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MYELOMA CANADA ADVOCACY HANDBOOK

Advocacy for, and on behalf of Canadians with multiple myeloma

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WHAT IS ADVOCACY?



Advocacy is a simple concept that most people are more familiar with than they might initially believe. All humans have rights, personal values and beliefs that shape their actions. Advocacy refers to actions motivated by our values, our beliefs, and the understanding of our rights.

Simply said, advocacy is an assertion of ourselves and what we believe in, with the goal of improving our lives and/or the lives of others.

WHO IS AN ADVOCATE?

You are! Along with anyone who has an idea, cause, unanswered question, or principle they feel strongly about and have the desire to speak up, and act on those feelings.

WHY IS ADVOCACY NECESSARY?

Everyone has **rights** that need to be **respected** and a **voice that deserves to be heard**. In our society, advocacy is essential in ensuring that your voice is not muted and that your rights are not dismissed.

WHAT DOES ADVOCACY LOOK LIKE?

The act of advocating may seem overwhelming and perhaps unnatural to engage in, but it is far less complicated than it looks. In reality, we all regularly advocate in day-to-day life, for example: calling your bank to dispute an unexpected credit card charge, researching the candidates' positions before you vote, or asking someone to explain something you're having trouble understanding.

In these instances, you are exercising your innate advocacy skills by giving voice to your opinion, values, and beliefs. Over the course of your myeloma journey, these core skills can be easily strengthened and applied to any of your advocacy efforts, like asking for a second medical opinion, or requesting more information about a treatment.

When we see advocacy in action, it often takes one of the following three forms:

- 1. advocating for yourself,**
- 2. advocating for others,**
- 3. advocating for systemic change to governments and institutions whose actions impact people living with myeloma.**



WHAT ARE MY RIGHTS AND WHERE DO THEY COME FROM?

Advocacy frequently emerges in response to or pre-emptive defence of *a person or group of people's rights*.

To best defend your rights, the Canadian government at times, finds it necessary to further define the specific rights of certain populations—for example, the rights of patients. Since the late 1990s, there has been a persistent concern that the prioritization of patients' well-being is sinking deeper into the bureaucratic chasm of Canada's complex public healthcare system as evidenced by increasingly lengthy wait-times across the country for various services.

In response, Parliament felt it necessary to directly express to Canadians through *The Canadian Patient's Bill of Rights (2001)*, the standards of conduct they can expect and should demand, of any interaction with the healthcare system. It has since become a key resource for Canadians living with myeloma.

By defining our rights as Canadians in the healthcare context, this document (along with the Charter) gives us the information we need to **easily recognize when our rights are in danger of violation** and provides a **framework** within which we can **better understand how to advocate in their defence**.

CANADIAN PATIENT'S BILL OF RIGHTS BILL C-26 (2001)

"An Act to establish the rights of patients in relation to health, treatment and records..."

ALL PATIENTS HAVE THE FOLLOWING PERSONAL RIGHTS:

- (a) the right to be fully informed as to their medical condition;
- (b) the right to be advised of the treatment options that are available to them;
- (c) the right to be **involved in the decision** as to which treatment to receive;
- (d) the right to information on the qualifications and experience of the health professionals from whom they receive services;
- (e) the right to receive **considerate, compassionate and respectful** public health services;
- (f) the right to communicate with health professionals in confidence;
- (g) the right to have access to all health records that relate to them, to have copies of such records and to have them corrected if they are shown to be incorrect;
- (h) the right to have their health records maintained in confidence and not used for any purpose other than the provision to them of public health services unless pursuant to informed and formal, written consent, which may not be implied or imputed;
- (i) the **right to designate a person to exercise their rights on their behalf** if they are not able to do so as a result of a physical or mental incapacity; and
- (j) the right to be informed of all rights and responsibilities they have under this Act and under other laws of Canada or a province with respect to public health services.



In 2019, the Global Myeloma Action Network, of which Myeloma Canada is a member, collaboratively developed the **Multiple Myeloma: International Bill of Rights (MMBOR)** *“to ensure that no matter where a person lives, the following principles apply to people affected by multiple myeloma and those involved in their lives and treatments.”* In short, the document describes the **rights and duties of patients, caregivers, doctors, and governments.**

If upheld and fulfilled, it will create the **best possible conditions**, for **all individuals embarking on their own myeloma journey.**

The MMBOR can serve as a point of reference for all myeloma advocates. We can refer to this document for a better understanding of exactly what the myeloma community needs and what can and should be advocated for.

MULTIPLE MYELOMA: INTERNATIONAL BILL OF RIGHTS (2019)

PEOPLE WITH MYELOMA HAVE THE RIGHT TO:

- (a) Equitable and timely access to safe, effective, appropriate multiple myeloma treatment, care and support.
- (b) Affordable access to medications and high-quality care, regardless of a person's income or where they live.
- (c) Timely diagnosis followed by timely, appropriate treatment, education and advice from their primary physicians, educators, nurses, pharmacists, and other appropriate specialists and advocates.
- (d) Emotional and mental health support, as well as support for their caregivers.
- (e) Be an active partner in decision-making and information sharing with their healthcare providers.
- (f) A second opinion and/or to change their primary physician or medical teams.
- (g) Access to their own medical records and other health information, and have it easily understood.
- (h) Information about myeloma, education and care that takes into account a person's age, culture, religion, personal wishes, socioeconomic status, language and education levels.
- (i) Privacy and confidentiality of their personal information protected. Personal privacy is maintained, and confidential handling of personal health and other information is assured.
- (j) Avoid unnecessary suffering and pain in each step of the illness.

THERE IS AN EXPECTATION PEOPLE WITH MYELOMA WILL:

- (a) Be honest and open with their health providers about their current state of health so that the most suitable treatment plan can be prescribed for them.
- (b) Actively seek out education, information and support to live well with multiple myeloma.
- (c) Respect the rights of other people with multiple myeloma and healthcare providers

CAREGIVERS OF MYELOMA PATIENTS HAVE A RIGHT TO:

- (a) Multiple myeloma information, education and support that takes into account a person's age, culture, religion, personal wishes, language and schooling.
- (b) Emotional and mental health support.
- (c) Understand that the patient is receiving the best possible care.
- (d) Be an active partner in decision-making with the patient and their healthcare team, should the patient willingly request this.

THERE IS AN EXPECTATION THAT GOVERNMENTS WILL:

- (a) Adopt comprehensive health policies and plans for the diagnosis, and treatment of multiple myeloma.
- (b) Collect data on myeloma, such as: costs, incidence, survival, mortality and complications.
- (c) Guarantee equitable and timely access to myeloma treatments.
- (d) Provide access to treatment for all multiple myeloma patients.
- (e) Provide a favourable research environment to promote discovery and access to clinical trials for innovative treatments.



NOTES

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ADVOCATING FOR YOURSELF

Self-advocacy for Canadians living with multiple myeloma

WHAT IS SELF-ADVOCACY?

Advocating for yourself as a myeloma patient involves listening to your body, making your own choices, engaging with your treatment process, and speaking up for yourself. It means keeping **your needs, your values, and your autonomy centre-stage, throughout** your myeloma journey. It does not mean that you alone are responsible for your myeloma care. In fact, **advocating for yourself frequently involves seeking the support you need from others.**

HOW CAN I ADVOCATE FOR MYSELF?

Self-advocacy does not consist of fixed rules to follow, it is inherently tailored to **you, your myeloma, and your journey**. How *you chose* to advocate for yourself will be very different from how other people living with myeloma chose to advocate for themselves, and that is okay. **The underlying principle of self-advocacy is self-determination.** By recognizing that **you** alone get to decide the course of **your myeloma journey** and remaining aware of **your rights**, the more tangible goals of **your** self-advocacy will begin to take shape.



Note

If you're still struggling to identify goals that are central to you and your myeloma journey, re-read the **Multiple Myeloma: International Bill of Rights**. Do any sections stand out to you and/or seem to reflect the goals you've already written down?

ADVOCATING FROM YOUR PERSONAL MYELOMA GOALS

Knowing how and when to advocate for yourself means first, getting a sense of what you want your myeloma journey to look like. You can approach this by first **identifying your goals** which can help guide you. These will comprise your personal goals.

1. Write down all the goals you can think of, then take a step back.

For example: you hope to... achieve remission, understand everything that happens to you, maintain a good quality of life, minimize time spent in a hospital, involve your family in the treatment process (or not!), etc.

2. Looking over your list of goals, narrow it down to 3-5 and decide which are most important to you.

Keep in mind, the goals you most badly want to achieve may not be within your control, and may conflict with other important goals. For example, your desire to live for as long as possible may conflict with your goal to remain mobile for as long as you can.

3. Write these goals down somewhere you won't lose them, ordering them by importance if you can. These are your personal myeloma goals to be updated or added to through the course of your myeloma journey.

Your myeloma moral code can be a great reference, for example when you are faced with a difficult decision, with so many opinions you begin to lose track of what matters to you, or you are uncomfortable in an interaction with the healthcare system.

4. Share your myeloma goals with your treatment team, caregiver, and/or whomever else you are comfortable sharing them with.

Volunteering this information to the people involved in your myeloma journey will allow them to consider your values—what you hold most important—in each act of care and support they give you.

SELF-ADVOCACY: AN EXAMPLE

You are uncomfortable making a treatment decision because you don't have all the information on the various treatments you might be eligible for, and you want to understand why your doctor is recommending this specific treatment for you.

You recognize that you have the right to ask for as much information as you need to confidently make the best decision for you.

STEPS YOU COULD TAKE IN THIS SITUATION TO ADVOCATE FOR YOURSELF...

1. Do your own **research** about the treatment recommendation, and any other treatment options.
2. Attend a **Support Group** meeting or reach out to a myeloma **Peer Support** volunteer to talk about your uncertainty, and see how others dealt with similar feelings, and faced similar decisions.
3. Open a **dialogue with your healthcare team** and ask questions – especially those you are afraid to ask – until you have gathered all the information you need to decisively go forward with treatment.
4. If your doctor is not a **myeloma specialist**, ask if they have consulted with a myeloma specialist or other doctors before recommending a particular treatment. If they have, ask to speak with the consulting doctor directly.
5. Ask your doctor what other **treatment options** are available, and why they recommended this course for you.

Exercise your right to a second opinion. Tell your doctor you appreciate their treatment recommendation, but that you want a second opinion before making any decisions. **Doctors are obligated to help you seek a second opinion;** they might not like it, but it is your body, and your decision.

SELF-ADVOCACY TOOLS & TACTICS

Self-advocacy can take many forms: asking questions during medical appointments and monitoring your health and treatments are only a few examples. Important principles and strategies for self-advocacy are detailed below, followed by a list of tools Myeloma Canada has created to help you advocate for yourself with more confidence and ease.

SELF-ADVOCACY, INFORMATION, AND OVERCOMING UNCERTAINTY

Amongst the whirlwind of emotions and questions accompanying a myeloma diagnosis, it is quite common to feel fear and uncertainty. These feelings are often amplified by having very little knowledge of myeloma.

Where our health is concerned, it is always safer to face an enemy you know: **listening to your body, understanding your diagnosis, your various treatment options, and asking questions** are some of the **best ways you can prepare yourself to confidently navigate your myeloma journey.**

The better informed you are, the more uncertainties you can minimize, and by actively seeking the information you need, the more you will feel in charge of navigating your personal journey.



Note

You should not, under any circumstances, decide to follow any health advice you encounter without consulting the members of your treatment team first. If there is any type of additional or alternative treatment you want to try, **speak to your oncologist/family doctor and ask for their opinion.**



FINDING AND EVALUATING INFORMATION

Professionals to ask for **health-related** information:

- Your oncologist and any members of your treatment team;
- Your family doctor or other specialists;
- Other healthcare professionals (e.g. your pharmacist, physiotherapist);
- Representatives of Myeloma Canada and other patient organizations or health charities.

Places to look for **health-related** information:

- Your local public library
- Community health service centres and public health professionals such as nurses or dietitians who are familiar with myeloma or cancer in general
- The internet

For many, the internet is the most convenient place to find health-related information. It is, however, important to note that it can sometimes be difficult to distinguish verified fact from false information, or from someone's opinion online.

When you seek out information for yourself, it is important to determine if the information is from a **credible source, independent from commercial conflicts of interest, and unbiased.**

IMPORTANT TO REMEMBER

Just as there are many ways to self-advocate, **there is no universal way to approach information gathering.** If delving into the internet for information is an uncomfortable or frightening process for you, self-advocacy may instead look like building **strong relationships with your treatment team**, trusting them to **give you the information you need** and **answer your questions.** It can also look like **asking for a second opinion, or a specialist's opinion**, both of which can help you verify or seek more information about your diagnosis and treatment options. The goal is to help you **make a confident decision.**

ASK YOURSELF THE FOLLOWING QUESTIONS TO DECIDE...

Can You Trust this Information?

- **What website did you find the information on?**
- **What is the purpose of the website?**
 - Is it trying to sell you a product?
 - Is it a social media platform?
- **Who owns the website?**
 - Are there any other organizations who fund the page or website?
- **Do they require you to input personal information before allowing you to read their content?**
- **What kind of companies advertise on the site?**
- **What other companies or organizations does the organization partner with?**
- **How current is the information?**
 - When was it published and/or last updated?
- **Does the site offer the titles of, or links to, other resources so you can read more about the subject? (and verify your information)**
 - Is it easy to check their references?
- **If the site presents information which is not the author or organization's original work, does the site provide references for the source of the information?**
 - You can evaluate this reference material as well to provide an extra layer of verification
- **Are the author's name, qualifications, and credentials presented?**
 - Who is the author, what else have they written, what is their educational background, what kinds of organizations are they associated with?



Note

When viewing US based websites, keep in mind that the healthcare system in the US is substantially different from the healthcare system in Canada, and some of the information is not relevant to Canadians.

ASKING FOR A SECOND OPINION

IT IS YOUR RIGHT AS A PATIENT TO SEEK OUT THE OPINION OF A SECOND MEDICAL PROFESSIONAL.

A second opinion may provide a different perspective on your diagnosis and treatment options, and/or reassurance that you are making the right decisions going forward.

The ever-changing nature of myeloma means that a second opinion can be especially valuable for people living with the disease. This is even moreso for patients living in remote locations and/or not receiving care at a major cancer centre, where many doctors may have seen little to no myeloma cases throughout their career.

- The best way to seek a second opinion is by **making a request to your current specialist.**
- You may feel uncomfortable asking this, which is understandable. It is important to keep in mind that **seeking a second opinion does not imply a lack of confidence in your current doctor's capabilities**, which is also something you can convey to them.

You could follow your request with something like, *"I'm very grateful for the care I am receiving from you, and I have complete confidence in your skills. What I really want from a second opinion is some peace of mind. In all likelihood, they will tell me the same things you have, which would help me feel even more confident in deciding what course of treatment to pursue. These are such important decisions; I need to be sure I cover all my bases"*.

- Most doctors are happy to direct you to a second opinion, but in some rare cases, they may refuse. At this point, depending on your comfort level, you can ask again, reminding them a **second opinion is your right**. You can also request a referral for a second specialist from your family physician.
- Alternatively, you may also wish to consult your family doctor on the best way to approach asking for a second opinion. Your family doctor may be able to help you to advocate for yourself, or advocate for you.

LISTENING TO YOUR BODY AND KEEPING RECORDS

The more information you have about your health, the better. Documenting things like your healthcare appointments, test results, or any changes in your mental and physical health, can provide doctors with a more complete picture, making it easier to identify and address your issues or symptoms.

Keep a dedicated 'doctor diary'. Jot everything down in a notebook, or on your phone so **all of your records are in one place.**

Keep your notebook on hand to take notes during appointments, to record any questions you may have, and to help you remember the questions you wanted to ask.

Record the dates of each entry. This will help your healthcare team track changes to your health over time.

Use the [My Myeloma Discussion Guide](#) or go paperless! You can do all the above and more with Myeloma Canada's [Myeloma Monitor](#) app (see more on this below).

IMPORTANT TO REMEMBER

Although your healthcare team is comprised of extremely intelligent, well-trained professionals with years of experience in medicine, **YOU are the ONLY expert on YOU and YOUR body**. If you feel like something is wrong and your healthcare team is not taking your concerns seriously, keep in mind that regardless of how many patients they have treated, **they have never treated you. You are the ultimate authority on how you feel and what you want.**



Once you have the referral, scheduling a second opinion can take some time. Since the doctor or hospital conducting the second opinion is likely very busy, second opinions may be given lower priority, and the doctor will need time to review your records prior to the visit.



MYELOMA CANADA

SELF-ADVOCACY TOOLS

Designed specifically for people with myeloma

ALL OF THE FOLLOWING SELF-ADVOCACY TOOLS ARE CONVENIENTLY LOCATED ON THE [MY LIFE. MY MYELOMA ONLINE RESOURCE CENTRE](#).

I. MYELOMA MONITOR

Your personalized interactive tool to organize, track, and manage your myeloma.

Developed entirely by Myeloma Canada, the **Myeloma Monitor** is an award-winning application (app) designed specifically to help you **organize, track, and manage** the changes that occur throughout the various stages of your myeloma journey. This will enable you to better understand your myeloma, and advocate for yourself.

Myeloma Canada's **Myeloma Monitor** has many features that make it simple to **keep track** of all **your** test results, appointments, medications, feelings, and **quickly jot down any questions for your healthcare team**. With options like charting blood test results over time, you can easily see changes in your health and **convey them to your healthcare team**.

All Myeloma Monitor features are customizable for your unique situation. You can choose which features to use to help you feel empowered and involved in all your healthcare decisions.

The **Myeloma Monitor** helps you keep **yourself**, and **your rights**, central to your treatment decisions. It allows you to remain **confident that the journey you are on, is your own**. For a more detailed description of the Myeloma Monitor app features and how to best use them, please refer to the [Myeloma Monitor How-to Guide](#).

[Download the free Myeloma Monitor app here.](#)

A few things the **Myeloma Monitor** can help you do...

- Keep track of all your medications and medical results.
- Graph your blood test results to see how they have changed over time.
- Keep track of any new or flaring symptoms, any patterns to their appearance, etc. and share these with your doctor/healthcare provider at your next visit. If you feel these are too important to wait for your next scheduled appointment, **contact your doctor as quickly as possible**.
- Add pictures to document the progression of any physical symptoms such as swelling, redness or rash to show or send to your healthcare provider.
- Organize valuable information in a calendar and set reminders in personalized filing sections.
- Generate and print reports from the information you have entered, and save these in your files or send them to your medical team.
- Record any questions you might have for your healthcare team right in the app, the moment they come to mind. You can easily refer to this list of questions during your appointment by keeping your Myeloma Monitor app open beside you.
- Keep track of how you are feeling or changes in your emotional state. Record instances when you may feel worried, scared, depressed, or anxious, as well as the moments you feel loved, relieved, supported, or happy. If you see negative patterns emerge you can talk to your healthcare team about seeing a specialist, reach out to your local Support Group, and/or contact the Myeloma Peer Support program.



II. MY MYELOMA DISCUSSION GUIDE

Questions to ask and consider in your healthcare conversations.

Self-advocacy is valuable at every single step along your myeloma journey, and the simplest way to advocate for yourself, is to *ask questions*.

For someone who is newly diagnosed, the best questions to ask will often be quite different from those of someone experiencing a relapse. That is why we have created a discussion guide for both situations. Reading the **Discussion Guide** that best reflects your experience will give you a sense of how to open a dialogue with your healthcare team along with the kinds of questions that are important to ask.

You can choose the questions you want to explore and/or add your own to the list. Topics covered include: your treatment plan, goals, sequences, and options that are best suited for you.

[Discussion Guide for Newly Diagnosed Patients](#)

[Discussion Guide for Patients Experiencing a Relapse](#)

III. TREATMENT DECISION-MAKING GUIDE

What to consider when making decisions that are right for you and your journey.

Myeloma Canada's **Multiple Myeloma Treatment Decision-Making Guide** will help you map out your thoughts and emotions and help you identify and understand what is important to you as you explore your various myeloma treatment options. Making educated choices by considering your priorities and concerns will give you the knowledge that, together with your healthcare team, you are making the right decision for yourself, and that your rights are being respected.

[Download the Multiple Myeloma Treatment Decision-Making Guide](#)

IV. MYELOMA DRUG ACCESS NAVIGATOR

Over the last 15 years, treatment options for people living with myeloma have increased significantly with the addition of novel, targeted drugs. However, the availability of these treatments, and drug coverage, vary across Canada. Trying to find which drugs are available and covered in your province and territory can be confusing, overwhelming, and even discouraging for some.

To simplify the process of uncovering provincial and territorial drug coverage information, Myeloma Canada has designed the **Myeloma Drug Access Navigator**. This online tool allows you to quickly see the drugs that are available and covered in each province and territory, so you can remain aware of the options available to you and stay actively involved in your treatment journey.

[Go to the Myeloma Drug Access Navigator tool](#)

V. MYELOMA VIRTUAL CARE GUIDE AND APPOINTMENT PLANNER

In the last few years, 'virtual care' – also referred to as 'telehealth' – alternative to in-person healthcare appointments have become very common. Virtual care allows you to connect with healthcare providers without an in-office appointment, through alternative means such as a video chat or phone call.

Virtual care can be a great tool, especially for Canadians with myeloma, as it offers remote access to a second opinion or a myeloma specialist, minimizes the risk of exposure to a virus or infection, and cuts down on travel time. This being said, virtual care might not be the best choice for every circumstance.

Myeloma Canada's **Virtual Appointment Guide** provides you with the information you need to decide if a virtual care appointment is right for you and how to get the most out of these appointments. It is accompanied by a printable and fillable, **Virtual Appointment Planner**.

Topics covered include **what to do** before your appointment, on appointment day, during your appointment, after your appointment, and between appointments.

[Access the Virtual Appointment Planner here](#)

[Access the Virtual Appointment Guide here](#)



VI. MULTIPLE MYELOMA CLINICAL TRIAL FINDER

Staying aware of your options is key to self-advocacy. Based on the specifics of your myeloma diagnosis, a clinical trial may be an option to consider for your treatment. Clinical trials may provide you with access to drugs or combinations of treatments that are not yet approved by Health Canada and are otherwise unavailable to patients, or that have been approved by Health Canada but are not yet covered by provincial insurance plans. Though there certainly are clinical trials for people with myeloma at all different phases of the disease, each trial will have its own specific requirements for participation. Sifting through all the pre-requisites and requirements for each trial can be a laborious process, which is why Myeloma Canada created the **Personal Clinical Trial Finder** tool.

The **Personal Clinical Trial Finder** presents only those clinical trials open to people living with myeloma. It allows you to filter results by location, study phase, and myeloma stage. You can also sign up to receive alerts for when new clinical trials matching your search criteria are added!

[Go to the Clinical Trial Finder](#)

VII. MYELOMA CANADA SUPPORT GROUPS AND PEER SUPPORT PROGRAM

Myeloma Canada has over **44 local support groups** across Canada, 4 virtual (Facebook) support groups that you can join regardless of where you live, and a **Myeloma Peer Support Program**, run in collaboration with Wellspring.

Joining a support group is a wonderful way to advocate for yourself and others, as someone living with myeloma or as a caregiver. A support group is a safe place where you can meet others and be part of a myeloma community, where you can share your experiences, fears, and questions with people who understand and have been, or are going through the same things you are.

The support of other people living with myeloma can at once empower you to take charge of your own myeloma journey, give you a better understanding of what you might face along the way, and provide you with a source of comfort and empathy from your peers.

[Find a local support group near you](#)

Join a virtual support group:

- Virtual Support Group for Caregivers
- Virtual Support Group for Young Patients and Caregivers
- Virtual Support Group for Patients and Caregivers of All Ages
- Virtual Support Group for Francophones

[Join here!](#)



NOTES

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ADVOCATING FOR OTHERS

Supportive advocacy on behalf of Canadians
with multiple myeloma

WHAT IS ADVOCATING FOR OTHERS?

Advocating for others is the act of being engaged with, and supporting people with myeloma by working with them on their myeloma journey. Advocating for others is also sometimes referred to as engaged advocacy.

To advocate for others is NOT to make health-related decisions for a person with myeloma unless you are legally designated to do so.

Engaged advocates can be the friends, family members, caregivers, support group or patient organizations of those living with myeloma. The term applies to anyone who shares a unified goal of operating to elevate the needs, and wishes, of people with myeloma.

As someone with myeloma, you can also advocate for others. You are one of the few people who have truly 'been there'. You have the experience and wisdom that can help others navigate their myeloma journey, regardless of stage, and learn to advocate for themselves.

If you have myeloma, there are many ways for you to ramp up your engaged advocacy efforts: you can get further involved in your local support group or start a new one, watch for opportunities to volunteer for a peer support program, etc. Please contact Myeloma Canada for more ideas!

Most, if not all self-advocacy tools and tactics presented earlier are equally applicable for engaged patients as well as advocates, especially if one of your goals is to try and help a person living with myeloma advocate for themselves.

On the following pages, we will address how people who care for someone with myeloma can be engaged advocates.



Note

Although Myeloma Canada staff are not trained health advocates and cannot provide the same services, we can direct you to the right resources. We encourage you to reach out to [Myeloma Canada](#) if you are interested in seeking advocacy support from others but are not sure how to do it or where to look.

ADVOCATING FOR OTHERS: TOOLS AND TACTICS

Supportive advocacy often involves...

- a) **helping individuals living with myeloma have their voices heard and their needs met;**
- b) **helping individuals find information relating to new and current myeloma treatments;**
- c) **helping people living with myeloma access the treatments and/or services they need;**
- d) **supporting the personal advocacy efforts of people with myeloma.**

I. TREATMENT DECISION-MAKING GUIDE

Questions to ask and consider in your healthcare conversations.

The simplest way to advocate for your loved one is to ask questions. As a newly diagnosed patient, the key questions will be quite different than those of someone experiencing a relapse. That is why we have created a decision-making guide for both situations. Reading the [Multiple Myeloma Treatment Decision-Making Guide](#) that best reflects your loved one's situation, will give you a sense of how to open a dialogue with their healthcare team, and what kind of questions are important to ask.

You can choose which questions you want to explore, and/or add your own to the list. Topics include treatment plan, goals, sequences, and options that are best suited for your loved one.

Go through the discussion-guide with your loved one, and encourage them to map out their thoughts, emotions, and **what is most important to them** as you evaluate myeloma treatment options together. Asking the right questions and providing reliable information along the way can help your loved one be more confident in their decision-making while feeling their rights are being respected. **Remember, you are advocating for someone else. Your actions are solely focused on their needs and are not based on your own beliefs.**

[Download the Multiple Myeloma Treatment Decision-Making Guide here](#)

II. TREATMENT RESEARCH & MYELOMA DRUG ACCESS NAVIGATOR

Help your loved one sort through all the information they need to find and choose the right treatment.

Over the last 15 years, treatment options for people living with myeloma have increased significantly with the addition of novel, targeted drugs. In Canada, however, the availability of these treatments, and drug coverages, vary across the country. The process of finding this information can sometimes be confusing, overwhelming, and discouraging. This is an area where you can advocate as caregivers, by doing thorough research, asking questions, and using the [Myeloma Drug Access Navigator](#) tool to get the most up-to-date information possible.

The [Myeloma Drug Access Navigator](#) is designed to simplify finding the drug coverage information you need. It allows you to see the drugs that are available and covered in each province and territory quickly and easily. As such, you can help your loved one remain up-to-date with the available options for their myeloma, and ways to access them.

[Go to the Myeloma Drug Access Navigator page](#)

III. MYELOMA CANADA SUPPORT GROUPS AND PEER SUPPORT PROGRAM

Myeloma Canada has more than **44 local support groups** across Canada, **4 virtual** (Facebook) support groups you can join regardless of your location, and a [Myeloma Peer Support Program](#), run in collaboration with Wellspring.

Encouraging people with myeloma to seek emotional support can be an important way to advocate for them. Sharing their experiences with others who have been through the same thing can be extremely valuable, as can seeking support from outside one's immediate family or friend circle.

Similarly, as the caregiver or loved one of someone living with myeloma, you have your own challenges and emotions. Without adding to the burden of your loved one, a support group enables you to express your emotions, experiences, useful advocacy strategies, successes, failures, good moments and bad moments, with other caregivers and loved ones in a safe and supportive environment.

[Find a local support group near you](#)

Join a virtual support group:

- Virtual Support Group for Caregivers
- Virtual Support Group for Young Patients and Caregivers
- Virtual Support Group for Patients and Caregivers of All Ages
- Virtual Support Group for Francophones

[Join here!](#)



NOTES

[illegible]



ADVOCATING FOR CHANGE

Advocating for public sector and private sector support
of Canadians with multiple myeloma

WHAT DOES IT MEAN TO ADVOCATE FOR CHANGE?

When the rights of people living with myeloma are violated, advocacy for change seeks to **inform decision-makers** of the problem, show them **why they should care** about it, and present them with solutions.

Powerful institutions like governments, universities, hospitals, and pharmaceutical companies face a multitude of issues that require their attention. They must constantly decide where to allocate limited resources – primarily time and money – and how to balance competing interests. Advocacy for change refers to both group and individual efforts intended to educate these institutional decision-makers, and often the wider public, about a particular cause or issue, and demonstrate why it deserves attention and funding. Our goal is that of **improving the circumstances under which Canadians live with myeloma**.

It is crucial to remember that the success of your advocacy for change is measured by how **effectively you make your voice heard** when speaking out about your issue, and *not by the outcome* of an advocacy effort.

UNDERSTANDING THE CANADIAN HEALTH SYSTEM

... AND HOW TO CHANGE IT.

The sheer size of the Canadian public healthcare system, and its fragmentation, is why healthcare administration and expenditures in each province and territory demand such a significant portion of resources – on average, over 30% of total spending – and why experiences with the Canadian healthcare system can often feel like navigating a maze of bureaucratic red tape. Establishing a general understanding of how the Canadian healthcare system functions is critical to successful advocacy and enables you to easily identify when change is needed, and how to go about making that change.

THE CANADA HEALTH ACT (1984)

The *Canada Health Act* (1984) is the foundational piece of legislation establishing the structure of the public healthcare system in Canada. It lays out the five basic conditions that all provincial/territorial health insurance plans must meet to receive federal funding. These conditions are, as listed in the act: **public administration, accessibility, comprehensiveness, universality, and portability**; they are the foundational principles upon which all Canadian healthcare programs and services are built.

- 1. Public administration** means that provincial and territorial insurance programs must be publicly accountable for the funds they spend. Provincial/territorial governments determine the extent and amount of coverage of insured services. Moreover, management of provincial health insurance plans must be carried out by a not-for-profit authority, which can be part of government or a semi-public agency or institution.
- 2. Accessibility** means that Canadians must have reasonable access to insured services without charges or user fees.
- 3. Comprehensiveness** means that provincial/territorial health insurance programs must include all medically necessary services. Comprehensiveness is broadly defined in the Act to include medically necessary services “for the purpose of maintaining health, preventing disease, or diagnosing or treating an injury, illness or disability.”
- 4. Universality** means that provincial health insurance programs must cover Canadians for all medically necessary hospital and physician care. Universality also means that Canadians do not have to pay an insurance premium in order to be covered by their provincial or territorial health insurance.
- 5. Portability** means that Canadians are covered by a provincial/territorial insurance plan during short absences from that province, and that moving to a different province will not compromise their healthcare.

FEDERAL GOVERNMENT'S ROLE

- Finance provincial and territorial healthcare services through fiscal transfers;
- Provide and fund other health-related functions;
- Set and maintain standards of care for the Canadian healthcare;
- Regulate pharmaceuticals and chemicals;
- Provide healthcare to First Nations, Metis, and Inuit people, and other specific groups (e.g., veterans, prisoners).

PROVINCIAL/TERRITORIAL GOVERNMENT'S ROLE

- Administration of their health insurance plans;
- Plan and fund care in hospitals and other health facilities;
- Deliver services provided by physicians and other health professionals;
- Plan and implement health promotion and public health initiatives;
- Negotiate fees for service with healthcare professionals.

[Click here for more detail on coverage in your province or territory](#)

HEALTHCARE DELIVERY VS. FINANCING

Healthcare delivery refers to how medical services are organized, managed, and provided. Financing describes how and by whom these services are paid for. Advocacy related to the rules and regulations of *healthcare delivery* is usually best directed at **provincial/territorial representatives and ministers**.

DRUG APPROVAL PROCESS IN CANADA

Before a drug becomes available for use by the Canadian public, it must go through a rigorous approval process by Health Canada. It is important to remember that it can take years from the time a drug receives Health Canada's approval and until patients have access to it. This is one of the reasons why consistent drug access in Canada, and throughout all provinces and territories, is *not necessarily guaranteed*.

Following its approval, the drug in question must undergo a Health Technology Assessment by one of the two appropriate Canadian bodies, the Canadian Agency for Drugs and Technologies in Health (CADTH) and Quebec's Institut national d'excellence en santé et services Sociaux (INESS). Once this is done, the potential market value of the drug is reviewed and a price recommendation is made. For the next and last step, a province or territory must choose to initiate the process of negotiating the drug's coverage by their provincial healthcare system (e.g., What is the price? How much will be covered? Who will be covered to receive it?). Other provinces will then follow until the drug can finally be accessed in each province and territory.

Frustratingly, provincial/territorial drug plans that are publicly funded have their own unique rules to follow, and so they often make different decisions on how a new treatment will be covered. This results in unequal access to drug treatments for patients in different parts of the country, and at times, even within the same province.



DECIDING WHERE YOUR ADVOCACY SKILLS ARE BEST USED

You may feel inspired to advocate for change if...

- A. you feel like *your rights* are being violated or not respected through your interactions with the healthcare system;
- B. you feel like *the care you are receiving is unequal to others* in your location and/or you are not being treated with dignity and respect;
- C. you are noticing that hospital and *healthcare professionals are violating the rights* of your loved one or someone else living with myeloma.

If any of the above are the case, you could begin advocating for change by talking to members of your treatment team, asking for a second opinion, finding out if there is a disciplinary board or an individual within the structure of your hospital or cancer centre to whom you can reach out with your concerns and who deals with public complaints.

- D. you want to *spread awareness* about myeloma –

*If you want to help increase awareness for myeloma, you could begin advocating for change by posting about the disease on your social media platforms, taking any opportunity to address a group, organize/participate at an event or fundraiser (like Myeloma Canada's annual **Multiple Myeloma March!**), and more. Please do not hesitate to reach out to Myeloma Canada for help with ideas or logistics.*

- E. you are interested in *accessing a treatment not yet available* in Canada or your province;
- F. you have identified an *upcoming policy change* that will negatively impact people with myeloma. Do not forget! **Advocating against the implementation of harmful regulations can be just as important as advocating for positive change;**
- G. you find *the cost of a lifesaving treatment to be prohibitively high* in your province/territory despite your provincial/territorial coverage;
- H. your insurance company does not cover your treatment.

REACH OUT TO MYELOMA CANADA

FINALLY, if you're interested in advocating for changes to drug access, out-of-pocket treatment costs for patients or changing public policies that harm people living with myeloma, we strongly encourage you to reach out to Myeloma Canada's staff for assistance.

It can often be unfairly difficult to identify which organizations and people you must influence with your advocacy in order to make change. Unfortunately, in some situations it may also not be possible to make a difference right now. Asking for Myeloma Canada's help will save you considerable time and frustration by pointing your advocacy efforts in the right direction. Similarly, Myeloma Canada

may already have or know of, an existing advocacy campaign on the issue you are concerned with. What this means is that creating your own key messages and an "ask" for action (which will be discussed below) may not even be necessary, but can certainly be coordinated!

Whether you contact Myeloma Canada or not, if scenarios E, F, G, and H above sound like the kind of advocacy you want to pursue, it is **always** a good idea to begin by contacting your provincial/territorial **Minister of Health**, and/or your local **Member of Legislative Assembly/Member of Provincial Parliament**.



THREE CRITICAL COMPONENTS OF SUCCESSFUL ADVOCACY FOR CHANGE

1. Key messages
2. A call for action
3. A personal narrative

1. KEY MESSAGES

HOW TO FRAME YOUR ISSUE:

Strong clear messages are the most essential elements of an advocacy campaign. To effectively convince someone of your position or to make the changes you request, you first need to have a **clear understanding of your issue, its impact, and why it matters**. Second, you need to be able to concisely convey this to people who potentially have *zero knowledge or experience with myeloma*.

Key messages will do exactly that. Have a few key messages that explain, in layman's terms, the salient points of your issue, describe **why others should do something about it**, frame the consequences of your issue for non-invested parties, and provide a solid foundation **upon which a consistent advocacy campaign can be developed**.

- If you are contributing to an existing advocacy campaign, it is important to ask if key messages have already been developed, for consistency.
- Each key message should be **twenty-five words** at most.
- A key message must always be direct, compelling, concise, and consistent and contain the answers to the questions below.

QUESTIONS FOR DEVELOPING KEY MESSAGES

- A. What is the problem?

- B. How does the problem impact you or other people living with myeloma?

- C. What would happen if we did not solve the problem? (How urgent is action?)

- D. What would it look like if we did solve the problem?

2. A CALL FOR ACTION

More than anything else, advocacy for change is a **request or demand for certain action(s) to be taken** or avoided. As such, its most essential component is the **request being made**.

Your key messages lay out the problem at hand and its importance. The call for action is your opportunity to **provide a solution**.

Your call for action should convey exactly **what you want done** about the issue in question. Whomever you are advocating to should be left with **zero ambiguity regarding the action(s) you are asking them to take**.

QUESTIONS FOR DEVELOPING YOUR CALL FOR ACTION

- A. What change do you want made?

- B. Who are you advocating to, and within what institution(s)?

- C. What types of powers and/or responsibilities do they have?
 - What kind of changes can they make?
Do they have the final say?

- D. How can they use those powers to help reach your advocacy goal?



3. YOUR PERSONAL NARRATIVE

Telling your personal story is a very powerful way to advocate for systemic change. Whether you are speaking to a politician, hospital administrator, company CEO, other advocates, or the media, **your personal narrative makes it easier for people to empathize with your issue.** Relaying a story of your personal experience will often grab decision-makers' attention more easily as it helps create a more meaningful and personal connection.

THINGS TO KEEP IN MIND FOR AN EFFECTIVE PERSONAL NARRATIVE

- **Be clear:** What is your personal connection to the issue, how is your life or that of a loved one, impacted?
- **Be brief:** You should take approximately 2 to 5 minutes (5 at the most) to tell your story.
- **Be yourself:** Share your experience, feelings, and observations about how this specific issue has genuinely affected your life. The personal touch goes a long way towards making an impression.
- **Be rehearsed:** The impact (noted above) of conveying the issue in a personal forum and genuine manner will be easily lost if you drift off-message, or sound like you're reading from a script. Rehearsing your personal narrative a few times will make it easier to be clear, concise, and your natural self.

QUESTIONS FOR DEVELOPING YOUR PERSONAL NARRATIVE

- What was your experience looking for information about myeloma? Did you have to go online? Was the information you found accurate? Was it confusing or frightening?
- Were you aware of myeloma before your or your loved one's diagnosis? Were your doctors? Your support system (friends, family, colleagues)?
- Has a lack of awareness of myeloma amongst doctors, nurses, colleagues, employers, friends, family members, etc. ever complicated or impacted your or your loved one's experience with treatment, and/or living with the disease?
- Have you had difficulty accessing new treatments? Why, and how has this impacted you?
- Has your or your loved one's health ever been compromised because of the issue at hand?
- Do you believe your or your loved one's diagnosis was delayed or made more difficult by a doctor's limited awareness of myeloma?
- Do you believe an earlier diagnosis could have helped your or your loved one's condition?
- How many treatment options have you or your loved one gone through; how many are left? How do you feel about this?
- What has it been like managing the COVID-19 pandemic as a significantly immunocompromised person living with myeloma, or as a caregiver to someone who is severely immunocompromised?



ADVOCATING FOR CHANGE: TOOLS AND TACTICS

There are a variety of tools and tactics you can use to advocate for your cause, each requiring a varying level of time, effort, commitment, and resources. Every advocate has a unique relationship with their cause and may support it in very different ways. Successful advocacy is more than the sum of its parts; each contribution, big or small, brings you closer to making a change!

PERSONAL ADVOCACY FOR CHANGE

THE 3 P'S: PARTICIPATE, POST, PETITION

The amount of time, energy and money you contribute to your cause is up to you. Personal advocacy is about how and what you do. Remember, Participate, Post, and Petition. Each action can be performed on an ongoing basis, integrated into your existing routine, and does not require time commitments to a group or organization.

FEELING ENTHUSIASTIC? – REMEMBER THE 3 P'S!



1. PARTICIPATE

For residents of a democratic society like Canada, advocating for change is both a right, and a privilege. Our *democracy is founded on the principle of participation*, and by our participation in the democratic process of voting in elections, **it gains its legitimacy**.

Participation can be understood as **a continued advocacy engagement process**. Though it can also be an **immediate act** – like voting – it is best accomplished when done on an **ongoing basis**.

Engaging with your issue can be as simple as [signing up for alerts from Elections Canada](#) or your corresponding provincial/territorial body, [signing up for Myeloma Matters, Myeloma Canada monthly e-newsletter](#), or following key players/stakeholders on social media who are involved with your issue. The information you gather and the connections you make by continuously engaging with your issue will provide you with the ability to quickly join or assemble a strong advocacy campaign if for instance, a bill is tabled, or an election is called.

Being engaged and participating in the issues you care about is one way of having your voice heard and taking action for change.



TIPS

- Engage with the actions of both political (legislative) and bureaucratic government bodies that deal with your issue, i.e., the Canadian Agency for Drugs and Technologies in Health (CADTH), and the Pan-Canadian Oncology Drug Review (pCODR).
- Engage with **companies and corporations** whose actions impact your issue, i.e., pharmaceutical companies with myeloma drugs under review or in development.
- Engage with **advocacy and awareness organizations** that address your issues, or those that address similar issues;
- Remain informed about upcoming local, provincial/territorial and federal elections;
- Stay up to date on **upcoming legislation or regulation changes** that relate to your issue, and how they might impact you or other Canadians with myeloma.



2. POST

With increasing frequency, social and political issues are brought to the attention of the broader public, and decision-makers, through social media. Platforms like Facebook, Twitter, Instagram, YouTube, LinkedIn etc. are used by millions of people and have the capacity to create a groundswell of support for previously unknown causes.

Many stories that receive attention from traditional media (TV, radio, newspapers) also attract coverage because they are “trending” on social media (if an issue or topic is currently very popular amongst social media users, and a vast number of these users are discussing the topic on one such platform, the issue would be ‘trending’).



TIPS

- As with any other audience, know your relevant key messages and stick to them.
- To make yourself known to stakeholders and decision-makers, learn where and how those you are advocating to (politicians, organizations) use social media and start interacting with them on these platforms.
- Your personal social media accounts can be a perfect place to share your **personal narrative**.
- Use social media to share educational/awareness resources and attract new supporters to your cause.
 - **Do NOT use social media as a primary information-gathering source.**
 - Try to independently verify any claims you encounter before repeating or retweeting them!
 - Use social media regularly and often; the more often you post and your social media accounts are updated, the more you will get noticed.
 - **PAUSE before posting something you have written quickly** – once something is online, it can live there forever and mistakes can quickly “go viral,” hurting your cause.

3. PETITION

Petitions are a crucial tool for advocates in a democracy like Canada as **they show politicians where public opinion stands on an issue**, and how their constituents want to be represented in that domain. Collecting signatures in support of your cause gives representatives a mandate upon which they can act. For example, petitions are often used when a bill (prospective legislation) is tabled that will either negatively affect the myeloma community or that may have a potentially positive impact on people with myeloma. In these situations, petitions are then created and circulated to gather evidence of public support, or lack thereof, for the bill under debate, and let to legislators know how their constituents want them to act on the issue, i.e., either stopping the bill from becoming law or voting to pass the legislation. Though they might not act directly in response to the petition itself, **it can generate greater attention for your cause from the media and provide justification for legislators to advance your issue.**



TIPS

- Online petition platforms are a great tool for easily **creating and sharing** new petitions to advance your cause.
- Some petition platforms also provide the opportunity to forge connections and communicate with other signatories who support your cause.
- Be cautious which online petition platforms you use, as they may store and/or sell your data.
- By **building relationships** in ways like this, you can cultivate your own advocacy network of people who support each other’s change-making endeavours.
- If you’ve received positive responses online, the issue is extremely important to you, and you want to take it directly to decision-makers in the House of Commons, follow their official guidelines for submitting such petitions, at [House of Commons Petition Guide](#).



COMMUNITY ADVOCACY FOR CHANGE

TOOLS FOR ORGANIZED AND PURPOSEFUL CHANGEMAKING

These community advocacy tools are set apart because they involve a little more organization and perform best when advocating for a widely held goal, such as making *CAR T-cell therapy available in Canada*. Every day advocacy tools can be used in tandem with community tools to advance a larger community advocacy effort, but alone, they lack the volume necessary to **make systemic change happen**.

ADVOCATING FOR CHANGE: AS A COMMUNITY

Advocacy rarely sees immediate, or easily measurable results. Having a clear, concise, **key message and call to action** that will be communicated consistently through the community's efforts makes it easy for public officials to understand your issue and identify your desired outcome.

For example, **consider this key message**: "Canadians with myeloma need access to CAR T-cell therapy. Without it, many of us will continue to be deprived of a lifesaving treatment option." Accompanying that key message should be your **personal narrative or story** which relates to the issue at hand, like your experience with myeloma, needing new treatments, and not knowing what will work, and/or being unable to access CAR T-cell therapy.



I. EMAILS AND LETTER-WRITING

The first contact you have with those you advocate to is often by letter or email. It will be important to stay in contact with this person once a relationship is established, as they will be a useful resource for future advocacy efforts.

Even if you have identified a need for a change, it might still be unclear to the politicians who can do something about it. Organized letter-writing campaigns can be effective in these situations as they convey a need for change to public officials by putting human faces to the issue.

GUIDELINES FOR LETTERS AND EMAILS

- Have a clear message for the recipient, concisely define your issue, and describe **what you want them to do about it**.
- Know and use the person's exact name and proper title – titles are especially important, particularly in government.
 - To address federal dignitaries
 - To address provincial dignitaries
 - To address indigenous leadership
- Include something that shows you know about the person's work, efforts, or a connection they already have to your cause. For example, "After reading in the local paper about your attendance at last weekend's lung cancer fundraiser, it's clear you care about people with cancer...."
- Do not just use form letters, *especially for an organized letter-writing campaign*. Individualize your letters to convey that there is a real person behind each of them.
- Demonstrate that you are writing to the recipient specifically by using their name, or referencing something about them/something they have said.
- Remember, each personal story they hear will further clarify the issue.
- Keep your letter as short as possible. State the facts you need to support your specific request, but no more, **so they do not lose sight of your message**. If it is crucial to include background material, enclose or attach it as a separate document.
- Make sure your name and contact details are presented clearly on the letter or at the end of the email – do not expect the recipient to find your address on the envelope.
- Provide an expected timeline for a response without being demanding. For example: "I hope you will be able to meet with me within the next two weeks...", or "understand you must be very busy. If I have not heard from you within the next two weeks, I will reach out again to follow up..."
- Always keep the tone polite and positive, even if you disagree with the person you are writing to.
- It is more effective to send politicians individualized letters. If it is necessary to send to a group of people, only copy others on the letter or email and make sure those copied are clearly identified. The exception is political staffers. **Copying an MP's Chief of Staff, Communications Manager, etc. ensures your letter makes it to their desk.**



II. COMMUNICATING AND CONNECTING

Delivering your **personal narrative, face-to-face**, is often the most effective way to get people to take an interest in your cause and to **educate them in a memorable way**. This is particularly true for those, like public officials, with *remarkably busy* schedules and *very full inboxes*. The traditional way of achieving this is with an in-person meeting, often in an official's office. Due to the rise of online communications and the COVID-19 pandemic, in-person meetings have become less frequent and even uncomfortable for many. Thankfully, some very advantageous elements of an in-person meeting — like the ability to respond to potential concerns in real time and having a person's full undivided attention — **are made possible with a video call**.

Familiarize yourself with one of the many computer programs and cell phone apps, like Zoom, which will allow you to organize video chat meetings when an in-person meeting is not possible!

GUIDELINES FOR MAKING CONNECTIONS

- You can use a letter or email to request a meeting (see previous page) but it is also especially useful to have others you know with close connections to an official or politician request the meeting for you or support your letter request.
- Politicians will prioritize meeting requests to the issues they care about or issues that are impacting their constituents, so connect your request to one of these, if possible.
- If they do not already care about your issue, grab their interest by describing its **impact on the area/people they represent** and/or by having one of their constituents make the request.
- Meetings with a politician's staff or a government employee connected to your issue are extremely useful in gaining coverage for your story and can lead to future meetings with politicians or others who can advance your cause.
- Connections are made **with people, and by people**. Using your personal narrative is a fantastic way to connect with others and subsequently raise awareness for your issue.



TIPS

TIPS FOR A SUCCESSFUL MEETING

- Prepare thoroughly by doing your homework and walk in knowing what you want to say.
- No last-minute additions of extra people — let them know in advance who will be with you.
- Stick to the scheduled time unless the person you are meeting wants to extend.
- Stick to your messages, make your request clear and show how it aligns with the person's own priorities.
- Have your supporting evidence but do not spend too much time on numbers.
- Let the human, emotional side of your story come across.
- Seek a reaction or a promise for a follow up — do not presume they will react well, or at all. Instead ask them how they feel about what you have said and the request you have made.
- Send a follow-up letter or email after the meeting to summarize the conclusions or commitments that were made. You can also send extra information that may have been requested.



Note

Do not get angry or make threats if you do not feel action is being taken. Try to channel your frustration into a question.

For example: A provincial health minister is describing the administrative and budgetary concerns regarding funding for a new myeloma treatment and seems to be missing your point. Instead of getting angry, you could say something like "I understand that administration is a serious concern for you and requires funding, but there are also significant costs to the system and our society when Canadians with myeloma die because they cannot access treatment. How do you think these costs compare? Are we able to save both, money and lives in the long-run?"



III. ELECTIONS ARE OPPORTUNITIES!

Elections of all kinds are an excellent time to get politicians to listen to your issue and make commitments to act on your goals if they are elected. This is particularly true when you can demonstrate that many people care about your issue or are affected by it.

WHO AND WHAT MATTERS IN POLITICS?

Canada is a parliamentary system and a representative democracy. Federally, you are **represented by the Member of Parliament (or MP) for your local area** who has a mandate to faithfully represent the interests of their constituents on a national scale. The same premise applies to the provinces and territories where you are represented by the local **Member of Provincial Parliament (MPP), or Member of Legislative Assembly (MLA)**.

These representatives (at all levels) are some of the most crucial decision-makers that advocacy attempts to reach with its message, making elections an extremely valuable advocacy tool.

MAKING YOUR VOICE HEARD IN A CAMPAIGN

- Request meetings with candidates from every party to brief them on your issue. Even if they do not win this time, it is one more person who is aware of your issue and another connection made.
- When you meet, leave them with background information about your issue and needs.
- Engage with candidates through social media to keep your issue on their minds.
- Write letters to newspaper editors to share your thoughts on the impact of the election on your issue.
 - i.e., Dear Editor, this election is a moment of unparalleled opportunity for Canadians with myeloma..."
- Attend all-candidate meetings or debates and ask them about your issue; it will get their positions on-record and might generate media coverage.

POSSIBLE QUESTIONS TO ASK CANDIDATES

- A. What are your views on making new cancer treatments available to patients once Health Canada has approved them? Should they not be made available to patients who need them?

- B. What is your party's position on cancer treatment funding by the provincial health system?

- C. How would you and your party work to reduce wait times for cancer clinics, surgeries and treatments?

- D. What would you do if elected to make myeloma treatment equally accessible to patients in remote areas of Canada?

QUESTIONS TO ASK A FEDERAL CANDIDATE/MP

Will your government:

- E. provide transfer payments to the provinces to allow them to manage the backlog of tests, procedures, and surgeries?

- F. encourage the governments of provinces and territories to include the continuation of essential cancer care in planning for future crises and pandemics?

- G. ensure that the Public Health Agency of Canada takes cancer patients' needs for dependable access to medical care into account in their plans and recommendations for future pandemics?



IV. NEWS MEDIA (TELEVISION, NEWSPAPER, RADIO, ETC.)

News coverage can be a powerful tool for advocates because it drives public opinion, and public opinion drives politics. If used at the right time and in the right way, news media can be extremely useful in getting your issue or story out there and putting public pressure on decision-makers to act.

The media like to communicate issues through *personal stories*. By **showing how one person, or one family is impacted, they hope to provide a glimpse of a larger problem**. Especially for health-related issues, having a compelling story about a local person can humanize the often complex, bureaucratic problems facing our healthcare system.

Bringing your *personal narrative* to the media provides a rare window through which other Canadians can clearly see and understand your issue.

WAYS TO USE NEWS MEDIA

There are many ways to use the various forms and outlets of media to advocate for change. News media is especially valuable if there are upcoming events (fundraisers, etc.), *submission deadlines* or *other important dates that relate to your issue* (even dates important to only you).

Timing your media advocacy efforts to coincide with a government initiative, awareness month/day, or a personal myeloma milestone, gives your issue a timely, newsworthy quality that will make journalists more interested in covering your story.

You can send, or request that Myeloma Canada sends, a press release or media advisory about an upcoming event, inviting media to cover it.

Myeloma Canada can also arrange media-trained spokespeople to conduct or help you prepare for interviews about your issue (on newscasts, talk shows, podcasts, etc.). Having a professional spokesperson 'on board' improves the consistency and clarity of your issue/campaign messaging.

Outside of reporting, newspapers also provide great ways to make your voice heard. You can write a letter to the editor that conveys both your **key message(s) and personal narrative**, advertise upcoming events like marches, rallies, sit-ins and awareness days in local papers (both through paid advertising and free local listings), and more. Please feel free to contact Myeloma Canada for ideas and tips.



HOW TO TELL YOUR STORY TO THE MEDIA

- Before sharing your story with the media, it is important that you have your **key message(s) and personal narrative well rehearsed**.
- Ask if there is anything the media will need to tell your story and prepare it thoroughly for them, in advance.
- Know what you want to “ask” the media audience to learn or do.
- Decide **who** your message **will target**, i.e., people in a certain area, members of a political party, younger or older audiences, lawmakers, the public.
- Decide **how** to convey your issue. Select the right emotional tone for the medium and for the target audience, i.e., positive vs negative, hopeful vs fearful, grateful vs frustrated/angry. There is a time and place for your anger and frustration. Be **sure** it is **both the time and the place before you use this tone in the media, and use it sparingly**.

Pick the right media to reach the target audience for your issue. When in doubt, reach out to Myeloma Canada and we will happily help you craft your message, or align it with similar communications from other community advocates.



SAMPLE EMAIL OR LETTER

To your provincial legislature member, John Smith, requesting a meeting:

Dear **Mr. Smith**:

I am a resident of your constituency, having lived almost all my life here in **Thistown**¹. I know from reading and seeing media coverage of you at various events that you are concerned about our healthcare system and about cancer in particular. I was sorry to hear you lost your brother recently to cancer.²

Unfortunately, my family is affected by a blood cancer, multiple myeloma. My husband was diagnosed last year³. Fortunately, we have benefited from having a good local doctor, **Dr. Jones**, and a very caring staff at the clinic he attends.⁴

Dr. Jones feels my husband might benefit from a new treatment for multiple myeloma called **Newdrug**, but unfortunately it is not available on the provincial drug plan⁵. I've found out we are not alone with this problem and have been working with others in the community who are similarly affected thanks to the group Myeloma Canada.⁶

I would like to request a meeting with you at your constituency office at the earliest possible date to discuss this issue⁷ and get your views on this situation and how we could best approach it together.⁸

Thank you for your attention to this request. I look forward to being able to meet within the next few weeks before the holiday season⁹.

Yours truly,
Your Name,
Your Street Address
Town, Postal Code
Email Address
Telephone #¹⁰

WRITING A LETTER

- 1 Starts with a compelling attention-grabbing statement to show why he/she/they should pay attention
- 2 Shows you know something about the person you're writing to and why they should care
- 3 States your personal situation
- 4 States a positive to give credence to the validity of your issue, you're not just complaining
- 5 States your specific problem
- 6 Shows that yours is not an isolated case and has broader implications
- 7 Makes a very specific request
- 8 Shows you want to work with them on solutions, it's not just on them
- 9 Politely set a deadline for response
- 10 Make sure he/she/they knows all the ways to reach you
- 11 Makes the story being referenced easy to understand and personal
- 12 Provides new facts from the writer's point of view
- 13 Summarizes the impact
- 14 States what the group is doing (if relevant)
- 15 Provides positive ideas to solve the problem
- 16 Clearly states what needs to be done and relates back to the original story



SAMPLE LETTER TO THE EDITOR (ACTUAL LETTER)

Letter to the editor, Feb. 23, 2022

Published in Cornwall Standard-Freeholder

I have cancer. My cancer is called multiple myeloma (also known as myeloma) and it is the second most-common form of blood cancer. Have you heard of it?

Every day, an average of 10 Canadians are diagnosed with myeloma, a number which has been steadily increasing since the early 1990s. Despite its growing prevalence, myeloma remains relatively unknown; most people living with the disease heard the words ‘multiple myeloma’ uttered for the very first time when they received their diagnosis.

I am writing to help bring public awareness to myeloma, a fatal disease that profoundly impacts the lives of so many in Canada.

We are calling on all levels of government across our vast country to officially proclaim March as Multiple Myeloma Awareness Month. Many jurisdictions in Canada, the United States and around the world have already recognized the month of March as Multiple Myeloma Awareness Month, and have designated a specific day in March as Multiple Myeloma Awareness Day.

Help us increase awareness of this incurable cancer to the Canadian population.

Myeloma manifests itself and develops differently which means patient’s responses to the same therapies differ greatly. This makes myeloma a difficult disease to both diagnose and treat.

Symptoms of myeloma are often vague, like fatigue, anemia, bone pain (resulting from bone fractures), and kidney problems. As such, there are many avenues that can lead to a diagnosis.

It is crucial patients and primary care physicians recognize early signs and symptoms of the disease. A delayed diagnosis is almost always associated with serious complications that impact the quality and length of life of patients with this cancer. Visit myeloma.ca to learn more.

People like me who have myeloma generally have a severely weakened immune system, making us more susceptible to frequent, reoccurring – and potentially dangerous – infections, like COVID-19. Access to adequate health care and services is essential to protect patients. Inequity in the services and health care received is unfortunately a reality that affects many Canadians because of where they live, their income, or their ethnic origins.

In recent years, considerable progress has been made in expanding the range of available treatments and improving the prognosis for those affected. However, not all Canadians have access to the same treatments. The daily reality of living with myeloma is frightening because it is never a question of whether we will relapse and if we will need a new treatment, but rather when we relapse, will there be new treatments available, and if so, will they be accessible in our province or territory?

This must change — more Canadians need to be made aware of the effects of this devastating disease so those who have it are diagnosed earlier and have the chance for a better outcome.

Through raising Canadians’ awareness for multiple myeloma, we can educate them on the early warning signs of the disease, and open the door to dialogue with the medical community and government authorities for equitable access to health-care services, innovative therapies, and clinical research.

By helping us make March Multiple Myeloma Awareness Month, you will help improve the quality and length of life for people living with this incurable cancer. Help us make March Multiple Myeloma Awareness Month in every province and territory. Together, we can get one step closer to a cure and raise awareness for this disease that has taken the lives of far too many Canadians.

Thank you for giving the 3,800 newly diagnosed Canadians this year, and all of us affected by myeloma, the strength, courage, and hope for a better future.

Linda VanderSchaaf

Cornwall



Note

This sample letter is long at 500 words. The normal limit in most papers for Letters to the Editor is about 200 words. The shorter the better to increase odds of being published and of being read!

NOTES

[illegible]



**MYELOMA
CANADA**
MAKING MYELOMA MATTER

THANK YOU FOR MAKING YOUR VOICE HEARD.

Whether you will be advocating for yourself, for someone else, or on behalf of all Canadians living with myeloma, you are a valued member of the community, and a passionate MYELOMA ADVOCATE, no matter where your strengths lie.

For more information, or if you have any questions: please email us at contact@myeloma.ca, or call toll-free: 1-888-798-5771.

myeloma.ca



Myeloma Canada – National Page



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