downs of living with myeloma may result in mental health problems (i.e., anxiety), impact your sleep, cause fatigue, and even affect how you deal with side effects and the disease itself.

If these feelings persist and start to keep you from fully engaging in life, it may be a sign to seek help. If you can, start by discussing how you're feeling with a close friend, family member, and your doctor or nurse. Often times, relief can be found by speaking to people that can personally identify and relate to you, your experiences and your feelings. Talking to others who are living with myeloma through local and/or online myeloma patient support groups can help you feel less alone, and provide some help and comfort. These are your true peers who can validate your experience, give you fresh ideas and a shoulder to lean on.

If you're still feeling overwhelmed and need more help, talk to your doctor or nurse about professional support (i.e., psychologist, psychiatrist, counsellor, social worker, mental health nurse) at your cancer centre. These professionals can help you explore your feelings and experiences, help you develop coping strategies and solutions to some of the problems you're facing. If your cancer centre doesn't provide these resources, or if you live far from your centre, speak to your general practitioner (family doctor) about public or private professional support resources you can access and that may be closer to home.

Be actively involved in your treatment decisions

Understanding your diagnosis, treatment, and being actively involved in your treatment decisions can also help you feel more in control and more positive. Studies have shown that patients and caregivers have fewer decisional regrets - and a higher degree of satisfaction with their care - when they play an active role in the decision-making process around their disease.

Be sure to initiate a discussion with your doctor about the role you would like to play in your treatment decisions. As the most integral part of your healthcare team, only you can make healthcare decisions that are consistent with your preferences, needs and values. Moreover, having a treatment plan in place for if and when a relapse occurs can help ease your mind.

Understanding the risks, benefits, administration and requirements of different therapies will help you make informed decisions. Consider asking your healthcare team the following questions:

- Will this treatment plan limit future treatment choices?
- What are the most common drug-related side effects?
- How are the drugs administered (e.g., oral, intravenous, injection)?

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- Is travel to the hospital required for treatment and, if so, how many weekly visits?
- Are there clinical trials available?

Please consult Myeloma Canada's resources listed below to help you better understand, manage and track your myeloma and treatment.

- **Myeloma Canada Educational Publications**
- **Myeloma Canada Educational Videos**
- **Clinical Trial Finder Tool (provided by Cancer Trials Canada / Q-CROC)**

Caring for yourself

Your health and your well-being are a priority. Be sure to take time for yourself and continue to do the things you enjoy. Prioritize what's most important and put aside what's not. Try using the following tips to look after yourself throughout your journey with myeloma:

- Eat well and get plenty of sleep to keep your energy level up:
  - Try to avoid the "grab whatever" habit;
  - Cook more than you need for each meal and freeze the rest;
  - Short afternoon naps can help you feel more rested;
  - A cup of herbal tea may relax you before bedtime;
- Get some fresh air, even just a few minutes can make a world of difference;
- Spend time with your friends and family members;
- Make time for exercise that's appropriate for you - and approved by your healthcare team - on most days of the week:
  - Any type of movement, even a walk, can help you sleep better at night, clear your mind and help you feel energized.
- Take breaks from whatever you're doing to clear your head each day:
  - Exercise;
  - Take a walk outside (visit the local park, stroll through your neighbourhood);
  - Speak to, or get together with, a friend or relative;
  - Read a book or magazine;
  - Take a class in something that interests you;
  - Continue or start a hobby;
  - Go shopping;
  - Take a relaxing bath or shower.
- If you need to, ask others for extra help;
- When offered, accept help from others;
- Take a holiday or go away for a few days.

Rather than thinking about your myeloma, one of the most important things you can do for your mental and physical health is to try and live in the moment and take things one day at a time.

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. Email us at contact@myeloma.ca for more information.

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 Caregiver Support Group on Facebook.

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Make Myeloma Matter

Every year, Myeloma Canada provides information to thousands of people impacted by myeloma through programs and services such as educational events, the Myeloma Matters online newsletter, educational and patient journey videos, and an extensive library of educational materials.

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 or through our Ways to Give page, over the phone by calling toll-free 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 our annual Multiple Myeloma March or Myeloma Canada Ride 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 myeloma.ca.

Myeloma Canada would like to thank Amgen, Bristol Myers Squibb, Janssen, Sanofi Genzyme, and Takeda for providing unrestricted educational grants that partially funded and helped make the creation of this Guide possible.

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