



# DIGITAL ADVOCACY AND STORYTELLING TOOLKIT

This Digital Advocacy and Storytelling Toolkit has been created to help you identify your issue, help you craft how to advocate for your issue via telling your story, determine the appropriate avenue to tell your story and the actions to take as the next steps.

Advocacy means working to provide support for a cause, policy, or action. Advocacy is also the pursuit of influencing outcomes. Everyone has the ability to advocate on his or her own behalf or on behalf of others. We advocate because we see a perceived inequality or imbalance. Therefore, when we advocate, we are asking for change. Whether you are meeting with a funder, an elected official, or a government representative, and whether you are raising awareness or asking for a policy change, a new program, or for funding, you are advocating.

As an individual diagnosed with breast cancer, you may advocate for your own cause or a collective cause that many breast cancer patients face. While there have been many advances made in the diagnosing, treatment and management of breast cancer, individuals diagnosed with or living with breast cancer still face issues that may need advocacy.

One way to advocate for an issue is to share how it personally affects you, in other words, by sharing your story. This Digital Advocacy and Storytelling Toolkit has been created to help you identify your issue, help you craft how to advocate for your issue via telling your story, determine the appropriate avenue to tell your story and the actions to take as the next steps. Please note that this toolkit should serve as a guideline on how to get started. What the final product will look like will be different for each person and issue.

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#### Breast Cancer Issues To Advocate For

There are various issues that you may be facing as a breast cancer patient. These can range from psycho-social issues to financial issues. While all the impacts and side effects from a breast cancer diagnosis are important to address, it is important that the issue you advocate for has specific, concrete, and measurable solutions and are issues that are shared with other breast cancer patients. This allows you to provide a story that does not just remain a story but rather, drives a cause that leads to change for yourself as well as other breast cancer patients.

Below we highlight some of the most prevalent issues that individuals diagnosed with breast cancer face and may need advocacy.

#### Metastatic Breast Cancer

For many Canadians affected by <u>metastatic breast cancer</u>, there continues to be a lack of awareness, understanding, resources, and support, surrounding this disease. If you are an individual living with metastatic breast cancer, you may need to advocate for:

- Increased awareness and understanding of metastatic breast cancer, including the lived experiences of Canadians diagnosed with metastatic breast cancer
- Equitable and timely access to effective treatments for metastatic breast cancer
- Increased investments in research to improve quality of life and health outcomes for Canadians living with metastatic breast cancer

#### Financial Burden of Breast Cancer

Cancer can be expensive, and not all costs are covered by the healthcare system. Major out-of-pocket expenses can include drugs, medical equipment, transportation, and childcare. The <u>financial burdens of a breast cancer diagnosis</u> can become compounded if you are unable to work or have to work reduced hours, do not have insurance, or do not have a high enough income to cover costs. Finance related advocacy can be:

- Increasing awareness of the financial burden of a breast cancer diagnosis on Canadian families
- Pushing for reforms of government income replacement programs, specifically Employment Insurance Sickness Benefits
- Ensuring that employers uphold the <u>Employment Equity Act</u>

## **Drug Access**

Currently, Canada lacks a national approach to prescription drug coverage. While each province and territory has its own independent system for providing cancer treatments, the eligibility requirements and nature of coverage varies greatly across provinces, territories, and other jurisdictions. Advocating for better drug access across Canada may look like:

- Pushing for greater transparency and accountability by Canadian health agencies
- Calling for and participating in opportunities for patient engagement throughout the healthcare system
- Participating in and raising awareness of CBCN's <u>mBC Access Matters</u> <u>campaign</u>
- Contacting government officials and bodies on drug access issues using <u>CBCN's Advocacy Guides</u>

#### **End-of-Life Care**

<u>Palliative end-of-life care</u> is a form of healthcare with a focus on relieving pain symptoms while providing emotional and spiritual support for those living with or dying from an incurable illness. It can begin at any point during your treatment to improve your quality of life and people can often move in and out of palliative treatment. If you are receiving palliative treatment and end-of-life care, you might advocate by:

- Calling for palliative care to be integrated into Canada's public and private healthcare systems
- Petitioning for a national standard of care that is monitored and enforced
- Pushing for targeted funding for palliative care nurses and palliative care resources

# Young Women with Breast Cancer

While the challenges faced by <u>young women diagnosed with breast cancer</u> can be faced by any breast cancer patient, they are experienced in a unique way when you are young. In particular, younger individuals may be diagnosed at a later stage as their symptoms are sometimes dismissed, due to the false belief that certain age groups are too young to have breast cancer. As a young woman diagnosed with breast cancer, you can advocate for causes specific to young women by:

Calling for more research that studies young women and breast cancer

- Raising and increasing awareness of the unique challenges faced by young Canadians diagnosed or living with breast cancer
   Urging for breast cancer resources and spaces that specifically target young women diagnosed with breast cancer

# Communicating Your Story as an Advocacy Tool

One way to advocate for an issue is to share how it personally affects you, in other words, by sharing your story. However, sharing your story as an advocacy tool means more than just stating what you are going through or have gone through. Using stories as an advocacy tool means focusing on a specific issue, strategically using facts and statistics, providing at least one solution, and including a <u>call-to-action</u>. A call-to-action is essentially an 'ask' of your audience. Including a call-to-action transforms your story from just a story to a form of advocacy as it moves people from reading to doing. You can find great examples of advocacy through telling a personal story on CBCN's <u>Our Voices</u> blog.

The following worksheet walks you through how to communicate your story as a form of advocacy.

#### What Are You Advocating For?

#### Problem

Identify the issue that you want to advocate for. Some common topics of advocacy for breast cancer patients include:

Metastatic Breast Cancer Financial Impacts of Breast Cancer Being a Young Women Diagnosed with Breast Cancer Breast Cancer Drug Access End-of-Life and Palliative Care

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	Summarize your key message in 25 words or less.

Sulfillialize your key thessage in 25 words or less

What is the main impact of the issue? How are most breast cancer patients impacted by this issue? Is it:
Mental/Emotional Physical Social
Financial
How are most breast cancer patients impacted by this issue? Add facts and statistics.
Solution
What would resolve the issue?

Propose a few solutions. Be as specific as you can.

What	positive impact would the resolution have?
	Focus on the impact on your life as well as the lives of others diagnosed with breast cancer.
How w	vill the proposed solution(s) help you? How will it help other breast cancer patients?
Call-	-To-Action
What	would you like to urge others to do?

What would you like people hearing your story and issue to do about it?

# What is Your Story?

Illustrate the scope and main impact of the issue on your life. Is it:
Financial Spiritual
Mental/Emotional
Physical Social
Consider adding how long this has been an issue in your life.
What impact has the issue had on your loved ones?
Your partner Your children
Your parents or parental figures
Your friends and other family members

Ask your loved ones how they have been impacted.

What has surprised you about this experience?
What are some things you were not expecting?
What has supported you/given you hope/motivated you/inspired you to keep going?
Recoanize the thinas and people in your life who have been there.

# **Determining Your Strategy**

When you choose to share your story as a form of advocacy, it is important to determine the right strategy and mode to tell your story. Determining a strategy looks like selecting one or more avenue(s) that you will share your story through. The avenue(s) you choose to share your story through will largely be based on your <a href="identified problem">identified problem</a>, <a href="solution">solution</a> and <a href="call-to-action">call-to-action</a>. That being said, it is important to choose the avenue(s) you are most comfortable with.

Some of the most common avenues to share your story and advocate for an issue include:

**Blog Writing** 

Social Media

Media Relations

**Government Relations** 

# Blog Writing for Advocacy

As part of your advocacy activities, you may want to consider starting a blog dedicated to your journey. Whether it's sharing your story, connecting with likeminded individuals, or contributing your ideas, blogging can be a meaningful way to document and share your experiences as an individual diagnosed with breast cancer. It also allows you to keep track of the various impacts of a breast cancer diagnosis. Although this guideline on blog writing focuses on creating a blog, the guidelines can also be followed if you are simply writing a single blog post and submitting it for publication through an already established blog.

Whether you already have a blog or are contemplating launching one, below are a few tips and ideas that you may find helpful.

## **Getting Started**

Depending on the topics your posts touch on, you may identify a breast cancer issue with proposed solutions, statistics and other elements of advocacy in some posts, but not others. To address this, feel free to use the 'About Me' section of your blog to address the items outlined in the "Communicating Your Story" worksheet. Here, you can identify the overall reason for creating your blog, outline the various issues your posts might address, and state what you hope to get out of your blog (solutions and changes that you would like to see). Your call-to-action can be as simple as asking readers to sign an online petition or as involved as asking people to join a lobbying group with you.

# Keep It Simple

When starting a blog, don't try to make it perfect or be overly critical of yourself, your writing, or the way your blog looks. The idea is to get started and become familiar with telling your story, your writing, and the platform you are using - allow yourself to let go and see where your blogging journey takes you.

#### Be Yourself

Find your voice, and let your personality come through. Every person's expression is unique, and your website is a space to create and share your story in the exact way that you want. If you don't know where to start, bookmark blogs and websites that you like and make a note of the writers' styles and overall approaches then find your unique style and voice from this. You can visit the 'Stories' category of CBCN's <u>Our</u>

<u>Voices Blog</u>, for ideas and inspiration on topics and styles that breast cancer patients use to tell their story.

#### A Picture is Worth a Thousand Words

If possible, try to include visuals. Are you an aspiring photographer? Has your son or daughter snapped a funny picture of you? Have you found an image with a quote that precisely describes how you feel? Images evoke emotions and enrich text-based content. Check out <u>Unsplash</u> or <u>Pexels</u> for inspiration. Both sites allow you to use their photos for free. While crediting the source is not enforced, it is a great idea to do so.

If you use other sources for pictures, make sure that you do not use copyrighted work without obtaining prior permission of the copyright holder. Many websites will describe how visitors are (or are not) permitted to use their content. The usage permissions can generally be found under the "Terms of Use" or "Terms and Conditions" section of their website.

#### Be Social

Those reading your posts may comment and ask you questions, be sure to respond to them. You may also consider sharing your posts to your social media accounts. Don't forget to invite your friends, family or followers to share, "like" and comment on your posts (both on your social media, if you share them there, and directly on your blog posts).

# Social Media for Advocacy

Social media is a great avenue for bringing attention to and raising awareness of the many issues that breast cancer patients face. While there is general knowledge of breast cancer, most people don't know about the everyday experience of having a breast cancer diagnosis.

You can choose to dedicate an entire social media account to advocating and sharing your experience, or you can make one-off posts when there is a specific issue you want to shine the spotlight on. Whichever option you go with, be clear about your overall message and goal by keeping the items outlined in the 'Communicating Your Story' guide in mind.

The following tips and guidelines provide an overview of the main social media platforms that can be used to help you connect with other social media users, extending the reach of your story, inspiring a discussion and creating needed change.

As a general rule of thumb, regardless of what platform you use, typically, the following should be avoided:

Posts that are commercial in nature, e.g. sell products and services, or recruit fans and followers

- Profanity or defamatory, libellous, offensive, abusive, discriminatory or demeaning content (including images, videos and links)
- Disparaging, threatening posts that condone violence or illegal behaviour
- Offering unsupported health or medical advice
- Personal information such as your home address or phone number
- Posts that violate another's copyright or intellectual property
- Excessively repetitive and/or posts that are disruptive to the community or spam
- Posts containing proprietary, confidential, sensitive, or non-public information

#### Facebook

#### Include Images

Posts accompanied by visuals get the highest amount of engagement on Facebook, so be sure to include images whenever you can. Make sure that you ask permission of individuals in the photos to share the image, or seek permission if the photo is copyrighted and provide photo credit to the photographer.

#### Make your Posts Mobile Friendly

Keep in mind that many people will be accessing your posts on their smartphones, so ensure that your posts are succinct and easy to read.

#### **Engage with Others**

Aim to respond to those who take time to comment on your content. If someone wants to learn more about an advocacy issue that you write about, have a link from a verified source that you can direct them to.

#### **Consider Timing**

If your goal is to attract more attention to your posts, try to publish content when most Facebook users in your time zone are online. Generally, the best day and time to post is Wednesday at 11AM and 1PM. Over time, you will learn which times work best for your followers. If you create a page dedicated to sharing your story (in other words, as a Facebook business page rather than a personal Facebook account), you can also track insights into how people interact with your page to find the time that works best for you. While the time you post is important, the quality and nature of your posts matter most.

#### **Inspire Action**

All your posts may not require a call-to-action, but if one can be applied, include it whenever possible; the more specific the request, the better.

#### **Twitter**

#### Think Real Estate

Given that you only have 280 characters to work with, it is important to keep your message to the point. However, if you feel restricted by the 280-character limit, don't worry, you can link tweets to each other and create a "thread" when you have a lot to say on a certain subject. Sacrificing grammar is often acceptable in the Twitterverse due to the space limit.

#### Be Social

Engage with content that others tweet: comment, retweet, and like tweets from others who discuss similar topics to you. This will help extend the reach of the overall advocacy message and topic that matters most to you.

#### **Inspire Action**

Give a clear call-to-action, ask a question, provide links to websites for people to learn more or request that your followers retweet your posts. Specific requests result in action and therefore, impact.

#### Leverage Tags and Hashtags

Incorporate hashtags so that people interested in what you are posting about can see it. Mention organizations and influencers (popular accounts that tweet about the same or similar advocacy topics) by tagging them in your posts. This will help your content get noticed, which is important, especially if you include a call-to-action. Twitter only allows 280 characters per tweet, so use only the most relevant hashtags. If you need to, create a thread and add the hashtags and mentions in a linked tweet

# Instagram

#### It's Not Just Photos

Instagram first started out with photos. Now, it also allows users to post short videos (up to 15 seconds) and longer videos (between 1 to 15 minutes long). Content posted to Instagram Stories, which are available to viewers for 24 hours, include photos, videos, 'Reels', boomerangs, and much more. Leverage the various Instagram content types to increase the reach and engagement on your main posts when you share your story and advocate for an issue. For example, you can use Instagram Stories to draw attention back to your main content.

#### Captions Are Everything

When you post photos, you will be telling your story in the captions. Even if you tell your story using longer videos, it is important to still use captions to summarize what you are speaking about in your videos. Be sure to use proper grammar, tell your story in a captivating manner, and close with a call-to-action. Instagram captions allow for 2,200 characters so take full advantage.

#### Follow Back

Follow your followers back and get to know them. Also, find organizations and influencers whose content you enjoy, learn from them and share their posts in your story if it resonates with you and the advocacy message you are trying to get across.

#### Leverage Tags and Hashtags

As with other social media platforms, use hashtags and tag relevant accounts. Instagram allows up to 30 hashtags so take full advantage of this.

#### YouTube

#### Clean, Clear, Clutter-Free

If you choose to tell your story using YouTube, record yourself in a space that is clean and free of clutter. It's also important to speak loudly and clearly so that you can be heard properly. You don't have to invest in expensive equipment if you choose to advocate via YouTube; great looking and sounding videos can be achieved from most smartphones, it's just a matter of recording yourself in a space that is well-lit, clean and quiet.

#### Get to the Point

While videos of up to 15 minutes can be uploaded (verified accounts can upload longer videos), it is important to be specific in your videos. Each video should cover one topic, that way you can provide enough details on the given topic. Be sure to end each video with a call-to-action whenever you can.

#### Be Social

As with all other social media platforms, engage with the content that others post, ask your viewers questions and respond to comments that they leave.

#### **Podcasts**

#### Choose the Right Host

Within the world of podcasting, there are various platforms or hosts that you can use. Conduct a Google search to find the pros and cons of the most popular podcasting hosts to ensure that you are using the one that is right for you.

#### Keep it Quiet

With podcasts, all your listeners get is audio. This means that it is very important to have a great sound. You don't need to invest in expensive equipment; achieving great sound can be as easy as recording on your smartphone with headphones in a closed, quiet room to ensure that there is no background noise.

#### Stay on Point

Depending on the podcast host that you decide on, the length of audio you can upload will vary. Pick a length of time that you are comfortable with and that you can consistently stick to, in order to ensure consistency. A good length for a podcast is 15-30 minutes; this allows you to discuss one topic in depth. Plan your content ahead, this will ensure that you stick to the subject at hand and stay within your time frame. Be sure to end with a call-to-action that listeners can easily follow.

# Contacting Media Relations for Advocacy

Contacting the media as a form of advocacy allows you to share your story and the issue that you are advocating for on a large scale. Getting involved with media relations is a great strategy for issues where your proposed, or one of your proposed, solution is raising awareness.

Media relations is a large umbrella that covers everything from radio stations, to online magazines, to national publications. Your approach and preparation will therefore be determined by which route you choose. Regardless of whether you contact a print publication or a radio station, it is important to ensure that you tell your story and advocate for your issue in a manner that is newsworthy. Referring to our "Communicating Your Story" worksheet will help you balance newsworthiness with focusing on the advocacy issue, resolution and call-to-action.

Beyond the newsworthiness of your story, the overall advocacy message and the five W's – Who, What, When, Where and Why – news stories are chosen according to the following criteria:

- Audience impact
- Controversy
- Conflict
- Credibility and public awareness of those involved
- Emotional impact

The following tips and guidelines focus on two avenues within the media relations umbrella: publications (which you can contact through a letter to an editor) and interviews (which you can try to arrange via a media pitch note).

#### Publications and Letters to an Editor

If you choose to share your story via a publication, you might consider sending a letter to the editor – a letter sent to a publication about issues of concern from a reader. Oftentimes, the letter comes from correcting a perceived error read in a previous edition of the publication or from a point of opposition or support of a stance taken by a journalist. It might also come when the particular topic is current/relevant. Good examples of this are when the topic is up for debate by a branch of the government, or a high-profile story that has gained a lot of media attention. These letters are meant to be published verbatim, so anything you write must be accurate and appropriate for the publication's audience.

Here are a few tips for sending a letter to the editor:

- To find the email address of the editor, go to the 'contact us' tab on the publication's website
  - This ensures you have the appropriate contact who has given their permission to be contacted
- Submit the letter in the body of your email (do not submit it as an attachment)
- Letters should be kept as short, clear and concise as possible
  - o Confirm the preferred length/word count on the publication's website
- While newspapers welcome letters on any subject, they do reserve the right to condense and edit at their discretion
- Where possible, localize the content to increase its chances of being pickedup by regional newspapers

You can use this sample letter to the editor as an example of what a letter to an editor looks like.

#### Interviews and Media Pitch Notes

If you are more interested in being interviewed, you might consider sending a media pitch note - a message meant to inform the media about your story. In a pitch note, you want to share your message in a way that can illustrate to the reporter how the story might unfold for their audience. The pitch note is your opportunity to introduce yourself, tell your story and explain why it's important that they highlight the subject of your choosing. A good idea would be to, when and if possible, mention any local support provided and complement your story with Canadian statistics and/or facts to help illustrate the issue.

Here are a few tips for sending a media pitch note:

- To find the email address of the right contact person, go to the 'contact us' tab on the website of the media platform you are interested in.
  - This ensures you have the appropriate contact who has given their permission to be contacted
- Don't overwhelm with too much detail
  - The pitch note should be about half of a page to one page long, maximum
- Only send out a pitch note to the media if you know you will be available to conduct the interview
  - In other words, don't send your pitch note right before a big surgery or a long vacation
- Cite relevant statistics whenever possible for credibility
  - Media can potentially use them as research points for any feature or more in-depth stories
  - Make sure you have consent of the sources that you are citing
- Have a high-resolution colour photo available to share if someone asks for it.

This photo could be of you – on your own or with your family and/or friends (get permission from them first). Make sure that there are no visible brand or company logos, and that the photo background is not cluttered

You can use <u>this sample media pitch note</u> as an example of what it looks like to pitch a story to the media.

#### Preparing for the Interview

It's important to be prepared to speak to the media when they get back to you to tell you that they are interested in interviewing you to learn more about your story. Speaking with media for the first time can be daunting, but preparation can alleviate much of the on-the-spot stress of conveying your message to an audience.

Once an interview has been confirmed, get and write down the following information:

- Name of the reporter/interviewer
- Length and date of the interview
- Deadline (date, time) for completing the story
- Details on the topic or the desired angle
- Names of people to be interviewed (is it just you or are there other interviewees and/or angles?)
- If the interview will be live or taped
- The type of interview (audio, visual or written)

#### Types of Interviews

#### **Audio** (Such as a podcast or radio)

Keep your message short and concise. There is no room for detail or long-winded answers, as audio-based interviews often work in "sound bites". Use your words to create the visual imagery for the listener, such as active verbs or anecdotes. Be articulate and make your voice sound pleasant to listen to and keep notes in front of you for easy access to information such as statistics.

#### **Visual** (Such as TV or a documentary)

Visuals are king (or queen!), and the interviewer will likely want to record the interview in a location that supports the message you are trying to convey (e.g. your home, etc.). If it is in your home, choose a room ahead of time and prepare it for the interview. Ensure there is no clutter, no brand or company logos and nothing distracting in the background. A family photo on a shelf is a good background visual

(get the permission of everyone in the picture first). Ask ahead if the reporter would want to film any clips outside, so you can prepare for poor weather.

When interviewing, look at the interviewer, not the camera. Avoid fidgeting or any nervous movement, as this can be distracting to the audience. However, be yourself; any artificial persona will show on camera.

**Written** (Such as a printed newspaper or an online blog)

Ensure you explain things thoroughly in a clear language. The great news is that with print reporters, you have the freedom to explain any specific terms and expand on a given topic as needed. Have notes with you so that you can continually refer to your key messages.

The interviewer may want an image to accompany your story; if this is the case, select one that is clear and recent. If you use an image with people other than yourself in it, get their permission before submitting it.

#### Final Thoughts

- There is no such thing as "off the record"; don't share anything that you would not want to read or hear in public about yourself
- Treat the media nicely and attempt to build relationships
- Turn negatives into positives at all opportunities
- You can take control of the interview or re-contextualize if need be
- Emphasize your advocacy message
- Don't answer questions if they are meant for someone else; if you are not a doctor, don't give medical advice
- Prepare to answer when the reporter says, "Is there anything else you wish to add?"
  - Use this time as an opportunity to reinforce your advocacy message(s)

# Contacting Media Relations for Advocacy: Sample Letters

There are various avenues to share your story as a form of advocacy. Should you choose to share your message via media relations, we provide sample letters below to get you started. These sample letters are written from the perspective of "Kelly Slynch", a metastatic breast cancer patient advocating for increased awareness of the everyday experiences of metastatic breast cancer patients. Feel free to refer to and use the following samples when sending a letter to an editor or sending a media pitch for an interview.

The highlighted sections refer to the types of information mentioned in our <u>Communicating Your Story</u> worksheet that you should be including in your communications, if they apply. Be sure to edit the letter to reflect your own personal information and situation. If you choose to send your communications via email, the text should be written within the body of the email and not sent as an attachment.

#### Letter to an Editor

Subject Line:

Letter to the Editor: Metastatic Breast Cancer Patients Need to be Acknowledged

Body:

Dear Editor.

Timely angle! Over the years, Breast Cancer Awareness Month has garnered much media attention, and that is to be commended. It is important to recognize this terrible disease and bring to light new information about treatments and supports for those living with it. [Identify issue] However, too often the messaging around breast cancer is focused solely on the "survivorship" aspect of the disease, and not on women like me, living with metastatic breast cancer. [Personal story] Now 54 years old, I was diagnosed with metastatic breast cancer (Stage IV) in June 2010. As someone living with metastatic breast cancer for a decade, it would be nice to recognize what survivorship looks like for others like me.

Insight/point of clarification Advocates have been calling on the Canadian government to officially declare October 13th as Metastatic Breast Cancer Awareness Day – an opportune time to educate people on our unique journeys with this late-stage disease. Though this is not an officially recognized day, it is noted around the world and among some breast cancer patient associations in Canada.

[Facts and statistics] Every year, approximately 25,500 Canadians are diagnosed with breast cancer. At least three Canadian women receive their first breast cancer

diagnosis of locally advanced or metastatic disease every day. Approximately 30 percent of those initially diagnosed with earlier stages of breast cancer later develop recurrent and/or metastatic disease. More awareness of this disease is certainly needed as survivorship for metastatic breast cancer patients is vastly different from survivorship for early-stage breast cancer patients.

Include details to show that it is an issue that affects others breast cancer patients! The Canadian Breast Cancer Network advocates for and provides information specifically for metastatic breast cancer. Their recently published guide, 'Metastatic Breast Cancer Handbook: A guide for individuals living with stage IV breast cancer' provides information regarding metastatic breast cancer, existing and upcoming treatment options and their side effects, clinical trials, and complementary therapies to relieve stress and anxiety.

[Call-to-action/repeat the lesson or reason for letter] I encourage all readers to visit the Canadian Breast Cancer Network's website (<a href="www.cbcn.ca">www.cbcn.ca</a>) to educate themselves on metastatic breast cancer. [Proposed resolution] My hope is that as the public becomes more aware of metastatic breast cancer, Metastatic Breast Cancer Awareness Day becomes officially recognized by Canada. [Impact of resolution/personal connection] Those of us living with this late-stage disease can often feel isolated from the greater breast cancer community and having this day officially recognized will help show that we are truly included in the breast cancer community.

Word Count: 345

Kelly Slynch linsert address and phone number at your discretion Vancouver, BC 778-000-0000

#### Media Pitch

Subject Line:

New year, new hope for local woman living with metastatic breast cancer

Body:

Hello Jane Editor.

[Timely news hook example] Monday, February 4th, is World Cancer Day, a critically important day to focus on those living with this devastating disease and share relevant information with your [readers/viewers]. For most Canadians, New Year's resolutions involve personal health improvement goals, such as eating better or exercising more. Now nearing the end of January, for many of those Canadians, these resolutions are already slipping or being forgotten altogether. But for women

living with metastatic breast cancer, like me, eating well and exercising is not just a New Year's resolution – it's integral to prolonging my survival.

[Facts and statistics] Every year, approximately 25,500 Canadians are diagnosed with breast cancer. At least three Canadian women receive their first breast cancer diagnosis of locally advanced or metastatic disease every day. Approximately 30 percent of those initially diagnosed with earlier stages of breast cancer later develop recurrent and/or metastatic disease.

[Personal story] Now 54 years old, I was diagnosed with metastatic breast cancer (Stage IV) in June 2010. As a mother and a new grandmother, I look forward to spending as much time with my loved ones as possible. And this summer, I'll be traveling across the U.S. and Canada with my family, visiting iconic landmarks I've never seen before – like Niagara Falls.

[Personal connection] For women like me, a new year brings new hope. New treatments are available to help extend the number of sunrises, road trips, laughs and hugs with family members – an important New Year's resolution to keep. Highlighting our stories is vital for the continued education of the Canadian public, given that metastatic breast cancer is rarely discussed within the larger breast cancer awareness movement.

[Contact for interview] I would gladly share more information about this important cause with you. [Proposed resolution and call-to-action] My goal is to bring more awareness to the challenges faced by individuals like myself who are living with metastatic breast cancer by encouraging others to share their story. Please advise if you would be interested in discussing this further and arranging an interview to share my story to support others affected by metastatic breast cancer and raise awareness of our unique needs.

Best regards,

Kelly Slynch Vancouver, BC 778-000-0000

# Contacting Government Relations for Advocacy

Most government officials that you speak to are genuinely interested in hearing what you have to say. People who run for elected office usually do it because they want to make a difference in their communities. They like talking to others and hearing their ideas on how to improve policies and programs. As an elected representative, speaking to constituents and members of their community is also part of their job.

The staff that develop and run the programs within the government are also interested in hearing about how their programs are working. They are not always able to fix things quickly and easily, but they do listen and will consider the feedback they receive from individuals and organizations.

You can send a letter to your MP, MPP or to a governing body, such as CADTH (Canadian Agency for Drugs and Technologies in Health) or PMPRB (Patented Medicine Prices Review Board) to voice your concerns over a specific policy or program that is impacting you and other breast cancer patients. While you need to identify the problem, solution and a call-to-action as outlined in our "Communicating Your Story" worksheet, you need to go more in-depth with this when contacting someone in government. Doing this ensures that the issue and the solutions that you propose are in fact within the scope of the government.

Below, we outline how to identify and ensure that your issue is within the scope of the government. If you are unable to answer a lot of these questions, then you might need to find another <u>strategy and avenue for your advocacy</u>.

#### Problem

What is the actual need for breast cancer patients and how is it not being met by the current policy or program?

#### **Needs Assessment**

- What is the need?
- What has external research identified as the need?
- Who is affected by the problem?
- What is the impact on their lives?
- What is the impact on the people around them?
- What is the impact on social and economic structures, such as the economy, use of government and non-profit services, etc.

Env	who is the program or policy currently benefiting, and who is being excluded? What aspects of your life are remaining stable or are improving, and which are not? What other options and resources, if any, do you have to fill the gap?

# Solution

What needs to happen to reduce or eliminate the gap between what is needed by breast cancer patients, and what is available? Are there existing models, best practices or successes that can be replicated or expanded?

# Policy

<ul> <li>What changes need to be made to more equitable and responsive to</li> </ul>	to the existing policy or program to make it actual need?
preventing some people from acc program?	c, and social and other barriers that are cessing, or benefitting from a policy or ition and delivery make it more responsive

#### Awareness

<ul> <li>How would strategies to better communicate, or raise the profile, of an existing policy or program make it more effective in reaching those that it needs to reach?</li> </ul>
Targets
Who are the people that have the authority and/or jurisdiction that can make changes? Who are the people that can advocate for, or influence others to make changes?
Bureaucratic
Who is involved in program planning and administration? Who can be an ally for internal change?

## MPs, MPPs and Senators

- Who are the elected officials representing the individuals that are experiencing the need?
- What government committees are involved in program or policy planning and priority setting?
- Who is already familiar with the issues?
- Who needs an introduction to the issues?
- Who are the gatekeepers that you need to engage as allies (legislative assistants and other staffers)?

Outcome
What are the tangible, measurable changes that will result from the proposed solutions?
Personal/Individual
<ul> <li>How will the life of an individual and his or her family improve because of this proposed change?</li> </ul>

#### Systemic/Institutional

•	governmental) improve because of this proposed change? What opportunities for savings are there?

• How will economic or institutional systems (governmental and non-

# Strategies

There are various strategies you can use when advocating for an issue if you choose to engage government relations. Depending on your issue, you may decide to employ a single strategy or a combination of strategies to have your issue addressed. Regardless of which strategies you decide to use, the key to successful advocacy is persistence and patience. These strategies include, but are not limited to:

- Petitions
- Demonstrations
- Lobbying and letter writing

#### Petitions

A petition can be a helpful tool to demonstrate support for a particular issue to influence decision-makers. Petitions are a collection of signatures from people who support change for a given issue. Petitions are particularly useful for straightforward issues - for example seeking to implement a new policy or program. A typical petition includes a brief explanation of the issue, a clear statement of what you are asking for, and a list of signatures supporting the petition.

It is important to note that <u>provincial</u> and <u>federal</u> governments often have very specific instructions for petition submission, so follow these rules to ensure that your petition will be accepted.

If you use <u>other strategies and avenues</u> to advocate for your issue, you can ask others to sign your petition as a call-to-action.

#### **Demonstrations**

Demonstrations are public events that can help bring widespread exposure to an issue. There are many different types of demonstrations, including marches and rallies. A march involves the advocating group moving from one location to another. The movement of the march can often attract attention from the community, resulting in greater public awareness of the issue. A rally typically takes place in one set location, often of political or symbolic significance. Regardless of the type of demonstration, the intention is the same - to invoke public interest and media attention to your cause.

<u>Social media</u> can be extremely useful in planning, promoting and documenting a demonstration, as well as for disseminating information to fellow advocates, the media and the general public. If you use <u>other strategies and avenues</u> to advocate for your issue, you can ask others to join your demonstration as a call-to-action.

#### **Lobbying and Letter Writing**

Lobbying involves engaging key decision-makers about your concerns. It can be done through writing letters, emails and meeting with elected and appointed representatives. It can be done at the local, municipal, provincial, or federal levels and you can lobby on your own or as part of a larger group. When lobbying a decision-maker, it is critical to keep your messaging brief and concise. You should be able to summarize your issue in a few short statements, propose 1-2 potential solutions to the issue and have a specific ask for the decision-maker. Sharing a relevant personal anecdote can help convey the impact of the issue and forge a connection with the decision-maker.

If you use <u>other strategies and avenues</u> to advocate for your issue, you can ask others to join a lobbying group as a call-to-action.

You can use these sample letters to government officials, <u>CADTH</u> and <u>PMPRB</u> as examples of what engaging government relations via letter writing looks like.

# Contacting Government Relations for Advocacy: Sample Letters

There are various avenues to share your story as a form of advocacy. Should you choose to share your message via government relations, we provide sample letters below to get you started. These sample letters are written from the perspective of "Kelly Slynch", a metastatic breast cancer patient advocating for increased awareness of the everyday experiences of metastatic breast cancer patients. Feel free to refer to and use the following samples when sending a letter to government officials or government bodies.

The highlighted sections refer to the types of information mentioned in our <u>Communicating Your Story</u> worksheet that you should be including in your communications, if they apply. Be sure to edit the letter to reflect your own personal information and situation. If you choose to send your communications via email, the text should be written within the body of the email and not sent as an attachment.

#### Letter to MPs/MPPs

Letter opener [If sent by postal mail]: Name of MP/MPP/Party Leader Street Address City/Town, Postal Code

Date

Subject line [If sent by email]:
More is needed for metastatic patients like me

Dear Name of Councillor, MPP.

As a constituent in your riding, I am writing to you to share my concerns as a woman living with metastatic breast cancer. [Identify issue/personal connection] Through my personal experience living with metastatic breast cancer, it is often common to feel isolated from the general breast cancer community. Many women living with a metastatic breast cancer diagnosis feel that the breast cancer information currently available simply does not address our unique needs. No matter where you are located, it is important for women living with metastatic breast cancer to feel supported and connected to a network of people who are facing similar challenges, especially as we try to better understand our diagnosis and access diverse treatment options.

[Facts and statistics] A few important facts about metastatic breast cancer:

- Advanced or metastatic breast cancer occurs when the cancer has spread to other parts of the body most commonly, the bones, liver, lungs and brain.
- Metastatic breast cancer is currently considered an incurable disease, though there are many treatments that can help to control disease progression.
- Every year, approximately 25,500 Canadians are diagnosed with breast cancer.
- Approximately 30 percent of those initially diagnosed with earlier stages of breast cancer later develop recurrent and/or metastatic disease.
- At least three Canadian women receive their first breast cancer diagnosis of locally advanced or metastatic disease every day.

[Personal story] Now 54 years old, I was diagnosed with metastatic breast cancer (Stage IV) in June 2010. As a mother and a new grandmother, I look forward to spending as much time with my loved ones as possible. And this summer, I'll be traveling across the U.S. and Canada with my family, visiting iconic landmarks I've never seen before – like Niagara Falls. For women like me, a new year brings new hope. New treatments are available to help extend the number of sunrises, road trips, laughs and hugs with family members – an important New Year's resolution to keep.

My story, experiences, and challenges as an individual living with metastatic breast cancer is important and should be highlighted and recognized along with other early-stage breast cancer patients. [Proposed solution] Advocates from across Canada have called on the government to officially recognize October 13th of every year as Metastatic Breast Cancer Awareness Day in Canada, a day intended to support and honour individuals living with metastatic breast cancer all across the world.

[Call-to-action] I call on you to commit to vote on the proposed proclamation up for debate in the upcoming council meeting and stand in solidarity with Canadian families affected by metastatic breast cancer.

Thank you for your commitment, and I look forward to receiving a response from you.

Sincerely,

Kelly Slynch Vancouver, BC, V5V 5V5

[Insert at least one form of contact if letter is sent via postal mail]

#### Letter to CADTH

#### **CADTH Contact Information:**

CADTH President
Ms. Suzanne McGurn
President and CEO
The Canadian Agency for Drugs and Technologies in Health
865 Carling Ave., Suite 600
Ottawa, ON Canada K1S 5S8

Minister of Health
The Honourable Patty Hajdu
Minister of Health
House of Commons
Ottawa, Ontario K1A 0A6
hcminister.ministresc@canada.ca or Patty.Hajdu@parl.qc.ca

Letter opener [If sent by postal mail]:
First and last name
Title
Government Department
Address

Date

Subject line [If sent by email]: More is needed for metastatic patients like me

Dear Ms. Gurn/Honourable Patty Hadju,

My name is Kelly Slynch and I am a mother and new grandmother living with metastatic breast cancer. I am writing today to share my concerns regarding the changes to CADTH's Drug Review Processes and the impact they may have on cancer patients.

Identify issue I am concerned that the changes to the drug review process could result in less availability and accessibility to cancer medications in Canada. Impact of issue These changes would limit the opportunities for clinicians to provide input to the process. Clinician input is essential for ensuring that authorities are making truly informed decisions about treatments and their use in Canada.

Most concerningly, the development and application of the provisional algorithm requires greater transparency. The provisional algorithm affects how cancer drugs

will be funded and implemented in clinical practice across provinces. It is essential that the process for developing and implementing the algorithm is disclosed transparently with the input of both clinicians and patient groups.

[Personal story] Now 54 years old, I was diagnosed with metastatic breast cancer (Stage IV) in June 2010. As a mother and a new grandmother, I look forward to spending as much time with my loved ones as possible. And this summer, I'll be traveling across the U.S. and Canada with my family, visiting iconic landmarks I've never seen before – like Niagara Falls. For women like me, a new year brings new hope. New treatments are available to help extend the number of sunrises, road trips, laughs and hugs with family members – an important New Year's resolution to keep. The proposed CADTH changes could greatly impact my ability to access medications that prolong my survival.

Proposed resolution and call-to-action I urge you to consider the recommendations made by the cancer patient community, including supporting continued opportunities for clinician input and ensuring a transparent process for the development and implementation of provisional algorithms for cancer treatment including opportunities for stakeholders to provide input.

Sincerely,

Kelly Slynch Vancouver, BC, V5V 5V5

[Insert at least one form of contact if letter is sent via postal mail]

#### Letter to PMPRB

#### PMPRB Contact Information:

Member of Parliament Name of Member of Parliament House of Commons Ottawa, Ontario K1A 0A6

Minister of Health
The Honourable Patty Hajdu
Minister of Health
House of Commons
Ottawa, Ontario K1A 0A6
hcminister.ministresc@canada.ca or Patty.Hajdu@parl.gc.ca

Letter opener [If sent by postal mail]:
First and last name
Title
Government Department
Address

Date

Subject line (If sent by email):
More is needed for metastatic patients like me

Dear Honourable Patty Hadju/Name of Councillor,

My name is Kelly Slynch and I am a mother and new grandmother and I am living with metastatic breast cancer. I am writing today to share my concerns regarding new changes to the Patented Medicines Prices Review Board (PMPRB) regulations and the impact they may have on cancer patients.

Identify issue I am concerned that the rapid implementation of these regulations could result in less availability and accessibility to innovative cancer medications in Canada. There is no doubt that medications in Canada should be more affordable for patients. Impact of issue However, some of the proposed changes outlined by the PMPRB could result in fewer therapy options for cancer patients. If Canada proceeds too quickly with implementing these changes, companies may decide to delay or halt drug launches in our country, leaving patients without essential and life-saving therapies available in other parts of the world.

These changes could also potentially impact the accessibility of clinical trials in Canada-which would have devastating consequences for cancer patients. For many cancer patients, clinical trials represent an opportunity to benefit from innovative therapies. This is especially true for patients who have exhausted other treatment options. If global drug manufacturers view Canada as a lower priority or a difficult market to enter, our access to clinical trials may also be compromised.

[Personal story] Now 54 years old, I was diagnosed with metastatic breast cancer (Stage IV) in June 2010. As a mother and a new grandmother, I look forward to spending as much time with my loved ones as possible. And this summer, I'll be traveling across the U.S. and Canada with my family, visiting iconic landmarks I've never seen before – like Niagara Falls. For women like me, a new year brings new hope. New treatments are available to help extend the number of sunrises, road trips, laughs and hugs with family members – an important New Year's resolution to keep.

Impact of issue The proposed PMPRB changes could greatly impact my ability to access medications that prolong my survival.

[Proposed resolution and call-to-action] I urge you to consider the recommendations that were made by the patient community in Canada, including instituting a phased approach to implementation, developing a rigorous monitoring and evaluation process and engaging collaboratively to make patient voices a permanent part of the decision-making process at PMPRB.

Access to new treatments and vaccines has never been more important. It is essential that our health regulatory systems are able to support access to innovative and life-saving treatments for all Canadians.

Sincerely,

Kelly Slynch Vancouver, BC, V5V 5V5

[Insert email at your discretion if letter is sent via postal mail] K.Slynch@kslynch.com

[Insert add least one form of contact if letter is sent via postal mail] 780-000-0000