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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 the act of supporting or promoting an idea, cause, or defending a right. We all have rights, personal values and beliefs that shape our actions. Advocacy refers to those actions motivated by our values, beliefs, and the understanding of our rights.

Simply put, advocacy is an assertion of ourselves and what we believe in, with the goal of making change to improve our lives /the lives of others.

WHY IS ADVOCACY NECESSARY?

Everyone has rights to be respected and a voice that deserves to be heard.

By empowering individuals to speak up for their own and/or others' rights and needs, advocacy ensures that the voices of people with myeloma are heard, and can drive positive change forward.

WHO IS AN ADVOCATE?

You are! People with myeloma, their care partners, friends or family members can all make equally amazing advocates. If you have an unanswered question or principle you believe in, and a desire to act on those feelings— you're ready to be an advocate.

WHAT DOES ADVOCACY LOOK LIKE?

Advocacy is far more familiar than it seems.

In reality, we all regularly advocate in our day-to-day lives, 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 advocating by giving voice to your opinion, values, and needs. Over the course of your myeloma journey, your innate advocacy skills can be 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 tends to take one of two forms:

PERSONAL ADVOCACY

1. Advocating for yourself and others (i.e. someone you care for), to address immediate concerns facing an individual person and their care.

SYSTEMIC ADVOCACY

2. Advocating for change to governments and institutions whose actions impact people living with myeloma.

THREE PILLARS OF EFFECTIVE ADVOCACY

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

Whether you are engaging in personal advocacy to address your immediate needs or systemic advocacy to create broader change, all advocacy is about connecting with people, and as result effective person-to-person advocacy relies on three fundamental pillars that work together to ensure your voice is heard clearly, and the right actions can be taken. The pillars are: your **key messages, personal narrative and call to action.** These pillars provide a framework for organizing your thoughts on an issue, conveying them to your audience, and allow you to effectively advocate for your cause.

For personal advocacy, c these pillars help you communicate clearly with healthcare providers, insurance companies, or employers about specific barriers you're facing. For example, if you are advocating for access to a particular treatment, your key messages could explain why the treatment is necessary for you, your personal narrative describes how you and your care team believe the treatment could improve your health and quality of life, and your call to action requests specific decisions.

Some personal advocacy strategies do not require developing the full three pillars, but others, like asking for a second opinion, may benefit from this organized approach.

For systemic advocacy, these same pillars enable you to influence policy makers and institutional leaders to create lasting change. When advocating for improved drug access policies, your key messages could outline the broader problem affecting the myeloma community, while your personal narrative illustrates the human impact of current policies, and your call to action requests specific legislative or policy changes that would benefit all patients.

1. KEY MESSAGES

FACTS AND (SOME) FIGURES.

To effectively convince someone of your position or to make changes you request, you first need to have a clear understanding of the problem you are trying to solve, its impact, and why it matters.

Second, you need to be able to concisely convey this to people who may have zero knowledge of myeloma.

Key messages will do exactly that. You should have a few key messages that explain in simple language, the salient points of your issue and describe why others should do something about it. Your key messages are the factual reasons for your call to action and should connect to your personal narrative.

DEVELOPING KEY MESSAGES

- Remember the 4 C's: Key messages must be **clear, concise, compelling,** and **consistent.**

QUESTIONS

A. **What** is the problem?

_____

B. **How** does the problem impact you or others with myeloma?

_____

C. **What** would it look like if we solved the problem?

_____

2. PERSONAL NARRATIVE

YOUR STORY

Telling your personal story is an extremely powerful tool for achieving both personal and systemic advocacy goals. Whether you are speaking to a healthcare provider about your treatment needs, a politician about policy change, or the media about broader issues, your personal narrative(s) allow people to easily understand and empathize with your situation, and thus your issue.

By creating a meaningful personal connection, sharing your story often captures decision-makers' attention more effectively than facts and figures alone. Remember, all advocacy is person-to-person.

THINGS TO KEEP IN MIND FOR AN EFFECTIVE PERSONAL NARRATIVE

- **Be clear (and accurate):** Clearly convey your personal connection to the issue, how your life or that of a loved one, is impacted, and how it could be improved if the situation were resolved.
- **Be brief:** You should take approximatel 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 positive:** L Even where the experience you're describing is an extremely difficult one, it is critical to end on a positive or hopeful note. You want decisionmakers to feel they can make a difference by taking action and avoid putting them on the defensive.
- **Be rehearsed:** The gravity of your personal story can be easily lost if you drift off-message, or you're reading from a script. Rehearsing your personal narrative a few times will make it easier to be clear, concise, and still your natural self. **Tip:** rehearse with someone else who can give feedback on how your personal narrative is received by listeners).

POSSIBLE QUESTIONS TO HELP DEVELOP YOUR PERSONAL NARRATIVE

Note: this list is not exhaustive, and your issue may not appear here. If you need assistance developing your personal narrative reach out to Myeloma Canada, or your local support group leader(s).

- 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/ your loved one's diagnosis? How could better awareness/knowledge of myeloma amongst doctors, nurses, colleagues, employers, friends, family members, etc. have improved your or your loved one's experience with treatment, and/or living with the disease?
- Have you had difficulty accessing certain health care resources (ex. care or treatments)? Why, and how would you be impacted by receiving that treatment/care?
- Do you believe your or your loved one's diagnosis was delayed? What do you think caused the delay? How might an earlier diagnosis have improved your/their condition?
- How many approved treatment options have you or your loved one received, how many funded lines of treatment are left? How do you feel about this?
- What is it like managing the increasing threat of infectious disease outbreaks as an immunocompromised person, or as a care partner of an immunocompromised person?

3. A CALL TO ACTION

THE 'ASK'

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

Your key messages lay out the problem at hand and its importance, your personal narrative humanizes the issue, and your call to action should convey exactly **what you want done** about it.

Whomever you are advocating to, should be left with **zero ambiguity regarding the action(s) you are asking them to take.**

DEVELOPING CALLS TO ACTION

- The call to action is your direct ask and should provide a *solution to the problem*.

QUESTIONS

A. **What** change do you need made?

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

C. **What** types of powers/ responsibilities do these people have; what changes can they make? Do they have the final say?

D. **How** can they use their powers to help reach your advocacy goal?

NOTES



ADVOCACY AND YOUR RIGHTS

WHAT ARE MY RIGHTS AND WHERE DO THEY COME FROM?

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

Typically, the rights we hear discussed most often are 'human rights'. These rights are broad principles enshrined in the Universal Declaration of Human Rights (1948), of which Canada, and other countries across the globe are party to. 'Human rights' cover a range of issues, from voting rights, the right to non-discrimination, to education rights, and the right to medical care. Ensuring that all citizens are able exercise their human rights, is a democratic government's most basic duty to their citizens. To further define the duties of the Canadian government, **towards anyone physically living in Canada**, your rights are constitutionally protected by the Charter of Rights and Freedoms (1982).

In 2019, the Global Myeloma Action Network, of which Myeloma Canada is a member, 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.* "

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 the myeloma community's needs and what 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, elective, 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) d 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 favorable research environment to promote discovery and access to clinical trials for innovative treatments.

NOTES



UNDERSTANDING CANADIAN SYSTEMS

UNDERSTANDING CANADIAN SYSTEMS

...AND HOW TO INFLUENCE THEM.

Establishing a general understanding of how our governments, and healthcare systems function is critical to successful advocacy. This knowledge enables you to identify when and why change is needed, who has the power to make said change, and how to go about making it.

GOVERNMENT AND POLITICS

Canada is a parliamentary system and a representative democracy. Federally, your elected representative is the Member of Parliament (or MP) for your local area. Your MP has a mandate to faithfully represent and protect the interests of their constituents as they relate to the duties of the federal government. The same premise applies to the provinces and territories where you are represented in your provincial/territorial legislature by an MPP/MLA/MHA/MNA.

These elected representatives are some of the most crucial decision-makers that advocacy attempts to reach, with provincial and territorial representatives serving as your first line of defense for most healthcare-related issues. Since most of the healthcare functions that directly impact people with myeloma fall under their jurisdiction, your provincial or territorial elected representative can more directly influence these issues than your federal MP.

HEALTH SYSTEM(S)

Note: information in this section is specific to publicly funded healthcare, though you could equally direct advocacy efforts at your own private insurance company.

We often hear phrases like 'Canadian healthcare system' and 'universal healthcare', but these are misnomers. There is no unified system under which all Canadians receive healthcare– each province and territory has their own. Still, the federal government and pan-Canadian institutions retain critical health-related functions like regulation of pharmaceuticals, food safety, etc. and not all aspects of healthcare are universally provided for by provincial/territorial government funding.

ELECTED REPRESENTATIVES

MP - Member of Parliament – Federal
House of Commons – Parliament of Canada

MHA - Member of the House of Assembly
Newfoundland and Labrador

MNA - Member of the National Assembly Quebec
Assemblée nationale du Québec

MPP - Member of Provinical Parliament
Legislative Assembly of Ontario

MLA - Member of the Legislative Assembly
(used in most provinces and territories)

- **British Columbia** – Legislative Assembly of British Columbia
- **Alberta** – Legislative Assembly of Alberta
- **Saskatchewan** – Legislative Assembly of Saskatchewan
- **Manitoba** – Legislative Assembly of Manitoba
- **Nova Scotia** – Legislative Assembly of Nova Scotia
- **New Brunswick** – Legislative Assembly of New Brunswick
- **Prince Edward Island** – Legislative Assembly of Prince Edward Island
- **Northwest Territories** – Legislative Assembly of the Northwest Territories
- **Yukon** – Legislative Assembly of Yukon
- **Nunavut** – Legislative Assembly of Nunavut

THE CANADA HEALTH ACT (1984)

The Canada Health Act (1984) provides a framework for publicly funded healthcare, which emphasizes equitable access to medically necessary services, and serves as a cornerstone for federal-provincial collaboration in health policy.

The Act is federal legislation which sets out the primary conditions provinces and territories must meet to receive full federal funding for insured health services. These 'conditions' are outlined in the Act as five program criteria: **public administration, comprehensiveness, universality, portability, and accessibility.** *The criteria apply specifically to insured hospital and physician services— the Act does not cover all aspects of healthcare delivery (i.e. prescription drugs, vision care, dental care, home care, ambulance services).*

In practice, the Canada Health Act is why you don't have to pay out of pocket for services you receive in a hospital. Its limited scope is also why other healthcare costs are not guaranteed to be funded by our public healthcare systems. The Canada Health Act doesn't forbid private providers from delivering health services, **as long as they don't charge for medically necessary services.**

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. **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."

3. **Accessibility** means that Canadians must have reasonable access to insured services without charges or user fees.

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 ROLES

- Finance provincial and territorial healthcare services through fiscal transfers, and the Canada Health Transfer.
- Monitor pharmaceutical prices to ensure they are not excessive, through the Patented Medicine Prices Review Board (PMRPB).
- Support health research
- Regulate pharmaceuticals, medical devices, and food safety and other chemicals.
- Provide healthcare coverage to 1. First Nations, Metis, and Inuit people 2. Members of the Canadian Armed Forces 3. Eligible Veterans, 4. Federal Prisoners 5. Refugees 6. Members of the Royal Canadian Mounted Police (RCMP)
- Manage disease surveillance, prevention and public health emergencies, through the Public Health Agency of Canada and other tools (i.e. tobacco legislation).
- Provide tax support for certain health-related costs (i.e. tax credits for disability, medical expenses, disabled dependent and caregivers).
- Administer the Special Access Program which, under special circumstances, provides public funding for drugs not yet approved by Health Canada.

PROVINCIAL/TERRITORIAL GOVERNMENTS' ROLES

- Administration of health insurance plans, including deciding which pharmaceuticals will be covered in their province/territory.
- Planning and funding development of hospitals and other public health facilities.
- Overseeing the delivery of services provided by physicians and other health professionals.
- Planning and implementing health promotion and public health initiatives.
- Negotiating fees for service with healthcare professionals.

DRUGS IN CANADA: FROM DEVELOPMENT TO APPROVAL TO REIMBURSEMENT

Note: not all myeloma treatments are drugs *(i.e. CAR T-cell therapy)*, but to be available for public reimbursement every treatment must go through the same regulatory process, within which all new treatments are widely referred to as 'drugs'. Thus, the terms 'treatment' and 'drug' are used interchangeably below.

RESEARCH AND DEVELOPMENT

Drug development typically takes 10–15 years from the initial discovery to final regulatory approval and involves multiple stages, from basic research, through preclinical testing, clinical trials, and finally, regulatory review.

For each single drug that is approved, roughly 5,000 - 10,000 compounds (chemical/biological substances with the potential to become drugs) enter the initial drug discovery pipeline. While around 10 % of drugs that reach clinical trials will be approved, that number is much lower for oncology drugs, at 3-4%.

CLINICAL TRIALS

- **Phase 1:** First time a potential new treatment is tested in humans and emphasis is on safety and major side effects. Involves small number of participants, who receive gradually larger doses of the treatment until the highest dose with the fewest side effects is identified. About 70% of drugs will pass this phase.
- **Phase 2:** Aims to evaluate the effectiveness of the treatment, gather more safety data, and further refine the best dosage. Usually involves a larger group of participants and begins to determine if the treatment works for a specific disease, while continuing to monitor side effects. About 33% of drugs will pass this phase.
- **Phase 3:** Compares the new treatment with a standard of care to determine which is safer and more effective. Data from these trials are typically the foundation of Health Canada decisions. Usually includes a much larger study population than earlier phases, and participants tend to be randomized. About 25-30% of drugs will pass this phase.
- **Phase 4:** Occurs after regulatory approval and is also known as 'post-marketing surveillance'. Includes monitoring for adverse events, and the collection/analysis of real-world evidence and real-world data.



CANADIAN REGULATORY APPROVAL AND REIMBURSEMENT PROCESSES

Before a drug becomes accessible to the Canadian public, it typically goes through multiple processes, starting with Health Canada approval. It can take years from the time a drug is approved until patients have access to it through provincial/territorial drug plans.

1. Regulatory Approval - Health Canada

Health Canada reviews clinical evidence from clinical trials, (usually Phase III data) to assess the safety, quality, and efficacy of a drug. If Health Canada determines a treatment to be effective and safe, they will grant a Notice of Compliance (NOC) allowing the manufacturer to sell (market) it in Canada. Once a drug has an NOC, patients can make special/exceptional access requests for coverage through provincial/territorial programs.

2. Reimbursement review – CDA / INESSS

Canada's Drug Agency (CDA-AMC) and Quebec's **Institut national d'excellence en santé et services sociaux (INESSS),** then conduct reimbursement reviews to assess the new drug's potential value and recommend if it should be reimbursed by provincial/territorial drug plans. CDA decisions apply to all provinces and territories except Quebec, and INESSS decisions apply to Quebec alone. CDA and INESSS consider clinical (trial) evidence, pharmacoeconomic (cost) information, and patient input. Myeloma Canada collects patient input from our community members through Patient/Caregiver Experience Surveys and submits this information in reports to both CDA and INESSS for each new myeloma treatment under review.

3. Pricing negotiations - pCPA

Next, if recommended for reimbursement by either CDA or INESSS, the drug goes to the **pan-Canadian Pharmaceutical Alliance (pCPA)** to be considered for negotiation. These negotiations are between the provincial/territorial drug plans and the drug manufacturers, to determine the cost of the drug to be paid by public drug plans. pCPA Negotiations are led by one province/territory but all jurisdictions must concur to reach an agreement and issue a Letter of Intent (LOI). All provincial and territorial drug plans, are involved with pCPA and impacted by their decisions, as are 5/6 federally administered drug plans. If negotiation is successful (an agreement is reached, LOI issued) the drug can more quickly and easily be listed by each province and territory. (Note: Unsuccessful or unpursued negotiations do not mean a Health Canada-approved treatment with a positive reimbursement recommendation will never be publicly funded, but these outcomes complicate and delay the process.)

4. Public Access – Provincial/territorial drug plans

Provincial/territorial drug plans have their own unique budgetary restrictions and rules to follow, so they may make different decisions on if or how a new treatment will be covered in their region and listed on their formulary. This can result in unequal access to treatment for patients in different parts of the country.

Note: Though this is the standard path from approval to reimbursement, there are a number of different variables along the way, meaning timelines are inconsistent, and seemingly 'guaranteed' outcomes, may not be.

NOTES

DECIDING WHERE YOUR ADVOCACY SKILLS ARE BEST USED

You may feel inspired to advocate if you or a loved one....

A. ... feel like your rights are being violated or not respected through your interactions with the healthcare system.

If this is your situation, you could begin by documenting specific incidents, requesting a meeting with your healthcare team to discuss your concerns directly, contacting the patient relations department at your hospital, and/or filing a formal complaint with your provincial/territorial college of physicians and surgeons or health authority.

B. ...feel like the care in your location is unequal or lacking elements that are important to you.

If you're experiencing care gaps, you could start by researching what services are available in other regions, asking for a second/specialist opinion, connecting with local patient advocacy groups to see if others share your concerns, contacting your MPP/MLA/MHA/MNA to discuss regional healthcare disparities, or reaching out to your provincial/territorial health minister's office.

C. ...you have noticed an issue with how your hospital or healthcare professionals are treating you, your loved one or others with myeloma.

If you've identified systemic issues, you could begin by speaking with the charge nurse or department manager, requesting a meeting with hospital administration, contacting the hospital's patient advocate or ombudsperson, or connecting with other patients to discuss and document patterns of concerning care.

D. ...you want to spread awareness about myeloma.

If you want to help increase awareness for myeloma, you could begin by posting about your experience with the disease on your social media platforms, taking opportunities to speak about your experience to others, organize/participate in an event or fundraiser (like a Myeloma Canada annual Multiple Myeloma March!), and more.

E. ...you are interested in accessing a treatment not yet available in Canada or your province.

If you need access to unavailable treatments, you could start by finding out if it is Health Canada approved, if not you could pursue access through Health Canada's Special Access Program, and if so, you could ask your oncologist about compassionate access through the manufacturer, or provincial/territorial exceptional access programs. You could also research clinical trials in Canada and internationally, and/or connect with patient advocacy organizations.

F. ...you have identified an upcoming policy change/ decision that will impact people with myeloma.

If you're concerned about policy changes, you could begin by investigating if there are public consultations on the issue, reaching out to Myeloma Canada to ask if we intend to provide comments, drafting a response (alone or with MC) based on your personal experience, and/ or contacting relevant politicians to discuss the policy's potential impact.

G. ...you find the cost of a treatment to be prohibitively high in your province/territory despite your provincial/territorial coverage.

If treatment costs are overwhelming, you could explore pharmaceutical company patient assistance programs, ask a Drug Access Navigator for help, contact your provincial drug plan to understand appeal processes, research charitable foundations that provide financial support, or advocate to your MPP/MLA/MHA/MNA for improved coverage.

H. ...your insurance company does not cover your treatment.

If facing insurance coverage denials, you could begin by requesting a detailed written explanation for the denial, gathering supporting documentation from your healthcare team, filing a formal appeal with your insurance company, or seeking assistance from a Drug Access Navigator, patient navigator or advocacy organization familiar with insurance processes.



ADVOCATING FOR YOURSELF & OTHERS

Personal advocacy for Canadians impacted by myeloma

WHAT IS SELF-ADVOCACY?

Advocating for yourself as a myeloma patient is the act of participating in your own healthcare. This includes understanding your condition, treatment options, rights, and communicating your needs to those who can help.

Self-advocacy involves listening to your body, asking questions, making informed choices, and speaking up for yourself. It means keeping your **needs, values,** and **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.

WHAT IS ADVOCACY FOR OTHERS?

Advocating for others is the act of supporting people with myeloma and its precursor conditions by helping their voices be heard and their needs met.

Supportive advocacy involves helping look for information related to new and current myeloma treatments, asking questions, helping find access treatments and/or services, and supporting the personal advocacy efforts of individuals with myeloma.

Supportive advocates can be friends, family members, care partners, support groups, patient organizations etc... People living with myeloma can also be supportive advocates. As one of the few who have truly 'been there', your experience can help others navigate their own myeloma journey and learn to advocate for themselves.

Note: Though the following pages are written primarily with patient readers in mind, most, if not all personal advocacy strategies and tools presented in this section are equally valuable for supportive advocates.

PERSONAL 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.

Being well informed is very important to you, and you know you have the right to ask for as much information as you need to confidently make your decision.

STEPS YOU COULD TAKE:

1. Do **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 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 a myeloma specialist before recommending the 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 over those.
6. Exercise your **right to a second opinion.** Tell your doctor you appreciate their recommendation, but that you want a second opinion before deciding. **Doctors are obligated to help you seek a second opinion–** it is your body, and your decision.

SUPPORTIVE ADVOCATES

The person you care for is presented with a treatment recommendation and is uncomfortable making a decision.

You know it is very important to this person that they have as much information as possible before deciding.

STEPS YOU COULD TAKE

1. Start by **asking if they would like your help.**
2. If yes, you can **follow the applicable steps** on the previous page, **suggest** others to the patient, and find out how you can be most **helpful to the patient in executing them.**

   What kind of information would be most valuable to you right now, and can I help you find it? Do you want to talk this decision/the information through with someone? Would you like me to look into other myeloma specialists to ask for a second opinion?
3. Let the patient know you are there to **support them getting what they need by asking before you take action** and **checking** in with them regularly.

PERSONAL ADVOCACY IN PRACTICE

Personal advocacy does not have a set of fixed rules to follow. How you chose to advocate may be very different from how others impacted by myeloma chose to advocate, and that is completely normal.

The underlying principle of personal advocacy is self-determination- *the patient alone gets to decide the course of their myeloma journey*. Keeping this principle in mind, and remaining aware of your rights, will help you find the advocacy strategies best suited to support you.

EXERCISE: YOUR PERSONAL ADVOCACY COMPASS

Knowing how and when to advocate for yourself means first getting a sense of what you want your myeloma journey to look like.

If you are advocating for someone with myeloma, have them complete the exercise and go through the questions together to be sure you're on the same page.

Take 15-20 minutes to reflect on and write down your thoughts for each of the following 4 areas. There are no right or wrong answers—this is about defining what matters most to you.

1. **My Treatment Priorities**

   What aspects of treatment are most important to you?

   - Ex. Maintaining independence and daily activities
   - Quality of life/Managing side effects
   - Improved prognosis
   - Maximizing time with family and loved ones
   - Allowing you to work or fulfill other responsibilities
   - Other...

2. **My Communication Preferences**

   How do you want to interact with your healthcare team?

   - How much detail do you want about your condition and treatment options?
   - Do you prefer to bring a support person to appointments?
   - How do you best process medical information? (written summaries, diagrams, and/or verbal explanations; on your own, or in conversation)
   - What's your preferred method for asking follow-up questions (phone, email, patient portal etc...)

3. My Decision-making Approach

How do you want to be involved in treatment decisions?

- Do you prefer to research treatment options extensively on your own, or rely on recommendations from your care team?
- Do you want family members to play a role in your decisions?
- What do you typically need to make important decisions? (time, space, discussion, information etc...)

4. My Support Network

Who are the key people in your support network?

- Primary care partner or professional support person
- Family members who should be kept informed
- Friends who provide emotional support
- Members of your care team
- Psychosocial support professionals (therapists, counsellors, social workers etc...)
- Patient advocacy organizations or support groups

MY GUIDE

YOUR PERSONAL ADVOCACY COMPASS

Based on your reflections above, complete these statements:

- "I want my healthcare team to know that _____ is/are most important to me."
- "I am not okay with _____ and I will speak up if/when _____."
- "I need help advocating for myself if/when _____. I will seek this help by _____."
- "Before making a treatment decision, I need to _____."

MY ADVOCACY TEAM INCLUDES:

1. **Me:** I can .... Ex. Ask questions, seek out information
2. _____ Ex. My care partner: They can help by... taking in information at appointments, etc...
3. _____ Ex. My support group: They can...

Keep these reflections handy and revisit them regularly. Your needs and priorities will change throughout your myeloma journey, and that's completely normal. Use this framework to help you:

- Prepare questions before medical appointments
- Evaluate whether your care aligns with your needs and values
- Identify when you might need additional support or resources
- Communicate your needs to your support network.

Note

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

PERSONAL ADVOCACY STRATEGIES

Personal advocacy can take many forms— seeking information, asking for a second opinion, and keeping track of health and treatment records, are only a few examples. Refer to the Self-Advocacy Framework Exercise on page 20 to help you figure out which strategies can best support your needs.

Vous trouverez ci-dessous quelques principes et stratégies pour assurer la défense de vos droits, suivis d'une liste d'outils que Myélome Canada a créés pour vous aider à défendre vos droits.

PERSONAL ADVOCACY, INFORMATION, AND OVERCOMING UNCERTAINTY

Feelings of fear and uncertainty often accompany a myeloma diagnosis and may be amplified by having little prior 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 treatment options,** and **asking questions** are some of the **best ways you can advocate for yourself.** The better informed you are, the more uncertainties you can minimize, and the more confident you can feel in your decisions. Actively seeking the information you need helps you feel in charge of your myeloma 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, always **speak to your oncologist/family doctor and ask for their professional opinion.**

IMPORTANT TO REMEMBER

Just as there are many ways to advocate, **there is no universal way to approach information gathering.** As a patient, if doing your own research is uncomfortable or frightening 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,** or **asking for help from your care partner/support network.**

The goal is to help you **make decisions with confidence.**

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 can help direct you to reliable sources of information.

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

- Your local public library
- Your hospital or cancer centre
- Community health service centres and public health professionals such as nurses or dieticians 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. However online, it can be difficult to tell verified fact from false information or someone's opinion.

When you seek out information for yourself, it is important to first determine if the information is from a **credible, unbiased source.**

ASK YOURSELF THE FOLLOWING QUESTIONS TO DECIDE...

Can You Trust this Information?

1. **Where is this information from?**

   - What website, platform, or source did you find it on?
   - Who owns or runs the site/platform?
   - Is it a recognized news outlet, academic institution, or government site?
   - If it's on social media or a blog, is the post original or AI-generated (look for signs of automation, repetitive phrasing, or no clear author)?

2. **Who created it?**

   - Is the author named?
   - Are their qualifications, expertise, or credentials provided? Are they linked to reputable institutions?
   - What else have they published?
   - If AI-generated, is there a human reviewer/editor named, are its sources human-created?

3. **Why does this source exist?**

   - Is the purpose to **inform, educate, entertain, persuade, or sell**?
   - Does it rely on sensational or emotionally manipulative language (common in clickbait and AI-generated spam)?

4. **How is it supported?**

   - Does the content provide **clear references, citations, or links?**
   - Are references from independent and trustworthy sources?
   - Can you cross-check the information elsewhere?
   - If AI-generated, are its sources transparent (or are references missing/fake)?

5. **When was it published?**

   - Is the content recent and updated?
   - Is there a clear publication or last-updated date? Be cautious: AI-generated articles may not mention dates at all, or they may cite outdated/ incorrect timelines.

6. **What influences are present?**

   - Who funds or sponsors the site or study?
   - What companies advertise on the page?
   - Does the publisher or author partner with groups that could bias the message?
   - Does the site ask for personal information before showing content?
   - Be cautious of **AI-generated "fake news" sites** built for ad revenue or data harvesting.

7. **How trustworthy is the overall presentation?**

   - Is the writing professional, balanced, and free of major errors?
   - Does it avoid exaggerated claims or "too good to be true" promises?
   - Are images, videos, or audio authentic (or could they be AI-altered deepfakes)?



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.

The ever-changing and personalized nature of myeloma makes a second opinion especially valuable. This is even more so for patients living in remote locations where healthcare professionals may have never cared for a myeloma patient before.

- The best way to seek a second opinion is by making a request to your current specialist.
- If you feel uncomfortable asking, 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.
- 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. These are such important decisions; I need to be sure I cover all my bases."*
- Alternatively, you can request a referral for a second specialist from your family physician.

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.

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.

TIPS FOR KEEPING TRACK OF YOUR HEALTH

- Keep a dedicated binder or folder for all the papers you may receive along your journey (test results, drug information, etc...). If you tend to lose papers, take photos of everything you receive and store it in a dedicated folder/album.
- Keep your notebook/phone on hand to take notes during appointments, record any questions you may have, and to help you remember questions you wanted to ask.
- Record dates of each entry, and if you feel any changes in your health. This will help you and your healthcare team track those changes over time and interpret what they could mean.
- If your doctor is okay with it, voice record their answers to your questions, or complicated explanations they provide. **You must ask any healthcare professional's permission before recording, and ONLY in private settings where you, your doctor (and your care partner) are the sole individuals behind a closed door.**
- However you record your health information, try to keep **all your records in one place (and easily accessible).**

Note

Once you have the referral, scheduling a second opinion can take some time. Since doctors and hospitals are generally very busy, second opinions are often given lower priority, and the doctor will need time to review your records prior to the visit. Ask to schedule your appointment virtually to speed things up.

MYELOMA CANADA PERSONAL ADVOCACY TOOLS

Designed specifically for people impacted by myeloma

I. MY MYELOMA DISCUSSION GUIDE

Questions to ask and consider in your healthcare conversations.

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

The key questions to ask for someone who is newly diagnosed, may be quite different than for someone experiencing a relapse. This 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 you might want 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

II. 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 beings respected.

Download the Multiple Myeloma Treatment Decision-Making Guide

III. 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

IV. MYELOMA VIRTUAL CARE GUIDE AND APPOINTMENT PLANNER

In the last few years, 'virtual care' – also referred to as 'telehealth – alternatives 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 for Canadians with myeloma, as it can offer remote access to a second opinion or myeloma specialist, minimizes the risk of exposure to a virus or infection, and cuts down on travel time. That being said, virtual care might not be available, or the best choice in every circumstance, and you may feel more comfortable speaking with your healthcare team face-to-face.

Myeloma Canada's **Virtual Appointment Guide** provides you with the information you need to decide if/when virtual care 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

V. 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



VI. MC LOUNGE - MYELOMA CANADA ONLINE COMMUNITY

MC Lounge is a secure online community designed specifically for Myeloma Canada's community. It is a dedicated space to connect, share, and support others impacted by myeloma across Canada.

Engaging with the community can provide you with a source of comfort and empathy from your peers, give you a better understanding of what you might face, and empower you to take charge of your own myeloma journey.

Similarly, inquiring if others have faced similar access/advocacy concerns, how they handled them, and what they learned can help strengthen your advocacy efforts.

Join the community here

VII. MYELOMA CANADA SUPPORT GROUPS AND PEER SUPPORT PROGRAM

Myeloma Canada has many **local support groups** across Canada, and even virtual (Facebook and MC Lounge) support groups that you can join regardless of where you live, and a Myeloma Peer Support Program. Joining a support group (and/or MC Lounge!) is a wonderful way to advocate for yourself or others. 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 ask questions to others who understand what you're going through.

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



ADVOCATING FOR CHANGE

Advocating to improve our systems for
Canadians with multiple myeloma

WHAT DOES IT MEAN TO ADVOCATE FOR CHANGE?

Institutions like governments, regulators, health organizations, universities, hospitals, and pharmaceutical companies have the power to directly impact the lives of people with myeloma. They control research funding, approve new treatments, set drug coverage policies, healthcare delivery standards and more.

Decisionmakers at these institutions can both remove barriers for people with myeloma and create new ones. Thus, advocacy for change refers to strategic efforts to **educate** decisionmakers about issues affecting people with myeloma, **demonstrate** the real-world impact of their choices/policies on patients and families, and **motivate** them to take specific action(s) that will benefit people with myeloma. The goal is not just to highlight problems, but to **provide clear solutions**. Advocacy for change may also involve engaging the public to build awareness, support, and increase the pressure on decision-makers to make positive change.

Decisionmakers face numerous competing priorities when allocating limited time and resources. This means **your advocacy efforts will be competing for attention with many other important issues**.

It is crucial to remember that while the success of your advocacy for change is measured by whether someone took the direct action you requested of them, its *effectiveness* is measured by **how well you make your voice heard when speaking out about your issue.** Educating decisionmakers, shifting public opinion, and establishing connections are all achievements of effective advocacy, as they grow your ability to make future change, even if your immediate goal is not achieved.

To cut through the noise and effectively advocate for change, you need a structured approach to maximize your impact. The three pillars of effective advocacy—key messages, personal narrative, and call to action (page 7)— provide a framework ensure your advocacy efforts are clear, compelling, and actionable. Developing these components will help you communicate complex myeloma-related issues in accessible language, connect emotionally with decision-makers through your lived experience, and provide them with clear solutions to the issues you care about.

IMPORTANT TO REMEMBER

When developing your **key messages, call to action, and personal narrative** it is essential that you remain both **factually accurate and positive** in your approach.

Factual accuracy builds your credibility — decision-makers rely on advocates to provide reliable information they can act upon with confidence. Inaccurate information undermines your reputation and can detract from your advocacy efforts.

Maintaining a positive or hopeful tone, even when discussing serious challenges, makes decision-makers more receptive to your message and positions you as someone offering solutions rather than just complaints. A positive approach demonstrates you're invested in helping resolve an issue, builds stronger relationships, and creates an environment where decision-makers feel empowered to help rather than defensive about current shortcomings.

REACH OUT TO MYELOMA CANADA

If you're interested in advocating for change to government/institutions (ex. for drug access, reducing out-of-pocket treatment costs for patients or changing public policies which impact people living with myeloma), **we strongly encourage you to reach out to Myeloma Canada's staff for assistance.**

It can be difficult to identify or connect with the institutions and people that can act on the changes you are asking for. Myeloma Canada can help save you time and frustration by pointing your advocacy efforts in the right direction.

Similarly, Myeloma Canada may already be pursuing a solution to your issue and can share important information to help you create your key messages and call to action.

ADVOCATING FOR CHANGE: STRATEGIES AND TOOLS

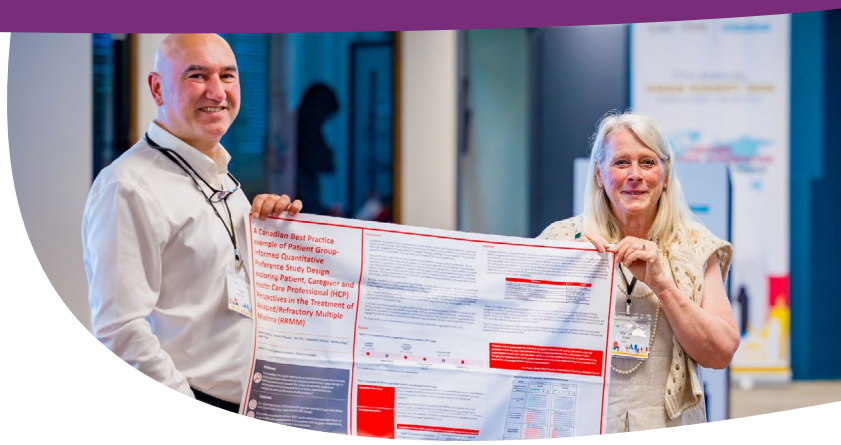
There are a variety of tools and tactics you can use to advocate for your cause, each requiring a varying level of time, effort, commitment, and resources. Every advocate has a unique relationship with their cause and may support it in very different ways. Effective advocacy is more than the sum of its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

SYSTEMIC ADVOCACY STRATEGIES

THE 3P'S: PARTICIPATE, PARTNER, POST

The amount of time and energy you put towards your goal is up to you. If you want to advocate on your own time, remember **Participate, Partner,** and **Post.** Each action can be performed on an ongoing basis and integrated into your existing routine.

Like with all strategies and tools in this handbook, **you do not need to use them all– just what works for you.**



WANT TO GET ENGAGED? – REMEMBER THE 3 P'S!

1. PARTICIPATE

In a democratic society like Canada, advocating for change is a right, and participation is a duty. *Democracy is founded on the principle of participation,* and it is our participation in the democratic process by voting in elections, that gives our leaders their legitimacy.

Participation can be understood as a **continued process of engagement** with the advocacy issues that matter to us. Though it can also be an **immediate act** – like voting – it is best accomplished an **ongoing basis.**

There are many simple ways to participate in the issues that impact you, like signing up for alerts from Elections Canada or your corresponding provincial/territorial body, signing up for Myeloma Matters, Myeloma Canada's monthly e-newsletter, or following key players/organizations on social media.

Staying engaged in the issues you care about helps you be prepared to take swift action when needed.

TIPS

- Engage with the actions of both political (legislative) and bureaucratic government bodies that deal with issues you care about, i.e., your provincial territorial Minister of Health, Canada's Drug Agency (CDA-AMC).
- Participate in opportunities to provide patient input, like Myeloma Canada's patient/caregiver experience surveys (the data from which is submitted to CDA and INESSS's reimbursement review processes).
- Engage with companies and corporations whose actions impact your issue, i.e., pharmaceutical companies with myeloma drugs under review/in development, who often hold consultations with groups of patients/caregivers to hear about their experience with myeloma/treatment, to inform their future programs.
- Remain informed about upcoming local, provincial/territorial and federal elections, and vote in them.
- Stay up to date on upcoming health policy changes or decisions that relate to issues important to you and consider how you or other Canadians with myeloma might be impacted.

2. PARTNER

Partnering is a powerful tool for advocates in a democracy as it amplifies your voice by demonstrating others share your goals. Building personal partnerships with decision-makers, other patients, caregivers, and organizations, strengthens your capacity to make change.

Even if you do not have a current issue to work on with them, creating a network of partners allows you to share information, best practices, support each other's change-making endeavours, and you'll have those partners to turn to when a relevant issue does arise.

Each individual voice matters and partnering unifies these voices to create the collective power often needed to drive meaningful change.

TIPS

- Connect with Myeloma Canada - they have existing relationships that can help advance your cause.
- Join support groups / online groups like MC Lounge– connect with others facing similar issues either online and in-person to share experiences, resources, and coordinate efforts around your shared concerns.
- Build relationships with other advocates who share similar goals so you can coordinate and support each other's work.
- Ask members of your care team to support your advocacy efforts with clinical evidence and professional credibility.
- Connect with your local elected representatives who can champion your cause in their respective levels of government.
- Connect with myeloma advocates across regions to learn from their experiences with different healthcare systems and access to different treatments and resources.



3. POST

Note: this strategy is optional. If you're not comfortable posting on social media, you can still be a successful advocate by focusing on other strategies, or by joining forces with other myeloma advocates who are active on social media.

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, X/Bluesky/Threads etc.., 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 currently very popular/widely discussed amongst social media users ('trending').

Consider posting on social media or engaging with others' content to add your voice to the conversation!



TIPS

- As with any other audience, know your relevant key messages and stick to them.
- Make yourself known to interested parties and decision-makers. Learn how they use social media and start interacting with them on their favourite platforms.
- Your personal social media accounts can be a perfect place to share your personal narrative and get new people talking about your issue.
- Use social media to share resources/information with other advocates and attract new supporters to your cause.
- Use social media regularly; the more often you post, and your social media accounts are updated, the more you will get noticed.

WORDS OF CAUTION

- **Do NOT use social media as a primary information-gathering source.** Try to independently verify any claims you encounter before repeating or sharing them!
- **PAUSE before posting something you have written quickly** – or even better– **run it by someone!** Once something is online, it can live there forever and may be seen by the wrong people, hurting your cause.

SYSTEMIC ADVOCACY TOOLS

The following are just a few useful tools to help you advance your cause and/or bring attention to your issue. All of them require you to develop strong key messages, personal narrative, and call(s) to action. **If you need help making use of these tools, or you're not sure which is best suited to your issue, contact Myeloma Canada or your local support group leader for assistance!**



I. EMAILS AND LETTER-WRITING

The first contact you have with those you advocate to is often by letter or email. A letter and/or email is a great initial way to connect with someone, and written communication gives you the time to ensure you're conveying your key messages, personal narrative, and call to action effectively.

Even if a decision-maker you contact is unable to assist with your current concerns, it is important to stay in touch with this person once a relationship is established, as they can be a useful resource for future advocacy efforts.

Organized letter-writing campaigns can also be useful at times as they convey a widespread need for change and put human faces to an issue. If you are participating in an organized letter writing campaign, key messages and call to action will already be developed, so your personal narrative becomes the most important part of your letter/email.

For an example of a successful letter written by myeloma advocates in our community see page 38.

GUIDELINES FOR LETTERS AND EMAILS

- **The quickest method of sending a letter to a decision-maker is by email.**
- Make sure your **key messages, call to action,** and **personal narrative** are clear: concisely define your issue, and describe what you want them to do about it.
- Always keep the tone polite and positive, even if you disagree with the person you are writing to.
- 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 provide background material, enclose or attach it as a separate document.
- Provide an **expected timeline for a response** without being demanding. For example: "I 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…"
- **Do not use form letters,** especially for an organized letter-writing campaign. Individualize your letters to convey that there is a real person behind each one they receive. Remember, every personal story they hear will further highlight the issue's importance.
- Show you are aware of work the recipient has done on your issue, or a connection they have to it. E.x. "*Your speech at last weekend's lung cancer fundraiser, made clear you care about people with cancer in our community…*" "*Your government's recent cancer plan included important steps in the right direction…*"
- Demonstrate that you are writing to the recipient specifically by using their name in the body of the letter.
- **Make sure your name and contact details are presented clearly** on the letter, and at the end of the accompanying email. If there are multiple signatories, make sure one contact person is clearly identified.

ADDRESSING YOUR LETTER/EMAIL

WHO?

Connecting with the right people at the right level of government who can take action on your issue is critical to effective advocacy. Depending on your issue, finding out who those people are can be complicated, as different issues fall under different or multiple jurisdictions and departments (ex. occupational health issues may fall under the authority of provincial/territorial ministries of labour and health).

- **For most health-related issues—your local provincial/territorial elected representative is the best place to start.** Since healthcare is primarily a provincial/territorial responsibility, your MPP/MLA/MHA/MNA is often your most direct route to influence on issues impacting people with myeloma like drug coverage, treatment access, and healthcare delivery (wait times, resource shortages etc...).
- Your provincial/territorial representative likely cannot make the changes you request alone, especially if they are not part of the governing party, but they can serve as your advocate within the system—putting you in contact with the right ministers or officials, raising your issue in the legislature, connecting you with relevant committees, and providing ongoing support for your cause. See the Government and Politics (view page 12) section to find your representative.
- **You may also want to contact your provincial/territorial health minister directly,** as they have decision-making authority over issues like drug formularies, healthcare and health infrastructure funding.
- **For federal issues** like Health Canada drug approvals, patent regulations, etc. or if the federal government administers your health insurance plan, contact your federal MP and/or the federal health minister.

Remember that advocacy often requires multiple touchpoints with different decisionmakers. A successful advocacy campaign might involve contacting your local representative, the relevant minister, committee chairs, and opposition critics who can champion your cause from different angles. **Myeloma Canada can help you identify the right targets for your specific issue and locate their contact information—reach out to us for help navigating the system!**

HOW?

Know and use the person's exact name and proper title – titles are especially important in government.

- To address federal officials
- To address provincials officials
- To address indigenous leadership



Note

FOR HANDWRITTEN LETTERS

- **Ensure your letter is well-presented and your handwriting is completely legible** – illegible or unprofessional looking letters are more likely to be set aside and ignored.
- **Include your full contact information directly in the letter** – do not expect the recipient to find your address on the envelope. Providing a phone number and/or email address also enables faster responses.
- **Be specific about follow-up plans** – state clearly when and *how* you plan to follow up (e.g., "I will call your office in two weeks to discuss your response" or "I plan to visit your constituency office next month to continue this conversation").
- **Keep a copy for your records** – you'll need to reference your original message during follow-up communications.

II. MEETINGS

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. An in-person meeting is the traditional way of achieving this, often in an official's office, but due to the rise of online communication platforms like Zoom and Microsoft Teams, in-person meetings have become less frequent and necessary. 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 largely possible with a video call.

MEETING TECHNOLOGY

Familiarize yourself with one of the many computer programs/cell phone apps, like Zoom, which will allow you to organize and participate in video chat meetings when an in-person meeting is not possible. See Myeloma Canada's Intro to Zoom InfoSheet for instructions.

Organizations like Connected Canadians also provide 1-1 support to help you familiarize yourself with new technology and troubleshoot any issues you encounter.

If you need access to a paid zoom account, or help setting up your meeting— reach out to your local support group leader or Myeloma Canada and we'll be happy to assist.

GUIDELINES FOR MEETINGS

- You can use a letter or email to request a meeting (see previous page). If possible, it can also be useful to ask someone with close connections to an official or politician support your request (i.e. family/community connections, other representatives from their political party, staff).
- Politicians will prioritize meeting requests for issues they care about or issues that are impacting their constituents, so link your request to one of these.
- If they do not already have a connection to the issue you want to discuss (personally or professionally), grab their interest by describing its impact on the area/people they represent and/or by having one of their constituents make the request.
- Reaching out to a politician may result in a meeting with their staff. Meeting with a politician's staff members or civil servants connected to your issue is still extremely valuable in gaining ground for your issue— these are likely the individuals who will be working on your request anyway.
- There is strength in numbers! Meetings will feel less intimidating when you have support, and an extra brain 'in the room' can help you ensure you cover all your intended points.

Contact Myeloma Canada for help! Our staff has experience requesting and conducting meetings with elected representatives and would be happy to support your efforts.

TIPS

TIPS FOR SUCCESSFUL MEETINGS

- Prepare thoroughly based on the amount of time you have for the meeting and walk in knowing what you want to say.
- Let them know in advance who will be with you and introduce everyone there.
- Lead with your **personal narrative**.
- Stick to your **key messages**, make your **call to action** clear, and show how your ask aligns with the person's own priorities or obligations.
- Have your supporting evidence and be factually accurate but do not spend too much time on numbers.
- Be prepared to stop and answer questions at any point.
- Seek a commitment from the person you're meeting to act within a given timeline, or a promise to follow up.
- Send a follow-up letter or email after the meeting to summarize the conclusions or commitments made. You can also send extra information they may have requested.

TIPS

VIRTUAL MEETINGS

- If it will be a virtual meeting, **ensure you have tested the technology you plan to use beforehand.** (i.e. Zoom platform, webcam setup, microphone). Support groups, Myeloma Canada Staff, friends, family members, are all great resources to help you set up and test a new platform.
- Tech issues may happen despite your best efforts. So, if possible, have another device nearby from which you could join the meeting if something goes wrong (such as your phone).
- Charge your devices in advance and keep your power cord(s) nearby.
- Mute your microphone if you won't be speaking for a bit to minimize background noise— and don't forget to unmute!
- Even though the person you're meeting cannot see your desk/screen, **do not read from a script**, they will be able to tell, and it will take away from the emotional impact of your story.

Note

When meeting with decision-makers, try not get angry or make threats if you feel action is not 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 expressing your anger, you could say something like

"I understand that ___ 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 can we balance those costs to save both, money and lives in the long-run?"

III. ELECTIONS ARE OPPORTUNITIES

Elections offer multiple ways to advance your advocacy goals: **voting on the issues** that matter to you (healthcare, drug access, research funding, etc.), **building connections** with politicians you can leverage for future efforts, and getting **fresh eyes on your issue** from new candidates and parties.

Elections also provide a chance to reframe your key messages to be **timely**, by aligning them with new government objectives and contemporary political narratives.

While a new government/mandate brings new people into power and creates opportunities to advocate in different ways, it can similarly disrupt ongoing advocacy efforts if you've invested significant time and energy working with the previous government.

During an election, the political landscape shifts significantly. Your current elected representatives (MPs, MPPs/MLAs/MHAs/MNAs) are no longer in those roles—they become **candidates** hoping to be re-elected or retain their seats, alongside new candidates from various parties competing for the opportunity to represent you. **This means your usual advocacy targets are no longer available in their official capacity** but you have an opportunity to engage with multiple candidates who are actively seeking to support their community, while seeking support from their community.

While the legislative branch dissolves during elections, the machinery of government continues to function. The executive branch— Prime Minister/ Premier and Cabinet Ministers— stay in their roles during the election period, maintaining operations until a new government is formed. Similarly, civil servants—the (unelected) public service employees who implement government programs and policies — will typically remain in their positions throughout elections and often continue serving the new government afterward. **Understanding this continuity can help you maintain momentum on urgent advocacy issues even during political transitions.**

MAKING YOUR VOICE HEARD

Elections create two distinct windows of opportunity for advocacy. **During the election** is the perfect time to raise awareness about your issue, and make new connections, while **after the election** you can capitalize on the energy of a new government/ mandate to advance your cause.

DURING THE ELECTION

A. Contact all candidates - Request meetings/ write letters to local candidates and leaders from every party. Even losing candidates can become valuable connections.

B. Align your message - Connect your advocacy goals to election issues and the current political climate.

C. Use social media - Engage with candidates and other advocates online to make your issue visible.

D. Write to editors - Share your perspective on how the election impacts your community or issue. Ex: "*Dear Editor, this election is a moment of unparalleled opportunity for Canadians with myeloma because…*"

AFTER THE ELECTION

Follow up!

E. Act quickly – Contact newly elected representatives/appointed ministers within their first 100 days while they're setting priorities.

F. Follow up on election promises – Congratulate members of a newly elected government, remind them of their campaign promises and ideally, how taking action on your issue can help fulfill those promises. Reference specific conversations, or relevant points in their platform.

G. Build new connections – Introduce yourself and your issue to relevant newly elected cabinet ministers, shadow cabinet ministers/opposition critics, and most importantly, your own representative.

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 provide insight to a larger problem.** Especially for health-related issues, having a compelling story about how they impact a local person/people 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 with no connection to myeloma can clearly see and understand your issue.





WAYS TO USE NEWS MEDIA

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

Newsrooms are most interested in things happening right now. 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. Press releases can elicit news coverage without paying for newswire services, by simply emailing them to news organizations along with your personal story.

Newspapers also provide ways to make your voice heard beyond reporting. You can write a 'letter to the editor' that conveys your **key message(s), personal narrative and call to action,** and/or advertise upcoming events like marches, rallies, or awareness days in local papers (both through paid advertising and free local listing. 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), personal narrative, and call to action 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 **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 frustrated/angry. There is a time and place for 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.*
- Consider what kind of media will best support your goal. The main newspaper in your provincial/territorial capital is a usually good target for provincial issues, but a local TV or radio station might be a better choice if you're addressing an issue facing your local community or publicizing an event.

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.

EXAMPLE LETTER

This letter was crafted and sent by community members to provincial elected representatives in the hope of addressing a local issue. It successfully achieved meetings with 2 MPPs with whom our community members are still engaged and working on the issue.

Jane Doe, Member of Provincial Parliament for London-Fanshawe[1]
100 Address Rd.
CITY, ON

July 10, 2025

Additional Recipients: MPP [Name] Hon. MPP [Name] [Ministerial title], MPP [Name][2]

Subject: Request for Meeting — Concerns Regarding Potential Occupational Exposures at [COMPANY NAME] Facility

Dear MPP Doe,

Congratulations on your recent re-election! We wish you continued success as you serve the people of London-Fanshawe. We are writing to request a meeting regarding a matter of serious concern to your community. We, the undersigned, are former employees of the recently closed [COMPANY NAME] automotive parts manufacturing facility in your riding.[3]

Recently, we learned there are 8 of us—that we know of— who have been diagnosed with multiple myeloma, a rare blood cancer. This unexpected cluster has raised significant concerns about potential exposure to hazardous substances in our workplace.[4]

Most of us worked at [COMPANY NAME] for many years, received our diagnoses after retirement, and until recently, none of us had considered a possible link between myeloma and our work. However, upon connecting with one another through the local Support Group, we have become increasingly alarmed by the possibility that our cases may reflect a broader occupational health risk that has gone unrecognized.[5]

We are concerned that:

- Potential links between our diagnoses and past chemical exposure are not being documented and thus going uninvestigated.
- Current provincial systems for occupational disease surveillance— through the Ministry of Labour and WSIB—may not be capturing cases of myeloma, especially when patients are diagnosed post-retirement. Similarly, Ministry of Health/ Cancer Care Ontario processes do not systematically collect occupational history information from patients.
- Without investigation or record preservation, this potential occupational disease cluster and others like it, may remain invisible.[6]

To that end, we are seeking your support in understanding how we could best address these issues to improve the system for current and future workers in Ontario.[7] We would be grateful for the opportunity to meet with you, either by zoom or if needed, in person, to share our experiences, concerns, and discuss possible solutions.[8]

[Support Group Leader name] Leader of the [Support group name], has been supporting our efforts and would be pleased to coordinate meeting arrangements. She can be reached directly at contact@email.com.[9]

Thank you for your time and attention to this urgent matter. We look forward to your response.

Sincerely,
[Employee Name]
Contact: [Support Group Leader name, title] - contact@email.com

WRITE A LETTER

1. Addresses the recipient with their full name and title
2. Clearly identifies additional recipients of the letter using their correct titles. In this case, all additional recipients represent different ridings in the same area.
3. Shows you know something about the person you're writing to, and why they should care about the issue.
4. States the problem and your specific situation.
5. Shows that your experience is not an isolated case and has broader implications.
6. Provides enough detail to contextualize your issue, without overloading on facts.
7. Provides a hopeful, positive framing of why you care about the issue, and why they should too.
8. Makes a direct request for a meeting, and for assistance addressing this issue.
9. Identifies their primary contact person and provides contact information.

ADVOCATING FOR CHANGE AS A COMMUNITY

Working together to achieve community goals

WORKING TOGETHER TO ACHIEVE COMMUNITY GOALS

When advocating as a community towards a shared goal, it is essential that all advocates are on the same page.

Having clear, united, key message(s) and call(s) to action that will be communicated consistently through community members' individual efforts makes it easy for public officials to understand your issue and 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 potentially 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 ongoing treatments with serious side effects, your inability to access CAR T-cell therapy, and how your live might change if you could access it.



MANY VOICES, ONE MESSAGE

Advocating as a community amplifies your message, making it harder for decision-makers to ignore the issues that mater most. By working in harmony, people impacted by myeloma can build momentum, share knowledge, and push for changes that benefit the entire myeloma community.

NOTES

MYELOMA CANADA
MAKING MYELOMA MATTER

THANK YOU FOR MAKING YOUR VOICE HEARD.

Myeloma Canada would like to thank everyone who collaborated with us to develop this handbook!

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