



**MYELOMA  
CANADA**  
MAKING MYELOMA MATTER

# **BECOMING A MYELOMA ADVOCATE**

Educational Workshop  
Handbook

2014

## What is advocacy?

Advocacy means speaking and taking action to support a particular cause, idea or policy in a manner that helps convince others, such as people in government or other decision-makers, to take an action you are seeking.

## Why is advocacy necessary?

Everyone, but particularly governments, have different issues that require attention so they must choose what gets attention. This means they must also choose where to spend money and funds are always limited. Advocacy helps decision-makers understand why your particular cause deserves their attention and funding.



## The three pillars of advocacy

### **Pillar #1: Know your issue better than anyone else**

You are the subject expert and it is essential for you to have a focused story and a clear request that is backed up by facts and/or a demonstrated need. This is the absolute foundation for successful advocacy.

### **Pillar #2: Position your issue**

You must present your issue in a way that resonates with the person you are advocating to so they can see easily why they should do what you are asking. Make it clear who will benefit from what you are seeking besides yourself.

### **Pillar #3: Build relationships**

Successful advocacy takes time both to attract others to your cause to help you advocate and to inform and win over those who can make the decisions you want. It involves meeting new people, keeping in touch with them and offering to help them.

***If you succeed in creating all three pillars, you will be well positioned for advocacy success.***

## Key messages

*“Tell me a fact and I’ll learn. Tell me a truth and I’ll believe.  
But tell me a story and it will live in my heart forever.”*

– Native North American proverb

Key messages are not just a collection of facts. Together, they must tell your story – a story that:

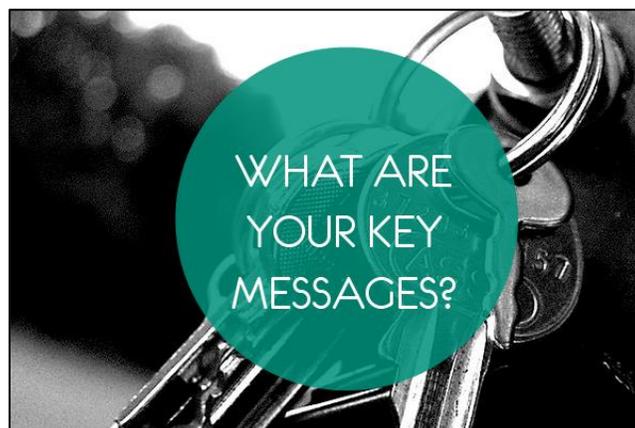
- Communicates what the issue is and why it is important to you;
- Makes the request you are advocating for;
- Is supported by facts; and
- Is emotionally compelling to the listener because it touches something important to them.

You might think you know your story and the facts, but it’s vital to write them down and refine them so they are simple, compelling and supported by data that no one will dispute.

Having key messages will ensure you are telling a consistent story to everyone, without contradictions. When you repeat them many times to people, they will have a cumulative effect so your story will sink in.

Make use of your key messages at every opportunity and in every type of communication – speaking to someone, in a letter or email, on social media or in a media interview.

*Remember:* Your key messages must be designed to inform someone who knows NOTHING about your issue, so you need to include very basic information: e.g. “Multiple myeloma is a type of blood cancer.”



## SAMPLE KEY MESSAGES

### To convince your spouse of the need to renovate the kitchen

Start with a basic premise that is easy to agree with

**1. It's important to keep our house modern and well maintained to get maximum value when it's time to sell.**

- a) A real estate agent I spoke to says a modern-looking house in "move-in" condition sells for at least 15% more than other houses, and much faster too
- b) We don't want to sell right now but we might in a few years, and you never know when we might feel we need to or want to

State some key facts that build the basis for your argument

**2. We've done lots of work to keep things looking good over the years.**

- a) We fixed up the basement five years ago
- b) We painted two bedrooms two years ago
- c) We had all the floors sanded last year
- d) Overall things aren't too bad

Demonstrate the problem in a way that is hard to disagree with

**3. The big weakness we have now is that our kitchen looks old and dated.**

- a) We haven't done anything with it since we moved in 15 years ago
- b) Kitchens are the centre of a home – both for us living here and as a focal point when we want to sell
- c) Fixing up the kitchen could also make it more practical and convenient to use
- d) You've always said you wanted a nice breakfast nook; maybe we could include that

Show the solution, its benefits and how possible drawbacks can be addressed

**4. At the very least, we need to paint, re-decorate and get new appliances, so this might be the ideal time to do more.**

- a) If we agree we have to make an investment anyway, let's make it a bit more and really add value to our house
- b) Interest rates are really low on the line of credit to pay for it and we'd be able to pay it off quickly
- c) We'd save on our energy bill with more efficient appliances, and enjoy them more
- d) We could design cabinets that exactly suit our needs and give us more storage so there's less clutter
- e) You could have your breakfast nook!

Make it important to them!

## Advocacy Tool #1 – Letters and Emails

The first contact you have with someone you want to influence with your advocacy is often by a letter or email. It will be important to stay in contact with this person because a relationship has been established. Sometimes a letter-writing campaign to politicians is needed and can be effective. All letters and emails should follow some basic rules.



### Rules for letters and emails

- Have a well-defined objective and state it clearly – what do you want the recipient to do after they’ve received the email or letter?
- Don’t use form letters, even for an organized letter-writing campaign – individualize each one to show you are writing specifically to that person
- Know the person’s exact name and proper title and use it – titles are very important, particularly in government
- Include something that shows you know about the person’s work or efforts or the connection they already have to your cause – “After reading in the local paper about your attendance at last weekend’s breast cancer event, it’s clear you care about people with cancer...”
- Keep it as short as possible – state the facts you need to support your specific request, but no more. If it is crucial to include background material, enclose/attach it as a separate document so the letter itself is kept short
- Make sure your name and contact details are presented clearly on the letter or at the end of the email – don’t expect the recipient to find your address only on the envelope
- Provide an expected timeline for a response without being demanding – “I hope you will be able to meet with me within the next two weeks...”
- Always keep the tone polite and positive, even if you disagree with the person you are writing to
- Only copy others on the letter or email if it is absolutely necessary and if you do, make sure those copied are identified clearly

## 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. 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.

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

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 plan. 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.

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

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

Yours truly,

Your Name,  
Your Street Address  
Town, Postal Code  
Email Address  
Telephone #

Why he should pay attention

Shows you know something about him & why he should care

States your personal situation

States a positive to give credence to the validity of your issue – you're not just complaining

States your specific problem

Shows that yours is not an isolated case and has broader implications

Make a very specific request

Shows you want to work with him on solutions – it's not just on him

Politely set a deadline for response

Make sure he knows all the ways to reach you

## Advocacy Tool #2 – Meetings

Despite all the great ways we have to communicate electronically, in-person meetings are still the best way to educate someone about your cause and convince them to support what you want – particularly government officials and politicians.

You can use a letter or email to request a meeting (see previous page) but it's also very 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 if at all possible to one of these. If they don't already care about your issue, get their interest by having the request made by one of their constituents.

Meetings with a politician's staff or government employees connected to your issue are very useful to get your story known and can lead to further meetings with politicians or others who can advance your cause.



### Tips for a successful meeting

- Prepare thoroughly by doing your homework and preparing what you want to say and what you want the result of the meeting to be
- Don't bring surprise last-minute 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 it
- Stick to your messages, make your request clear and show how it fits with the person's own priorities
- Let the human and emotional side of your own story come across
- Seek a reaction or a promise for follow-up – don't assume you "know" their reaction, you can ask them to state their reaction
- Don't get angry or make threats if you don't feel action is being taken
- Send a follow-up letter or email after the meeting to summarize the conclusions or things that were committed to, or to send further information that was asked for

## Advocacy Tool #3 – Election Campaigns

Election campaigns are an excellent time to get politicians to listen to your issue and make commitments if they are elected. This is particularly true if you can demonstrate to them that a lot of people care about or are affected by your issue.

### Getting heard in a campaign

- Request meetings with candidates from each party to brief them on your issue; even if they don't win this time, it's one more person who is aware of your issue
- When you meet, leave them with background information about your issue and needs
- Engage with candidates through social media to get their reaction to your issue (see also page 8)
- Write letters to the editor of papers to give your thoughts about the impact of the election on your issue
- Attend all-candidate meetings or debates and ask them about your issue – it will get their positions on the record and might generate media coverage



### Possible questions to ask at a campaign meeting

- What's your view on making new cancer treatments available to patients once Health Canada has approved them? Shouldn't they be made available to patients who need them?
- What is your party's position on funding of cancer treatments by the provincial health system?
- How would you and your party work to reduce wait times for cancer clinics, surgeries and treatments?
- Do you think cancer patients should be able to get new treatments once they have been approved by Health Canada?
- What would you do if elected to get more cancer care clinic spaces available in our community?

## Advocacy Tool #4 – Media

If used at the right time and in the right way, media can be very useful to get your story out and put pressure on decision-makers regarding your issue. News coverage of your issue can be a very powerful tool because it drives public opinion.

Before taking your story to the media, you must understand how they work and what they need to tell your story in an effective way to advance your issue. Media want to communicate about issues through personal stories – how one person or one family is being impacted. For health issues, having compelling local patient stories is key.

### How to tell your story to media

- You need to know exactly what you want to say, and stick to saying it – your key messages are vital
- Know what you ultimately want to “ask” the media audience to learn or do
- Decide how to say it – select the right emotional tone (a “fighter,” a “victim,” etc.)
- Ensure what you tell media aligns with what you have been telling other audiences
- Pick the right media to tell your story to reach the right audience for your issue



### Ways to use the media

- Send a press release about your issue
- Offer media-trained spokespeople for interviews about your issue (for newscasts, talk shows, etc.)
- Send a media advisory to invite media to cover an upcoming event or public forum about your issue
- Advertise upcoming events in local papers (paid advertising and free local listings)
- Write a letter to the editor

## EXAMPLE LETTER TO THE EDITOR (real letter)

# Fair access to cancer medications

Letters to the Editor (*The Guardian*, Charlottetown, PEI)

Published on March 11, 2008

Makes clear the story being referenced

The recently profiled plight of Hannie van der Kaay who is not able to receive coverage for a much-needed cancer treatment is unfortunately not a unique experience on Prince Edward Island. Mr. van der Kaay's story profiles a situation many Islanders are faced with when diagnosed with cancer; they find out the treatment recommended for their disease is not covered by our public health-care system.

Provides new facts from writer's point of view

Approximately 25 per cent of all Islanders do not have drug coverage from either a public or private provider; the lowest level of coverage in the country. In fact, in 2006 when the Canadian Cancer Society surveyed cancer patients in P.E.I. we found that 25 per cent needed help in paying for medications and of those, 25 per cent had never had that help.

Summarizes the impact

P.E.I. has the lowest number of new cancer drugs added to our provincial formulary, or drug list, when compared to the rest of the country. For those medications we do add, we have the longest time in listing them. These are more grim statistics. What does this mean for cancer patients? It means that even if they are covered by our public health-care system, patients may not be able to access the treatment they need, when they need it.

States what group is doing

Mr. van der Kaay and the many other Islanders who are impacted by the lack of adequate drug coverage in P.E.I. are the reasons why the Canadian Cancer Society has been active in advocating to our provincial governments. We have spoken out for patients and lobbied both the previous and the current government to make much-needed changes to our system.

Provides positive ideas to solve problem

The Canadian Cancer Society believes that all Canadians - including Islanders - must have equitable access to cancer medications regardless of where they live or their ability to pay. We believe that the process for selection and approval of drugs must be timely, open and transparent and include patients in the policy decisions made about their treatment. This is a message we have been taking to government for many years. We have recommended the development a catastrophic drug program for all Islanders and an approval system similar to that of our recommended drug selection/approval system that ensures medications are available to patients when they need them.

Clearly states what needs to be done, relating back to the original story

We at the Canadian Cancer Society, and we believe all Islanders, are watching our elected officials to see that they will honour their commitments, and to see what they will do to help Mr. van der Kaay as well as all Islanders who are diagnosed with cancer.

The government of P.E.I. must put cancer patients first and make this issue a priority. We must ensure that anyone diagnosed with cancer is able to focus on one fight - his or her fight against cancer - not one with our health-care system to get the treatment that he or she needs.

*Dawn Binns,*

*Executive Director, Canadian Cancer Society, P.E.I. Division.*

**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 both of being published and of being read!

## Advocacy Tool #5 – Social Media

More and more, issues are brought to broader public attention – and the attention of decision-makers – through social media: Facebook, Twitter, YouTube, LinkedIn and other tools that are used by millions of people. They are watched closely by politicians and decision-makers.

As well, many stories today that get covered by traditional media (TV, radio, newspapers) get their attention because they are “trending” on social media.

### Tips for using social media for advocacy

- As with any other audience, know your key messages and stick to them
- Learn how your advocacy targets (politicians, organizations) use social media themselves and start interacting with them in that way to get yourself known to them
- Use social media to attract new supporters to your cause
- Use social media regularly and often – your social media sites and tools always need to be up to date and the more you post the more you will get noticed
- Pause before posting something you have written quickly – online can live forever and mistakes can quickly “go viral” and hurt your cause



## Other Advocacy Tools & Tactics

There are a variety of other tools you can use to advocate for your cause. Each can be very effective if used at the right time and in the right way.

**Petitions:** Collecting many signatures in support of your cause shows decision-makers that you have many supporters so they should pay attention. They might not act directly in response to the petition, but it can lead to greater attention to your cause from decision-makers and media.

**Report cards:** These compare the status of your issue in different jurisdictions – comparing provinces or countries for example. These can be useful in attracting media attention and in drawing attention of decision-makers, particularly in areas that have fallen behind others.

**Opinion polls:** You can commission an opinion poll to give you reliable information about how the general public or specific groups feel about your issue. Favourable results can be very powerful for media attention and for showing decision-makers your cause is important.

**Policy papers:** These pull together all the scientific or other evidence to support your cause and build a logical argument for it. They can be powerful, particularly if they are endorsed by credible academics or other authorities.

**Speeches:** Many service clubs, community groups, and chambers of commerce offer speaking opportunities to tell about your issue to audiences of influential people. These speeches can also get media coverage.

**Seminars/Symposia:** These sessions bring experts on your issue together to discuss it, or a particular aspect of it. They can attract new supporters, decision-makers who want to learn more, and media coverage, and the results of the discussion can also be published as an academic article or policy paper.

**Political fundraisers:** It can be useful to invest in tickets to political fundraisers to have the opportunity to raise your issue, or make yourself visible, to the politician involved, perhaps as a way to secure a further meeting with the politician or their staff.

**Marches/Rallies:** A useful way to attract and mobilize supporters to your cause, generate media attention and get noticed by decision-makers.



## Useful Resources

### National

- Myeloma Canada: [www.myeloma.ca](http://www.myeloma.ca)
- Health Canada: [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca) (click on “Drugs & Health Products”)
- Health Canada (clinical trials database): <http://www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdonclin/index-eng.php>
- U.S. & global clinical trials: [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)

### British Columbia

- Health Minister: [www.gov.bc.ca/health](http://www.gov.bc.ca/health) (click on “The Minister”)
- Legislature: [www.leg.bc.ca](http://www.leg.bc.ca) (click on “Members” to find your MPP)
- BC Pharmacare: [www.health.gov.bc.ca/pharmacare](http://www.health.gov.bc.ca/pharmacare)
- BC Cancer Agency: [www.bccancer.bc.ca](http://www.bccancer.bc.ca)

### Ontario

- Health Minister: [www.health.gov.on.ca](http://www.health.gov.on.ca)
- Legislature: [www.ontla.on.ca](http://www.ontla.on.ca) (click on “Members (MPPs)” to find your MPP)
- Ontario Public Drug Programs: [www.health.gov.on.ca/en/public/programs/drugs](http://www.health.gov.on.ca/en/public/programs/drugs)
- Cancer Care Ontario: [www.cancercare.on.ca](http://www.cancercare.on.ca)

### Quebec

- Ministre de la Santé et des Services sociaux: [www.msss.gouv.qc.ca/ministere/ministre.php](http://www.msss.gouv.qc.ca/ministere/ministre.php)
- Assemblée nationale: [www.assnat.qc.ca](http://www.assnat.qc.ca) (“Députés”)
- Institut national d’excellence en santé et en services sociaux (INESSS): [www.inesss.qc.ca](http://www.inesss.qc.ca)
- Coalition Priorité Cancer au Québec: [www.coalitioncancer.com](http://www.coalitioncancer.com)

### Newfoundland & Labrador

- Health Minister: [www.gov.nl.ca/health](http://www.gov.nl.ca/health)
- House of Assembly: [www.assembly.nl.ca](http://www.assembly.nl.ca) (click on “Members” to find your MHA)
- Prescription Drug Program (NLPDP): [www.gov.nl.ca/health](http://www.gov.nl.ca/health) (click on “Prescription Drug Program”)
- Eastern Health Cancer Care: [www.easternhealth.ca](http://www.easternhealth.ca) (click on “Cancer Care” under “Services Quick Links”)