



Multiple myeloma *international bill of rights* (2019)

In 2019, the Global Myeloma Action Network (GMAN), 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.

Refer to the MMBOR for a better understanding of exactly what the international myeloma community needs and for what we can and should advocate.

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:

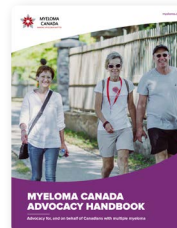
- (a) Be honest and open with their health providers about their current state of health so that the most suitable treatment plan can be prescribed for them.
- (b) Actively seek out education, information and support to live well with multiple myeloma.
- (c) Respect the rights of other people with multiple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



The Myeloma Canada Advocacy Handbook is an essential guide to learning what advocacy is, how to advocate for yourself, for someone else, and on behalf of all Canadians living with myeloma. Download or request your copy today.

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

