



Multiple Myeloma Caregiver Handbook





MYELOMA CANADA

MAKING MYELOMA MATTER

www.myeloma.ca





Reviewers

Patients & Caregivers

Debbie Basevitz
Montreal, QC

Tony Brathwaite
St John's, NL

Lorelei Dalrymple
Edmonton, AB

Trish Macdonald
Halifax, NS

William Paine
Vancouver, BC

Editors

Marcie Baron
Manager, Communications & Marketing
Myeloma Canada
Montreal, QC

Gabriele Colasurdo, MSc
Manager, Education & Patient Services
Myeloma Canada
Montreal, QC

Michelle Oana
Associate Director
Development & Community Relations
Myeloma Canada
Montreal, QC

Jessy Ranger
Communications Coordinator
Myeloma Canada
Montreal, QC

Disclaimer

The information in this Handbook 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

Like most cancers, multiple myeloma impacts more than just the person living with the disease. Caregivers experience their own set of challenges and must manage their own stress levels and energy reserves, all while supporting their loved one when they are receiving treatment, managing day-to-day care and navigating the healthcare system. If you are supporting a loved one living with myeloma, you are a caregiver—and this Handbook is intended for you. It provides practical information about caring for your loved one and maintaining your own well-being.

Some of the more technical or unusual words appear in ***bold*** the first time they are used and are explained in the glossary on page 29. As you read through this Handbook, 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 loved one's healthcare team to explain any terms you have trouble understanding. Sometimes, during treatment, a caregiver may be the only one who can speak or ask questions on behalf of the person living with myeloma.

In this Handbook you will find information on:

- helping your loved one through ongoing treatment, medical visits, side effect management and daily care
- speaking to others around you and asking them for help
- caring for yourself and getting your own support

Moreover, this resource will give you a brief overview of myeloma and its treatment so that you can better understand what your loved one is going through, determine the best ways to help them, as well as how to cope with living life with myeloma. Over time, both of you will learn how to adjust to the "new normal" and optimize the quality of your lives.





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 the quality of life for those impacted by myeloma through awareness, education, advocacy, fostering an empowered community and supporting clinical research.

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

For more detailed information about myeloma and living with the disease, visit **www.myeloma.ca** and click on "Resources". Here you can download Myeloma Canada's educational publications, watch educational videos, find a local support group and so much more. To order your free 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*
- *Myeloma Bone Disease InfoGuide*
- *Understanding Your Blood and Blood Tests InfoGuide*
- *Myeloma and the Kidney InfoGuide*
- *Clinical Trials as a Treatment Option InfoGuide*
- *High-dose Therapy and Autologous Stem Cell Transplantation InfoGuide*





Table of Contents

A New Journey 1
- What Does It Mean to be a Caregiver? 1
- Understanding and Accepting Your Feelings 2
- Understanding and Accepting Your Loved One's Feelings and Needs 2
- Getting Started 3
- Treatment 4
- Advocating for Your Loved One 4

About Myeloma 5
- What is Multiple Myeloma? 5
- Symptoms and Diagnosis 6
- Treatment Options 7
- Understanding Relapse 11

Helping Your Loved One with Treatment 12
- Before and During Medical Visits 12
- Patient's Rights and Responsibilities 13
- Questions for the Healthcare Team 14
- Helping with Therapy 15
- Researching and Planning Future Treatment Options 16
- Drug Access and Reimbursement 17
- Managing the Side Effects of Treatment 17

Helping Your Loved One with Life 19
- Tasks of Daily Living 19
- Longer-term Planning 20
- Putting Some Fun into Life 20
- Caring for Someone with Advanced Disease 21

Talking About It 22
- Speaking to Your Loved One 22
- Speaking to Other People 22
- Speaking to Children 23

Taking Care of Yourself 24
- Caring for Yourself 24
- Honouring Your Feelings 25
- Recognizing When You're Burnt Out 26
- Getting Your Own Support 26

Caregiver Associations 28

Glossary 29

Make Myeloma Matter 31

Myeloma Canada Scientific Advisory Board 32



A New Journey

It's undoubtedly fair to say that you wish that you didn't have to be a part of this new journey. We understand and we're here to help. This Handbook was created to give you a glimpse into what it means to be a caregiver and to help you understand - and accept - your and your loved one's feelings and needs. It also offers practical advice and strategies on how to start supporting yourself and your loved one throughout this experience.

What Does It Mean to be a Caregiver?

What makes you a caregiver? You don't need to be a family member or even a close friend to qualify. Just as the word suggests, a caregiver is someone who gives care. You may step into the caregiver role little by little, or find yourself thrust into it all at once. You may take the person for whom you're caring (referred to as your loved one throughout this Handbook) to all doctors' visits or simply provide them with the occasional ride or meal. You may have a talent for speaking to doctors or a knack for cheering people up. As long as you give care, you're a caregiver.

Before anything else, you should evaluate how much care you are willing and able to give. This will depend on several factors, including your loved one's symptoms and treatment plan, as well as your own work, commitments and physical and mental reserves. Think about:

- what your loved one needs most
- the type of support you are best suited to provide
- how much time you can realistically devote
- what other people (ie, family and friends) can help you with
- what government and/or private healthcare resources can help you with

Many caregivers are worried or feel guilty about leaving their loved one alone. It's important to remember that you also have personal responsibilities to keep up with. If you live a considerable distance away, or if you are not able to give as much support as you would like, something as simple as a phone call, email or text message can help lift their spirits.

If you work outside the home, it's a good idea to inform your employer about your situation at an early stage. Find out if your employer or benefits plan allow for a paid or unpaid leave of absence for caregivers. Try asking your employer if you can modify your working hours or do more work from home. You may also be eligible to receive financial assistance through employment insurance offered by the Government of Canada.

Myeloma vs. Melanoma

Myeloma is often confused with ***melanoma.*** Myeloma is a cancer of the plasma cells, a type of immune cell, in the bone marrow. Melanoma refers to a form of cancer that usually occurs in the skin, but can also occur in the eye and mucous membranes.

Understanding and Accepting Your Feelings

Alone, sad, confused… unprepared, anxious, overwhelmed… determined, hopeful, accepting… No two caregivers are alike and no feeling is "wrong." It's common to experience an array of emotions given your specific and unique situation: hopeful one minute, despondent the next. It's all normal and expected.

The very word "cancer" strikes fear in many people's hearts. When you first hear the diagnosis, your mind may race ahead of you, imagining worst-case scenarios. Remind yourself to take things one day at a time. Each day will bring new learnings, skills and coping strategies.

For many people, accepting the "new normal" takes some time. You may wish that things could go back to the way they used to be. If you acknowledge and accept these feelings, they may eventually subside.

Understanding and Accepting Your Loved One's Feelings and Needs

Your loved one might find it difficult to have to depend on you; they may also worry about being too much of a burden on you. Conversely, you may sometimes feel that you're being overbearing, or not helping enough.

Talk to and work with your loved one to find a balance that enables you to both have control over your own lives. Ask them what they are feeling, what they need from you, and tell them what you need from them. Remember to keep communicating with them in this way on a regular basis because both your needs might change. You're a team and in this together – remember to keep an open dialogue for discussion.

To help your loved one feel better about being cared for, allow them to maintain their independence whenever possible:

- Ask them to make their own decisions and choices
  - These rights should always be respected unless their decisions can result in harm or negatively impact your or their life
- Encourage them to do the things that they are still capable of doing
  - Only help them do the things they can no longer do
- Ensure that you do the things that you promise to do for them

Sometimes, a person living with myeloma will need a lot of care (eg, when undergoing treatment or experiencing symptoms and side-effects); other times, they may be relatively symptom-free. To help keep a sense of normalcy, take advantage of the days they're well by planning activities you both enjoy.

Getting Started

Collecting information can help you and your loved one better understand, cope and manage the condition. As early as possible following the diagnosis, it is helpful to start collecting and organizing key information such as:

- Name and contact information for members of the healthcare team
- Dates and the reason/purpose of all appointments
  - List all outcomes and decisions that were made
- Copies of lab results (eg, blood, urine, imaging, etc.)
  - In Canada, patients by law must be given access to their medical information. If requested, a reasonable fee may be charged to cover printing/copying costs. In some provinces, you may have access to this information through an online portal.
- Record of energy and pain levels on a scale of 0 (lowest amount) to 10 (highest amount) at different times during the day (can help identify trends)
  - Pain: Include a description of the type of pain experienced, where it is and whether it moves or changes throughout the day

As a caregiver, there are a few more things you can do to start supporting your loved one:

- Join them for their appointments, help them ask questions and take notes
- Help arrange transport to and from appointments, if required
- Help them plan their schedule and manage their appointments
- Participate in fun activities with them when their energy levels are usually at their highest

Treatment

Consider preparing a chart with treatment schedules, prescriptions and lab results, and keep it where their medications are stored. You can also use electronic or online tools to help you maintain and update the details of their prescribed treatment regimens, such as:

- dates medications are prescribed and received
- dosage (eg, how and when to take)
- possible side effects
- side effects experienced and when they are felt
- when and how to report side effects to the healthcare team and when to go to the hospital (see page 18)

Advocating for Your Loved One

When a person is diagnosed with myeloma, major changes occur in their life. To help your loved one through these changes, you can become their advocate. Advocacy can take on many shapes and forms. Here are a few examples:

- Sort out the information and services they need and identify the most appropriate person or organization to contact to best address these:
  - Medical needs: the healthcare team (eg, nurse practitioner, hematologist, oncology nurse, pharmacist, etc.); emotional needs: social worker or counsellor; personal issues (eg, housekeeping, transportation): family; job-related and/or financial issues: their employer, an accountant or lawyer
- Attend appointments
  - Prepare and keep track of questions for each appointment ahead of time
  - Take, review and store notes for each appointment. Don't expect to accurately remember all details from memory
- Learn how the disease is treated and managed. This can help you better understand the specific details of your loved one's condition so that you can be an active partner when discussing management strategies and a treatment plan with their healthcare team.
  - Visit Myeloma Canada's website **(www.myeloma.ca)**
  - Ask the healthcare team for booklets, brochures and reputable websites to consult
- Involve others to help support your loved one in different ways
  - Some people may offer emotional support while others may offer practical support, such as running errands or driving places
- Find and join a local myeloma patient support group for your loved one
  - Patient support groups can be valuable sources of information and support, and many arrange for educational talks by healthcare professionals
  - Visit Myeloma Canada's website **(www.myeloma.ca)** or ask the hospital or cancer centre if there is an existing local patient support group in your area. If there isn't, why not consider forming one yourself? Myeloma Canada will gladly provide you with the information and support you need on how to get started. You can contact us at **contact@myeloma.ca** or call us toll-free at **1-888-798-5771** to learn more. If there aren't any groups nearby or if travel is difficult, consider joining Myeloma Canada's online support groups on Facebook (see page 23).





About Myeloma

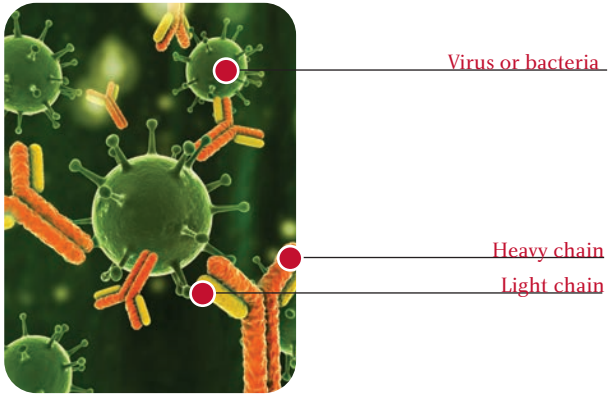
What is Multiple Myeloma?

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 (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.

Did You Know?

Myeloma 2019 Facts and Figures

Approximately 3,300 new cases of myeloma are diagnosed every year—that's 7.7 out of 100,000 people.

- Myeloma represents 1.7% of new cancers in men and 1.3% in women
- Myeloma is fairly rare before age 40; the average age of diagnosis is in the mid-60s
- Factors that may increase the risk of myeloma include:
  - Exposure to toxic chemicals
  - Exposure to radiation
  - Obesity

Studies have shown that there are some genetic variations that can increase the likelihood of a person developing myeloma. These genetic variations are inherited, however, their effect is very small. This means that individuals may inherit a certain combination of genetic variations that puts them at higher risk of developing myeloma, but the inherited factors are only a small piece of the puzzle. It is certain that other genetic and environmental factors are needed before myeloma develops.

Symptoms and Diagnosis

During the early stages of myeloma, there may be no symptoms. Most people first go to their doctor because of vague symptoms that can be difficult to diagnose, such as fatigue, recurrent infections or back pain.

Diagnostic or ***prognostic*** tests for myeloma involve looking at the blood, urine and bones.

The condition is diagnosed through (diagnostic) lab tests that help:

- establish whether M-protein is present in the blood or urine
- confirm the presence of myeloma cells in the bone marrow
- determine whether or not there is organ damage as a result of the myeloma (eg, bone damage or kidney dysfunction)

Prognostic tests help determine the best course of treatment by:

- determining tumour burden (severity of the disease)
- suggesting how aggressive the cancer is

Some prognostic tests can even characterize genetic abnormalities of the myeloma cells.

The Importance of Drug Adherence

Drug therapy for myeloma can be complex, and some patients may find it difficult to follow and adhere to the prescribed regimen. Not surprisingly, poor adherence can lead to worse outcomes. In general, motivation to follow therapy increases if the patient knows what each drug is for. You can help by providing reminders as needed, especially at the start of a new drug regimen. Keep in mind that it is important to report any and all side-effects your loved one is experiencing to their healthcare provider, even if they feel it is minor or if they're worried about the treatment being stopped.

Treatment Options

Once the disease has been treated and is under control, people with myeloma can spend periods of time with few or no symptoms and experience relatively normal lives. Bear in mind, however, that myeloma is a very individual disease and not all patients experience the same symptoms, responses to treatments and/or ***overall survival.***

A number of factors are considered before a person's myeloma is treated:

- Physical examination and diagnostic test results
- The stage (severity) of the disease
- Presence of prognostic indicators (eg, genetic mutations)
- Patient's age and general state of health
- Symptoms being experienced (eg, bone pain or fractures)
- Complications being experienced (eg, kidney disease, anemia or infections)
- Existing health problems (eg, heart disease, diabetes)
- Previous treatments and how the myeloma responded to them
- New treatments available through clinical trials
- Patient preference

Once a diagnosis has been made, each patient is assessed individually. What works for one person may not work for another. Regardless of the treatment, the goals are similar:

- Stop the production of myeloma cells
- Strengthen bones and prevent fractures
- Increase hemoglobin count and reduce fatigue
- Reduce the risk of infections
- Prevent kidney damage
- Promote well-being and enhance quality of life

Treatment is customized to each situation. The initial treatment is called ***first-line therapy***. If the patient does not respond or the disease comes back, the next treatment is called ***second-line therapy***. Depending on the specific case, treatment may combine various approaches:

- Observation
- Radiotherapy
- Corticosteroids (steroids)
- Chemotherapy
- High-dose therapy and autologous stem cell transplantation
- Immunomodulatory agents (IMiDs)
- Proteasome inhibitors (PIs)
- Monoclonal antibodies (MoAbs)

Staying informed on the treatment of myeloma is important for both patients and caregivers so that you can be more involved with treatment-related decisions and together with the healthcare team, build a treatment plan. At the time that this Handbook was printed, a number of new and emerging therapies were becoming available.

Observation

Sometimes, the best treatment is no treatment at all. If the myeloma is stable (not progressing or getting worse), a reasonable option may be to simply monitor the condition.

Radiotherapy

High-energy radiation may be used to damage myeloma cells and prevent them from growing. Radiotherapy is typically used on specific parts of the body to treat bone pain and ***plasmacytomas,*** usually in combination with some form of chemotherapy.

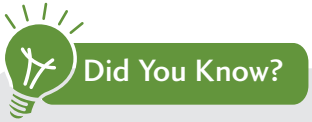
Corticosteroids (steroids)

Corticosteroids are chemicals naturally produced by the adrenal gland to help prevent inflammation. The synthetic or man-made steroids most commonly used to treat myeloma are prednisone and dexamethasone. They can be used alone or in combination with other drugs.

Chemotherapy

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. There are many forms and combinations of chemotherapy regimens. Some of the most common in Canada are:

Agents	MP	CyBorD	CyBorP	CRd	VMP	MPT
Chemotherapy						
Cyclophosphamide (Cytoxan)		X	X	X		
Melphalan (Alkeran)	X				X	X
Proteasome Inhibitor						
Bortezomib (Velcade)		X	X		X	
Immunomodulatory Agents (IMiDs)						
Thalidomide (Thalomid)						X
Lenalidomide (Revlimid)				X		
Corticosteroids (Steroids)						
Prednisone	X		X		X	X
Dexamethasone (Decadron)		X		X		



Although called a stem cell "transplant", there is no actual organ removed from a donor to a recipient. As stem cells were traditionally collected directly from the bone marrow rather than from the circulating blood, the procedure was originally referred to as a bone marrow "transplant".

High-dose Therapy and Autologous Stem Cell Transplantation

There are two main types of stem cell transplant approaches:

- *High-dose therapy and autologous stem cell transplant:* The stem cells come from the patient. An autologous transplant is the ***standard of care*** and most commonly used therapeutic approach for newly diagnosed transplant-eligible patients with myeloma.
- *Allogeneic (donor) stem cell transplant:* The stem cells come from a matching donor such as a relative (usually a sibling), or a matched unrelated donor (MUD). Allogeneic transplant is not the standard of care for treating myeloma. This approach is generally undertaken under the supervision of a clinical trial setting.

NOTE: This Handbook will exclusively provide a brief overview of high-dose therapy and autologous stem cell transplantation. For more information, please consult Myeloma Canada's High-dose Therapy and Autologous Stem Cell Transplantation InfoGuide.

The goal of an autologous stem cell transplant is to achieve a deeper, more durable response to ultimately improve quality of life and overall survival. When considering any treatment, however, it's important to think about the potential advantages and evaluate if they outweigh the potential disadvantages, risks and side effects. An autologous stem cell transplant is usually the most intensive treatment someone with myeloma will receive, therefore it's important that your loved one be well-informed. To help you better understand and assess whether an autologous stem cell transplant is right for your loved one, the following section will clearly outline the 7 steps involved, before, during and after the procedure.

1. EVALUATION: Not every newly-diagnosed patient is eligible for an autologous stem cell transplant. The high-dose therapy step (step 5 – ***conditioning***) is very intensive and generally limited to people that are strong enough to tolerate the treatment.

2. INDUCTION: The patient receives a chemotherapy regimen to kill as many myeloma cells as possible with the aim of reducing symptoms and lessening ***end-organ damage***. This step also prepares for the mobilization and collection of the stem cells.

3. MOBILIZATION: To enable stem cell collection, a medication is given to mobilize (release) some stem cells from the bone marrow to the patient's blood.

4. COLLECTION: Stem cells are collected from the patient's blood. This step is also referred to as stem cell harvest.

5. CONDITIONING: High-dose chemotherapy is used to kill as many of the remaining myeloma cells in the patient's body and bone marrow as possible.

6. RESCUE: This step involves the thawing and infusion of the collected stem cells back into the patient's body to "rescue" the bone marrow. These stem cells contain healthy blood-forming cells that will make new blood cells to replace the cells destroyed by the high-dose therapy through a process known as ***engraftment***. A successful engraftment enables the bone marrow to recover and re-establish blood cell production.

7. **RECOVERY:** Depending on the person, the recovery period can vary widely from a few months to a year. During this time, your loved one will be followed closely by their healthcare team.

To determine whether someone is eligible for high-dose therapy and autologous stem cell transplantation, overall health, fitness, age, previous treatments and the presence of other diseases or conditions (co-morbidities) are considered. Many hospitals have a general rule that an autologous stem cell transplant is not routinely offered to people above a certain age, such as 65 or 70 years; however, these are not "hard-and-fast" rules and the important thing is general health, rather than age.

Age cut-offs vary between hospitals and can be somewhat flexible depending on the case and the hospital. For example, a "fit" 71-year-old person could be considered for an autologous stem cell transplant while a "frail" 64-year-old person may not be eligible. In other words, someone who is deemed not healthy enough to withstand the high-dose therapy (conditioning step) of the procedure will not be eligible for an autologous stem cell transplant. Moreover, a person considered ineligible can become eligible for a transplant if the reason for their ineligibility changes.

More Information

For more detailed information about stem cell transplantation, refer to Myeloma Canada's High-dose Therapy and Autologous Stem Cell Transplantation InfoGuide by visiting **www.myeloma.ca,** click on "Resources" and then "Myeloma Canada Patient and Caregiver Educational Publications".

To order free copies, send an e-mail to **contact@myeloma.ca** or call **1-888-798-5771** toll free.

The Three R's of Treatment Response

- ***Remission:*** Complete or partial disappearance of signs and symptoms
- ***Relapse:*** Reappearance of signs and symptoms after a period of improvement
- ***Refractory:*** Relapse with lack of response to treatment

Immunomodulatory Agents (IMiDs)

Instead of destroying both myeloma and healthy cells (like chemotherapy drugs), IMiDs only attack myeloma cells and enhance the immune system cells that identify and fight cancerous myeloma cells. There are presently three IMiDs approved for the treatment of myeloma in Canada: thalidomide (Thalomid), lenalidomide (Revlimid) and pomalidomide (Pomalyst).

Proteasome Inhibitors (PIs)

Proteasome inhibitors are targeted drugs that block the activity of the proteasome, a substance in myeloma cells that breaks down protein. Blocking the proteasome causes myeloma cells to die. In Canada, there are three PIs approved for use in myeloma: bortezomib (Velcade), carfilzomib (Kyprolis) and ixazomib (Ninlaro).

Monoclonal Antibodies

Monoclonal antibodies enlist the natural immune system functions to fight cancer. They're designed to bind to protein that are generally more numerous on the surface of cancer cells than healthy cells, thereby providing a more "targeted" approach to killing myeloma cells. In Canada, one monoclonal antibody has been approved for the treatment of myeloma: daratumumab (Darzalex).

Understanding Relapse

It's important to understand that the cure for myeloma has not yet been found, however, there are instances of some patients undergoing extended periods of remission. Although treatments are able to kill most myeloma cells, they're not able to kill them all. With time, these residual myeloma cells start multiplying and lead to relapse.

Once relapse occurs, treatment options may include:

- a myeloma drug, usually in combination with a steroid such as dexamethasone
- a second transplant
- new treatments through clinical trials

Before recommending future treatment options, your loved one's doctor will take into consideration the amount of time your loved one was in remission and their past treatments.

Relapse, or the fear of relapse, can be a major source of anxiety for both patients and caregivers. Having a treatment plan in place when relapse occurs (see page 16) can help ease the mental burden. See the "Taking Care of Yourself" section on page 24 for a few tips on how to manage stress and anxiety.

More Information

For information on the various drugs used to treat myeloma, please refer to Myeloma Canada's Multiple Myeloma Patient Handbook by visiting **www.myeloma.ca,** click on "Resources" and then "Myeloma Canada Patient and Caregiver Educational Publications".

To order free copies, send an e-mail to **contact@myeloma.ca** or call **1-888-798-5771** toll free.





Helping Your Loved One with Treatment

Depending on the type of care your loved one requires, there's a whole team of dedicated healthcare professionals who are ready to help, playing either primary or supportive roles:

- **Doctors:** family doctor, oncologist, hematologist, radiotherapist, rheumatologist, surgical oncologist, orthopedic surgeon
- **Nurses:** oncology nurse, nurse educator, nurse practitioner, pivot nurse, registered nurse
- **Other:** pharmacist, dentist, drug access navigator, dietitian/nutritionist, exercise specialist, social worker, support group, psychiatrist, psychologist, counsellor, spiritual advisor

Most caregivers don't have formal training so you can learn a lot from the healthcare team. The following list outlines some of the important things you should inform yourself about from the healthcare team:

- How and when to communicate with the healthcare team
  - Contacts at the hospital, department phone numbers and extensions
- List of side effects to look for and when medications should be given
- What constitutes an emergency, when to go to the hospital and whom to notify
- What to do when the doctor or on-call doctor can't be reached
- Anticipated changes in the foreseeable future
- Resources and services offered by the hospital or cancer centre (eg, social worker, physiotherapy, nutrition, etc)
- Available at-home medical services (eg, private or government)
- Hospital information (eg, parking, site maps, ombudsman, etc)
- Their professional assessment of your loved one's physical and emotional condition

Before and During Medical Visits

Encourage and help your loved one start a file with important information about their condition. If you have a flair for organization, consider preparing a chart with their treatment schedules, medications and lab results, and keep it in a safe place near their medications or use electronic or online tools.

To prepare for medical appointments, your loved one should record symptoms and jot down questions. If they're unable or forget to do so, you can prepare the list. If you're present during visits, provide the healthcare team with this information at the beginning of the appointment. If there isn't enough time to cover all of the items, request a follow-up visit or ask if another member of the team can help address them. You may also want to take notes or record important discussions. Although a person in Canada is legally allowed to record a conversation they're a part of, as a sign of respect, ensure that the person you're recording is aware that they're being recorded. They may wish to discuss your concerns first and then only record a summarized version of the discussion.

The Oncology Nurse: Your Most Important Resource

If you need information or guidance, the oncology nurse is your go-to person. In addition to providing front-line care, today's oncology nurses may:

- assess the patient as a "biopsychosocial" being, including life situation and social supports
- educate and build relationships with patients and caregivers
- monitor patient status and listen to concerns
- liaise between patients/caregivers and physicians
- advocate for treatment access (on behalf of patients) to payers and other stakeholders
- navigate patients and caregivers through the healthcare system
- assist with sourcing information and suggest useful resources

Patient's Rights and Responsibilities

Keep in mind that patients have rights and responsibilities. As a caregiver, make sure that your loved one's rights and responsibilities are respected when interacting with the healthcare team.

Rights

- To be treated with respect and courtesy
- To be an advocate or to bring an advocate with them
- To be kept fully informed
- To have things explained in plain language that can be understood
- To be informed of all possible treatment options available at their centre or other facilities, including clinical trials
- To be allowed, and even helped, to obtain a second opinion if requested
- To be given the opportunity to participate in treatment decision-making, including the right to refuse any unwanted treatment(s)

Responsibilities

- Treat members of the healthcare team with respect and courtesy
- Tell the whole truth and nothing but the truth
- Speak up if unhappy or confused (it helps to be tactful when doing so)
- Try to learn about their own condition and treatments in order to participate in shared decision-making
- Comply with any mutually acceptable treatment plan

Questions for the Healthcare Team

Oncologist, hematologist or radiotherapist

- Who should be contacted in case of problems, especially after hours or on weekends (ask for names and telephone numbers)?
- What are the test results and what do they mean?
- What are all of the treatment options, which one do you recommend and why do you feel it is the best approach?
- Are there clinical trials available at this centre or other centres to consider?
- What can be expected during treatment?
- How do we know if the treatment is working?
- Are there any warning signs or side effects to watch out for, and if they occur, to whom should they be reported? Which need to be report immediately?
- How often will tests and follow-up care be required?
- Are there foods, vitamins, supplements or herbal therapies that should be avoided?

Surgical oncologist or orthopedic surgeon

- Can you explain the surgical procedure in detail?
- What can be expected before, during and after surgery? What will the recovery be like?
- When will the follow-up visit be?

Oncology nurse or educator

- What is your role in my loved one's cancer care?
- Are you the person to contact if there is a problem or question?
- Can you help us find reliable and accurate information on myeloma?
- What advice can you give us at this stage of treatment?
- What activities can you suggest to help stay as active as possible?
- Which activities should be avoided?
- Where can we find support?
- Who should I contact if we are experiencing trouble with drug access?

Pharmacist

- What is the purpose of this medication? What side effects are likely to occur and which ones should be reported immediately?
- Are there vitamins, supplements, herbal remedies or foods that should be avoided while taking this drug?
- Can you help us set up a system, such as daily pill boxes or blister packs, to ensure all of the prescribed medications are taken?

Dentist

- Are there any infections or dental problems that should be taken care of before beginning treatment for myeloma?
- Are you familiar with the requirements for treating someone with myeloma and/or with a ***central line*** in place?
- What can be done to reduce the risk of requiring extractions or other traumatic dental work during myeloma treatment?

Dietitian

- Is there anything you can recommend to help with eating or appetite difficulties?
- Is there anything you can recommend to help with overeating due to steroids?
- What foods should be avoided while on treatment?
- Start new therapy: What do we know about this treatment's effect on appetite, digestion, etc.? Is there anything you can recommend to reduce its effects?

Psychiatrist, psychologist, counsellor or spiritual advisor

- Can you help with the emotional aspects of caring for someone living with myeloma?
- Our family and loved ones are very upset about the diagnosis. What can we do to support them?

Social worker

- Can you help us learn how to cope with the life-changes caused by the disease?
- Can you help us figure out what benefits we may be eligible for, such as short or long-term disability leaves?
- Are there any financial assistance programs offered by an organization, the hospital or cancer centre?

Helping with Therapy

People living with myeloma usually take several different drugs with a daily schedule that may vary. Some medications can be taken orally at home, while others require regular hospital visits. Moreover, drugs have generic (scientific) as well as brand names; this can be confusing and may lead to taking the wrong medication. Setting up a system can make life a lot easier for your loved one and ease your own mind. Consider a simple chart with required medications, dosing schedule, drug storage instructions, and information on when refills are due.

It may be useful to pick up a pill box at the pharmacy to help organize tablets and capsules. If your loved one will be travelling or away from home, have them take a photo of their prescriptions with their smartphone to keep the information handy. When travelling, it may also be a good idea for them to take a small reserve of extra medication and store it separately in case a prescription replacement is needed, or in case there's an unforeseen event resulting in a delay returning home.

Some treatments may be injected or administered through a central line. If you are willing and able, the nurse can teach you how to clean the central line to reduce the risk of infection and discomfort. Alternatively, there may be private or government at-home services available to assist you with these types of tasks.

Researching and Planning Future Treatment Options

Your loved one's doctor may recommend a treatment plan, however it's the patient who makes the final decision. Understanding the risks, benefits, administration and requirements of different therapies will help your loved one make informed decisions. Consider asking your loved one's 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 (eg, oral, intravenous, injection)?
- Is travel to the hospital required for treatment and, if so, how many weekly visits?
- Are there clinical trials available?

As a caregiver, you can also help by researching treatment options. See the "Treatment Options" section on page 7 for more information on how myeloma is treated. For even more information, refer to Myeloma Canada's Multiple Myeloma Patient Handbook by visiting **www.myeloma.ca.** Be sure to also ask different members of the healthcare team (ie, oncology nurse or pharmacist) to share their observations and experiences with different treatment plans. After all, treatment isn't just about medical results: the patient's circumstances, preferences and quality of life also come into play. If needed, you can step in as a "second voice" to ensure your loved one is being heard.

More Information

Clinical Trials: Access to New Treatment Options

Clinical trials are research studies done with patients to evaluate new treatments or new ways of combining and administering existing treatments. By testing new drugs or combinations of drugs, each study is designed to find better ways to treat the disease, improve quality of life and answer scientific and clinical questions. Contrary to what some people believe, clinical trials are not only appropriate as the "last option" — trials may be available for patients at every stage of their disease, from ***smouldering myeloma,*** to newly-diagnosed, to relapsed and refractory disease. Often, the drugs or combinations of treatments being studied in clinical trials are not yet approved by Health Canada and therefore, unavailable to patients, except through a clinical trial. Clinical trials may also provide access to drugs or combinations of treatments that are approved by Health Canada but are not covered by provincial governments. If your loved one is interested in joining a clinical trial, bring it up at their next healthcare visit. To search for clinical trials in Canada, visit the **clinical trial finder tool** on our website**.**

For more details about clinical trials and for answers to frequently asked questions, please refer to Myeloma Canada's Clinical Trials as a Treatment Option InfoGuide by visiting **www.myeloma.ca,** click on "Resources" and then "Myeloma Canada Patient and Caregiver Educational Publications"**.** To order free copies, send an e-mail to **contact@myeloma.ca** or call **1-888-798-5771** toll free.

Drug Access and Reimbursement

Drug access and reimbursement for myeloma drugs can be a hurdle for many patients requiring treatment. There are 4 basic ways to pay for drugs:

1. Government health insurance plan (either as a general benefit or through special authorization)
2. Private health plan (if the plan covers the drugs prescribed)
3. Financial assistance from the drug manufacturer (must meet certain criteria)
4. Out of pocket (your loved one pays for the drugs)

To figure out the best payment strategy for a particular drug, start by talking to your loved one's doctor, nurse or a drug access navigator at the cancer centre. If the patient has a private drug plan, contact the insurer to find out which drugs the plan covers. Your provincial Ministry of Health can inform you about government assistance, and the companies that make specialty drugs often have coordinators who help with reimbursement. Aim to coordinate assistance from different sources so that your loved one bears little to no out-of-pocket costs. Myeloma Canada can also help you navigate through any issues you may be facing.

Coping with "Roid Rage"

Steroids can bring on various changes in mood and have also been linked to aggression in certain people. Ask your loved one to give you a "heads-up" when they take their steroids.

If your loved one seems more aggressive than normal, do your best to stay calm. You can also assure him or her that you know it's just the "roids" talking or ask them to focus their energy on an activity they can enjoy on their own. You may both discuss steroid dosing schedules with their healthcare provider as there may be some solutions that can help your loved one better manage the negative effects.

Managing the Side Effects of Treatment

Your loved one's healthcare team will monitor treatment side effects and suggest strategies to manage them. For example, anti-nausea (anti-emetic) drugs can help counteract the nausea caused by chemotherapy. If your loved one is in pain, speak to the healthcare team about the possibility of using different pain medicine (or higher doses). Also note that the healthcare team may not have the full picture, so don't hesitate to fill them in by reporting any and all side effects experienced by your loved one, even if you feel they're minor or if they only occured once. Keeping track of all side effects in a journal can support you and help you navigate issues with the healthcare team.

Did You Know?

"Chemo Brain" is Real

At various phases of treatment, your loved one may be exposed to chemotherapy treatments that may have an impact on mental functions such as memory and thought processing. Patients have termed this feeling of their brain "not being the same" or "fogginess" as chemo brain or chemo fog. Although the effects that are felt and their extent can vary from person to person, the most commonly reported are general "fogginess", slowed thinking, forgetfulness, periods of confusion and difficulty concentrating.

Chemo brain symptoms generally improve over time, however some individuals may continue to experience symptoms long after their treatment has ended and never fully regain that "normal" mental feeling.

There are no established treatments for chemo brain. Coping strategies such as memory aids, mild to moderate exercise and minimizing distractions (ie, avoiding loud places to improve concentration) can also help minimize its effects. Untreated depression, anxiety and sleep disorders (ie, apnea) may also worsen chemo brain symptoms.

Certain side effects require prompt action. If you notice that your loved one has any of the symptoms listed below, take the appropriate measures. Some people hesitate to mention their symptoms because they don't want to be seen as "complainers." If this is the case with your loved one, take the lead and ask about specific symptoms.

Contact the Patient's Nurse

- New cough, skin rash or pain
- Sore throat and/or trouble swallowing
- Mouth sores
- Nausea or vomiting that doesn't go away
- Changes in urine or bowel habits
- Shortness of breath at rest or after mild exercise
- Problems with the central line
- Inability to take medication
- Appetite changes
- Lethargy (eg, staring into space, unresponsive, weak, sluggish and/or hard to wake up)
  - Not to be confused with fatigue
  - Can be related to underlying physical (ie, infection) or mental (ie, depression) conditions
- Any other changes that seem concerning

Go to the Hospital Emergency Room

- Any major changes in vital signs
  - High fever (38.3˚C or more)
  - Severe drop or increase in blood pressure and/or heart rate
- Temperature higher than 38.0˚C for more than an hour
- Chest pain and/or trouble breathing
- More than three liquid stools per day
- Severe nausea or vomiting





Helping Your Loved One with Life

Your loved one can sometimes feel very tired or overwhelmed and may need help with everyday tasks. There may also be times when they feel reasonably well and can manage on their own. Make sure you're available to help them when necessary and let them be independent when you're not needed.

Tasks of Daily Living

Your loved one will likely have better days with enough energy to carry out most tasks, and worse days when you may need to step in a little more. Start by listing all the tasks that your loved one may need help with, using the box below as a guide.

Break it Down

Below are some practical ways to help your loved one:

- Helping with daily activities (eg, grocery shopping, cleaning, picking up prescriptions)
- Cooking and eating a nutritious, balanced diet
- Maintaining the household (eg, repairs, yard work)
- Providing transportation to appointments or other events
- Managing finances (eg, banking, paying bills)
- Providing emotional support and companionship
- Assisting with areas of personal care (eg, meals, getting dressed, bathing)

Due to the myeloma and/or its treatment, your loved one's blood counts may put them at higher risk of bleeding (platelet count below 50 x 10^9/L [50,000 x 10^6/L]) and infection (neutrophil count below 0.5 x 10^9/L [500 x 10^6/L]). If applicable, ask the healthcare team for home-care instructions and be sure to enforce special precautions in your loved one's home:

- Visitors should always wash their hands, or use an alcohol-based hand sanitizer, before they make contact with your loved one
- Ensure that your loved one:
  - washes their hands (or uses an alcohol-based sanitizer) after going to the bathroom and before/after eating
  - showers regularly, dries with clean towels and wears clean clothes
  - avoids flossing, brushes with a soft-bristle toothbrush after all meals and at bedtime, and uses a special mouthwash (provided by the healthcare team)
  - follows the diet recommendations set by the cancer centre's dietitian to avoid foods that may cause a stomach bug or indigestion
- Bed linens should be changed often

Remember: You don't need to do everything on your own. Reach out to other people such as family members so that they can share the workload. Friends are usually willing to help, but they are often too shy to ask or don't know in what capacity. Asking them for something simple and specific such as transportation or preparing a meal is an easy way to ease your burden. To help your loved one maintain a sense of privacy and dignity, consider delegating certain intimate tasks to a professional.

Longer-term Planning

It's a good idea to sit down with your loved one to review his/her financial situation. Make a list of income sources (including investments), savings, pensions, insurance policies, as well as debts and other financial commitments. If you think it may be difficult to pay off a debt such as a mortgage, call the lender and discuss options to ease the burden (eg, suspending payments for a period of time). Next, brainstorm strategies to help your loved one (and you, if you're the partner) increase income or reduce expenses, consulting financial or tax experts as needed. Here are a few suggestions:

- Reduce bills by shopping around for better deals
- Discontinue services you may not need (eg, storage, telephone landline)
- Make relevant insurance claims (eg, critical illness insurance, income protection insurance, caregiver benefit)
- Check eligibility for tax credits and disability benefits
- Get advice on debt management
- Consider early retirement, if it makes financial and logistical sense

It's never easy to talk about succession planning however, it is something to consider discussing at some point. Although it may be a sensitive topic, having a succession plan will put everyone's minds at ease in the long run. Broach the subject gently and tackle the job at a pace that feels comfortable for your loved one. A notary or attorney with expertise in living wills can provide guidance about other useful documents, such as a Power of Attorney instructions.

Putting Some Fun into Life

Long-distance Caregiving

Live far away? With just a little creativity, you can do a lot to brighten your loved one's days. Here are a few ideas:

- Take over some tasks that require just phone calls, such as negotiations with insurers
- Send flowers, a card or even a gift card
- Share photos, music, or podcasts
- Schedule regular phone or video calls
- Arrange for a meal delivery company to deliver one or more meals to your loved one

People impacted by myeloma adjust to several radical changes in their day-to-day lives and may feel that their role has narrowed to "full-time patient." As a caregiver, you may have a similar experience. Perhaps you feel that focusing on the disease will result in a better outcome. However, it's important for both of you to experience life beyond myeloma. When your loved one is feeling well enough, spend time together doing things that have nothing to do with treatment. It doesn't have to be much: a movie, a meal out in a restaurant, or a walk in the park can boost everyone's spirits. Don't be afraid to suggest out-of-the box activities, such as an evening at a comedy club or an outdoor yoga class.

Caring for Someone with Advanced Disease

Some of the simplest ways to care for someone who has advanced disease is to:

- Enjoy their company
  - Listen to music, watch television, read to them, play a card or board game
- Use touch to communicate
  - A squeeze of the hand or warm hug can say just as much as words and can also help with feelings of loneliness and isolation

If your loved one's condition has reached a point where they need extensive physical care, an occupational therapist or home care nurse may be able to show you how to provide physical care, such as:

- Mobility and comfort
  - Getting in/out of bed, chairs, the tub or shower
  - Turning or rolling over in bed
  - Moving/placing cushions
- Elimination/toileting
  - Getting on and off the toilet bowl
  - Helping with using bed/incontinence products, pans and catheters
- Hygiene
  - Washing and drying hair
  - Sponge bathing in bed
  - Trimming nails on hands and feet
  - Brushing teeth and rinsing mouth
  - Moisturizing and hydrating lips and skin
- Giving medication
  - Keeping track of times, dosages and storage

Once these tasks become too much for you, consider options for hiring a home care aide or nurse (government or private). You may find information pamphlets or guides on these services at the hospital or cancer centre.





Talking About It

Speaking to Your Loved One

You may hesitate to speak your mind for fear of causing pain, but honest discussions foster connection and engagement with life. At the same time, you don't want to get stuck in a pattern of reminiscing about "the way things were." Rather than dwelling on what you miss, keep the focus on the here and now. If a sensitive issue arises, deal with it sooner rather than later to prevent resentment from settling in. Perhaps most important of all is to open the door for your loved one to talk, while listening without judgment.

The Sex Talk

If the person you care for is your partner, you may find that myeloma affects your sexual intimacy and activities together. While you may hesitate to burden your loved one with your "needs," discussing the topic in the spirit of finding solutions may lead both of you to a better place. If traditional sex is off the table, holding hands, touching, and massages can help you both feel close and supported. A counsellor specializing in sexual issues can help with such challenges as arousal or erectile dysfunction.

Speaking to Other People

If you are the one to inform other people about the diagnosis, it may be best to keep the initial conversation short and simple, while stating that you'll be happy to answer questions at a later date. You can also give people a copy of this Handbook or the Multiple Myeloma Patient Handbook to review. And remember, it goes both ways: family and friends can help comfort you and serve as a sounding board for some of your own concerns.

Beyond Family and Friends: Caregiver Support

Sometimes, talking to people outside your immediate circle may be easier than talking to family and close friends. Ask your hospital or cancer centre if any caregiver support groups exist in your area, or consider forming one yourself. Myeloma Canada can help you get started. You may also be able to meet and connect with other caregivers through a patient support group or find strength and support by connecting with your religious institution, if you belong to one, or with online discussion groups for caregivers. Visit **myeloma.ca,** and choose **"Find Support"** to see our network of support groups across Canada.

Myeloma Canada has created, and is the lead administrator of an online, virtual caregiver-only support group on Facebook. This closed group offers a safe environment for caregivers to connect and exchange experiences with others facing similar challenges of caring for someone living with myeloma. 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.

Are you looking to connect and find support with other caregivers? To join, **search for the "Myeloma Canada Caregiver Support Group" on Facebook.**

Speaking to Children

If you and your loved one 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. For example: "Your mother has a type of illness that changes her blood cells. It's not contagious, there are several medicines that can help her get better, and doctors have already begun treating her. Any time you have questions, we're here to answer as best as we can." The hospital or cancer centre's social worker can also help by providing suggestions and strategies on how to speak with children.







Taking Care of Yourself

Caregivers often become exhausted and feel like they've lost control over their life – and it's common to neglect looking after yourself properly while trying to handle both caregiving and your regular daily responsibilities. You may notice that you're missing meals, losing sleep, stopping to see friends and feeling guilty about taking time for yourself because you're thinking that you're letting your loved one down. It's important to remember that a caregiver cannot possibly be at their best if they're physically or emotionally drained. When exhausted, you're more likely to make bad decisions and take your frustrations out on your loved one. In the long run, caregivers who neglect looking after themselves are at a higher risk of experiencing burnout and other health issues.

Caring for Yourself

Caregivers usually look back at their experience and either feel like they either didn't do enough or tried to do too much. Regardless, almost every caregiver wishes they had accepted or asked for help sooner. It's important for you and for your loved one.

Your health and well-being is a priority. Not taking care of yourself can result in long-term health problems, depression and anxiety. Be sure to take time for yourself and do the things you enjoy. Try to prioritize what is most important, and put aside what is not in terms of caregiving and your well-being. Using the following tips to look after yourself will help ensure that you'll be there for your loved one throughout the entire journey:

- See your family doctor when you're not feeling well
- 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 in the evening
  - A cup of herbal tea may relax you before bedtime
- When you can, take some time to 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 some exercise on most days of the week
  - Any type of movement, even a walk, can help you sleep better at night

- Take breaks 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
- Arrange for one of your loved one's friends to occasionally replace you
- Take a holiday or go away for a few days

Rather than thinking about what lies ahead, one of the most important things you can do for your mental health is to try and live in the moment and take things one day at a time. If you need a break from caregiving, arrange for a professional to come into your home, or consider getting ***respite care*** (eg, short stay in a facility) for your loved one.

Honouring Your Feelings

Your feelings are not right or wrong. They are what they are and they can come and go. Here are some common feelings experienced by caregivers:

- **Sadness:** You feel "down" and perhaps prone to tears; you don't respond to life with your usual humour or good cheer
- **Anger:** You may be angry at yourself, at friends who have it easier, or even at the person you're caring for
- **Fear:** You may be afraid of the immediate and long-term future, or even afraid to let your mind go there
- **Resentment:** You may resent that people don't fully appreciate your efforts, or that you've given up part of your career or independence
- **Grief:** You may be mourning the loss of what was and what could be, or simply the loss of your everyday life
- **Guilt:** You may feel guilty that you aren't helping enough, that you're healthy, or that you don't have the "right" attitude
- **Loneliness:** You may feel isolated from others—or simply misunderstood

Feelings tend to gain power if we bottle them up or pretend they don't exist. Instead, try to handle feelings by recognizing, acknowledging, accepting and expressing them. If a feeling persists and keeps you from fully engaging in life, it may be a sign to seek help. If you can, discuss how you're feeling with a close friend or family member other than the person for whom you're caring, other caregivers or a professional.

Recognizing When You're Burnt Out

The line between "working hard" and "burnt out" varies from person to person. That said, here are some signs that may help you differentiate between the two.

State of Mind	How it May Express Itself
Denial	You refuse to consider the seriousness of the disease: "I know my loved one will get better."
Impatience	You're annoyed by everyone's questions: "If I have to explain myeloma one more time, I'll scream."
Anxiety	You worry constantly about what the future holds and whether you can manage it.
Exhaustion	You don't have the energy to complete daily tasks and constantly fight the urge to lie down.
Lack of Concentration	You are more forgetful than usual, resulting in missed tasks, deadlines and appointments.
Withdrawal	You don't care about engaging in activities that once brought you pleasure and don't take steps to get together with other people.
General "Bad Feeling"	You can't remember the last time you felt energetic and positive.

Getting Your Own Support

To prevent or get past burnout, turn to other people—from family and friends to therapists and support groups. Aim to build up a core "tribe" that can help with logistical tasks and provide emotional support. Although you may consider your family to be your first resource, always remember that your loved one's healthcare team can also provide caregiver support. They are there to help, so reach out to them as needed.

Perhaps the most valuable thing of all is to connect with other caregivers. These are your true peers who can validate your experience, give you fresh ideas and a shoulder to lean on.

Meeting and speaking to people with shared experiences through support groups can truly provide you with invaluable information and support. Other caregivers 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. For more information on Myeloma Canada's online caregiver support group, or to find a support group near you, please visit **www.myeloma.ca,** "Find Support".

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 preparing a meal or helping out with 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 together, decide what tasks they can take on.

Help with Respite Care

As a caregiver, you may qualify for tax credits and/or help from provincial health services. Depending on your particular situation, a personal care worker or other health professional may provide medical care, personal support, or homemaking assistance. Contact the ministry in your province to discuss your options.

Words from the Wise

"Worry never robs tomorrow of its sorrow, it only robs today of its joy."

— **Leo Buscaglia**

"It is not the load that breaks you down. It's the way you carry it."

— **Lena Horne**

"You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face."

— **Eleanor Roosevelt**

"Some days there won't be a song in your heart. Sing anyway."

— **Emory Austin**

"It is not how much you do, but how much love you put in the doing."

— **Mother Teresa**

"Never believe that a few caring people can't change the world. For, indeed, that's all who ever have."

— **Margaret Mead**



Caregiver Associations

National

Carers Canada _____ **www.carerscanada.ca**
The Canadian Caregiver Network _____ **www.thecaregivernetwork.ca**
The Canadian Home Care Association _____ **www.cdnhomecare.ca**

Provincial

Alberta

Caregivers Alberta _____ **www.caregiversalberta.ca**

British Columbia

Family Caregivers of British Columbia _____ **www.familycaregiversbc.ca**

New Brunswick

New Brunswick Home Support Association _____ **www.nbhsa.ca**

Newfoundland

CareGivers _____ **www.caregiversnl.com**

Nova Scotia

Caregivers Nova Scotia _____ **www.caregiversns.org**

Ontario

Home Care Ontario _____ **www.homecareontario.ca**
Ontario Caregiver Organization _____ **www.ontariocaregiver.ca**
Ontario Caregiver Coalition _____ **www.ontariocaregivercoalition.ca**

Quebec

Association des proches aidants de la Capitale-Nationale _____ **www.apacn.org**
Carrefour des proches aidants de Québec _____ **www.prochesaidantsquebec.com**
Proche aidance Québec _____ **www.procheaidance.quebec**
Regroupement des aidants naturels de la Mauricie _____ **www.rdanm.org**
Regroupement des aidants et aidantes naturels de Montréal _____ **www.raanm.net**



Glossary

Antibodies (immunoglobulins): Protein produced by certain white blood cells (plasma cells) to fight infection and disease in the form of antigens (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. 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.

Bone marrow: The spongy tissue that is found inside your bones. It is soft, fatty and full of blood vessels. Your bone marrow is where most of the blood cells in your body are made.

Central line or central venous catheter: A tube that is placed in a blood vessel (usually in the upper chest) to provide a pathway for drugs or nutrients. The catheter allows medications, fluids, or blood products to be given and blood samples to be taken.

Conditioning: Treatments used to prepare a patient for stem cell transplant that may include chemotherapy, immunotherapy and radiation to the entire body. Conditioning regimens help make room in the patient's bone marrow for new stem cells to grow and help kill cancer cells that are in the body.

Diagnostic: The process of identifying a disease, illness or problem by its signs and symptoms.

End-organ damage: Refers to damage occurring in major organs due to uncontrolled disease. In myeloma, end-organ damage is defined as any one or more of the following CRAB features: elevated blood calcium (hyperCalcemia), kidney (Renal) failure, low hemoglobin (Anemia) and Bone pain and/or fractures (lesions).

Engraftment: When blood-forming stem cells start to grow and make new blood cells.

First-line therapy: Treatment that is used on people who have not had any previous treatment for their myeloma. If the myeloma does not respond (the disease is said to be refractory) or if it progresses after the first-line therapy has been completed (ie, there is a relapse), the subsequent therapy is referred to as second-line therapy.

Melanoma: A cancer of the pigment-forming cells of the skin or the retina of the eye. Not associated with myeloma

despite the similar-sounding name.

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 when an M-protein is present.

Overall survival: Length of time from either the date of diagnosis or the start of treatment when the patient is still alive.

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

Prognostic: Prediction of the most likely outcome or course of a disease; chance of recovery; life expectancy.

Respite care: Temporary institutional care of a sick, elderly, or disabled person, providing relief for their caregiver.

Second-line therapy: Treatment that is used on people following first-line therapy. If the myeloma does not respond (the disease is said to be refractory) or if it progresses after the second-line therapy has been completed (ie, there is a relapse), the subsequent therapy is referred to as third-line therapy.

Smouldering myeloma: An asymptomatic precursor of myeloma where plasma cells may make up 10-60% of the bone marrow, serum M-protein is greater than 30 g/L, and urinary M-protein is equal to or greater than 500 mg per 24 hours. However, there is still no anemia, renal failure, hypercalcemia, bone lesions or myeloma-defining events. Because the disease is not yet active, asymptomatic myeloma is usually observed but not treated.

Standard of care: A treatment (medicine or procedure) that is accepted and widely used by doctors as an appropriate therapeutic approach for a certain type of disease or condition.

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 (eg, muscle, nerve or blood), stem cells are unique because they are capable of long-term self-renewal. Stem cells are also unique because they are only partially developed (unspecialized) cells that can develop (or differentiate) into over 200 different types of specialized cells with useful bodily functions (eg, nerve cells in the brain being able to send messages of pain throughout the body).

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 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 impacted by myeloma through awareness, education, advocacy, fostering an empowered myeloma community and supporting clinical research so that a cure will be found. 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 **www.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.**



Myeloma Canada Scientific Advisory Board

Nizar J Bahlis, MD
Tom Baker Cancer Centre
Associate Professor
Arnie Charbonneau Cancer Institute
University of Calgary
Foothills Medical Centre
Calgary, AB

Andrew R Belch, MD
Division of Medical Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB

Christine Chen, MD
Assistant Professor
Division of Medical Oncology
& Hematology
Department of Medicine
Princess Margaret Hospital
University Health Network
Toronto, ON

Jonathan Keats, PhD
Assistant Professor
Integrated Cancer Genomics Division
Translational Genomics
Research Institute
Phoenix, AZ

Richard LeBlanc, MD
Maisonneuve-Rosemont Hospital
Clinical Assistant Professor
of Medicine
University of Montreal
Montreal, QC

Paola Neri, MD, PhD
Clinical Associate Professor
Arnie Charbonneau Cancer Institute
University of Calgary
Calgary, AB

Linda Pilarski, PhD
Division of Experimental Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB
Member, IMF Scientific Advisory Board

Donna E Reece, MD
Associate Professor of Medicine
Director, Program for Multiple
Myeloma and Related Diseases
Dept. of Medical Oncology &
Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON
Member, IMF Scientific Advisory Board

Tony Reiman, MD
Medical Oncologist
Saint John Regional Hospital
Assistant Dean of Research
Dalhousie Medicine
New Brunswick
Saint John, NB

Jean Roy, MD
Department Head & Hematologist
Dept. of Hematology & Oncology
Maisonneuve-Rosemont Hospital
Associate Professor of Medicine
University of Montreal
Montreal, QC

Michael Sebag, MD, PhD
Assistant Professor
Faculty of Medicine
McGill University
McGill University Health Centre
Montreal, QC

Chaim Shustik, MD
Associate Professor of Medicine
& Oncology
Faculty of Medicine
McGill University
Royal Victoria Hospital
Montreal, QC
Member, IMF Scientific Advisory Board

Kevin J Song, MD
BC Cancer Research Centre
Vancouver General Hospital
Vancouver, BC

Rodger Tiedemann, PhD, ChB, MB
Scientist, Ontario Cancer Institute
Staff Hematologist
Division of Medical Oncology &
Hematology
Princess Margaret Hospital
Assistant Professor of Medicine
University of Toronto
Toronto, ON

Suzanne Trudel, MD
Assistant Professor
Clinician/Research Scientist
Dept. Medical Oncology
& Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON

Darrell White, MD
Nova Scotia Cancer Centre
Queen Elizabeth II Health
Services Centre
Dalhousie University
Halifax, NS

Myeloma Canada would like to thank Amgen, Celgene, Janssen and Takeda for providing unrestricted educational grants that partially funded and helped make the creation of this Handbook possible.

Myeloma Canada

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

Telephone:
Toll-free: 1-888-798-5771

E-mail:
contact@myeloma.ca

Website:
www.myeloma.ca

Follow us on social media for the most up-to-date information and resources:

MYELOMA CANADA
MAKING MYELOMA MATTER

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

Sincere thanks to the fundraising efforts of the Canadian myeloma community who make myeloma matter by helping to advance Myeloma Canada's objectives of awareness, education, advocacy, community empowerment and support of clinical research so that a cure may be found.

Charitable registration number: 862533296RR0001

© 2019 Multiple Myeloma Canada First Edition: July 2019