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“My passion is advocacy and I believe in its value because it is an opportunity to make our voices heard. Who better to tell the story than people with dementia and their caregivers?

— Jim Mann, person living with dementia and advocate

Project manager: Rebecca Morris, Alzheimer Society of B.C.
Marketing & communications: Jon Yurechko, Ben Rawluk & Paula Brill, Alzheimer Society of B.C.
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IS THIS GUIDE FOR ME?
Did you know you can make a difference for people with dementia and their families? There is a role for you regardless of your previous experience, the amount of time you have, or your level of comfort in speaking with others about a cause which is important to you.

This guide will explain:
- What advocacy is.
- How to speak to others about dementia issues.
- How to engage politicians through letter writing or in-person meetings.
- How social and print media can make a difference.

WHAT IS ADVOCACY?
Advocacy refers to any actions you take to create change. Advocacy can be self-advocacy or systemic advocacy. Self-advocacy refers to things we do to improve a situation for ourselves or a family member. Seeking help from your doctor or applying for services or funding are examples of self-advocacy.

Systemic advocacy, the focus of this resource, is broader. It focuses on improving services and programs for the benefit of everyone connected to an issue.

People who are interested in issues related to Alzheimer’s disease and other dementias can advocate by:
- Sharing information through social media, or writing letters to the editor.
- Speaking to others about dementia issues.
- Speaking or writing to Members of Legislative Assembly (MLAs).
- Engaging other levels of government, for example Mayors, City Councillors or Members of Parliament (MPs).

WHY IS THERE A NEED FOR ADVOCACY?
The word dementia is an umbrella term that refers to many different diseases. Different types of dementia are caused by various physical changes in the brain. Alzheimer’s disease is the most common, accounting for approximately two-thirds of all dementias. Other kinds of dementia include vascular dementia, Lewy body dementia.
and frontotemporal dementia. You can learn about different kinds of dementia by visiting www.alzheimerbc.org.

Currently more that 70,000 people in B.C. are living with Alzheimer’s disease or another form of dementia. It is estimated that over 10,000 people with dementia in B.C. are under the age of 65. The number of people impacted is expected to double by 2030. Hundreds of thousands of wives, husbands, sons and daughters are also affected by this disease. In fact, it is estimated that annually in B.C. 33.1 million hours of care is provided by family and friend caregivers of people with dementia. A person’s risk for developing dementia increases as they age. However, dementia does not only affect older adults.

People with dementia and their caregivers often face challenges throughout the progression of the disease. These challenges can result in a journey with bumps and roadblocks. A smoother journey for people affected by dementia is possible, but only if you raise your voice along with other advocates.

WHAT CAN I DO?

Even small actions add up to a very powerful voice when many people deliver a consistent message. You can decide how involved you would like to be depending on how much time you have and your level of comfort.

The most common advocacy activities include:

- Speaking to others about dementia.
- Writing a letter to your MLA, MP, Mayor or City Councillor.
- Meeting your MLA, MP, Mayor or City Councillor.
- Using social media as an advocacy platform.
- Writing a letter to the editor.

SPEAK TO OTHERS ABOUT DEMENTIA ADVOCACY

Speaking to others about dementia issues reduces the stigma associated with the disease; it also spreads knowledge and information about what is needed as dementia affects more and more people in B.C.
Most of us don’t have politicians, members of the media or researchers in our social networks. Not a problem! You don’t need to know “important” people in order to be a successful advocate.

You may choose to share your experience, or even this guide, at your book club, your faith group, in your caregiver support group or even at your dinner table. Perhaps you will decide to tell others about your experience as a person with dementia or as a caregiver. Or maybe you let people know about the things you have already done as an advocate. For example, if you have written a letter to your MLA you may choose to encourage others in your network to do the same.

The more we speak about dementia, the more decision makers hear that dementia matters to their community.

WRITE A LETTER TO YOUR MLA

A Member of the Legislative Assembly (MLA) is a provincial, political official elected by the constituents in their area to represent the interests of those who live in that area. This person is a provincial representative and may have added responsibilities, like being a Cabinet Minister, for example.

Many people think that one letter won’t matter in the eyes of a busy politician. That’s not accurate. Elected officials rely on the correspondence they receive as an indication of which issues are important to those they serve. They want to hear from you!

Writing a letter to your MLA is a quick and effective way to let them know that dementia issues matter to their constituents. As a general advocacy rule, each letter a politician receives is considered representative of a much larger group of constituents who are concerned about the same issue.

In your letter it is important to outline your concern, why you are concerned, what action you would like to see taken and what follow up would be helpful. Follow up examples include:

- A meeting.
- Forwarding your concern to the Minister responsible or the Premier.
- Asking for their position on an issue.
- Asking your MLA to raise the issue at question period.
Here are some tips for writing an effective letter or e-mail:

- Succinct but personal is best.
- Use the correct salutation. If the MLA is a Minister address them as Minister ___, if not address them as Ms. or Mr. Address the Premier as Premier ___.
- Put your ‘ask’ in the first paragraph.
- Be courteous.
- Approach your MLA as an ally not an opponent.
- Consider asking for a meeting.
- Include your name and contact information.
- Send a copy of your letter to other politicians who may be able to help (e.g., the Premier, your Member of Parliament (MP) or the Minister of Health).
- Encourage others to do the same.
- Follow up on your letter in a month or so if you haven’t received a reply.

To download a customizable letter or to send one through our easy online tool please visit: www.alzheimer.ca/bc/Get-involved/Advocacy/ or 604-742-4939.
An effective letter may look something like this:

Dear Minister Partridge,

I am writing to ask you if you support increased access to adult day programs for people with dementia in our local area. Caring for a person with dementia is challenging, and appropriate, timely access to these programs can help caregivers like me cope. Few spaces and long waitlists have been a recurring theme for people at my support group.

Dementia is an important issue to me and my family, as my husband received a diagnosis of vascular dementia in 2009. The adult day program has been a lifeline. I would like to continue to care for my husband at home, but without access to programs like these I won’t be able to for much longer.

I would like to meet with you to talk about this more at your earliest convenience.

Yours truly,

Sandra McDougal

604-555-5555

A letter which may not be as effective and could be made stronger may look like this:

Hi Steve,

Why can’t you people get the health care system right? I was in emergency with my husband for 5 hours last week and some stupid nurse didn’t understand anything about dementia. The whole situation is unfair. He is a veteran after all. My cousin in Alberta says the same thing and she is also a caregiver.

We need change and we need it soon. Is the government doing anything to fix these problems?

Thanks,

Sandra McDougal
MEET WITH YOUR MLA

Setting up a meeting with your MLA gives you the opportunity to speak to him or her in greater depth about the dementia issues that are relevant to you. MLAs value meeting with the public because it connects them with their constituents and their concerns.

Here are some tips for meeting with your MLA.

BEFORE YOUR MEETING

- Consider going with another person who is also informed about the issues.

- Draft an agenda to send to the MLA’s office in advance or to take with you. Use the Meeting Plan template found in this document on page 13.

- Develop a script in point form. If you are there with others decide who introduces the issues, follows up with supporting information, reiterates the points raised, and thanks the MLA.

- Practice speaking about your connection to the disease—remember that personal stories often resonate with politicians.

- Prepare, but remember that you don’t need to be an expert. It is okay to say you don’t know or that you can get back to them with a response letter or e-mail.
AT YOUR MEETING

- Always be respectful and considerate.
- Be on time and keep yourself to the appointment time which has been set.
- Ask for a commitment. This could be:
  - Willingness to contact other politicians.
  - Willingness to speak to Cabinet.
  - Willingness to include this issue in their platform.
  - Willingness to speak to the Minister of Health and/or the Premier.
  - Willingness to ask questions in the Legislature.
- If there are follow up items summarize them at the end of the meeting.
- Ask if it is okay that you take a picture of you and your MLA so that you can post it on Twitter or Facebook.
- Express appreciation for the MLA’s time and interest.

AFTER YOUR MEETING

- Debrief the meeting with someone you trust. You can discuss what went well, what could have gone better and what your overall impressions of the meeting were.
- Follow through with any action items.
- Consider sharing on social media by tweeting or writing on the politician’s Facebook wall.
- Send a thank you note.
- Follow-up in six months to one year.
- Let the Alzheimer Society of B.C. know how your meeting went at advocacy@alzheimerbc.org.
USE SOCIAL MEDIA AS AN ADVOCACY TOOL

Using Twitter or Facebook is a great way to get the word out to others in your social network. In addition, many politicians use social media to get a sense of which issues are important to their constituents. If you use social media on a regular basis consider tweeting, sharing or liking Alzheimer Society of B.C. posts at www.twitter.com/AlzheimerBC or www.facebook.com/AlzheimerBC.

You may also want to consider tweeting to a politician. Here are some examples:

@SusanOHagan Thank you for speaking about your support for First Link! #Alzheimers #BCpoli

@BarbaraSawatzky Thank you for speaking about the need for better training in long term care! #Alzheimers #BCPoli

In the above examples @ refers to the person the tweet is directed to and # refers to the topic of the tweet, in these cases Alzheimer’s disease and B.C. politics. When enough people tweet something with the same hashtag (#) a topic can trend, which means it gets more attention.

Positive feedback can be powerful. You may choose to tweet about a recent meeting you have had with your MLA:

@SusanOHagan thank you for meeting with me to speak about dementia issues #BCpoli #Alzheimers

@ElizabethMcCabe thank you for sharing about your family’s experience with #dementia! #Alzheimers

At your meeting you may also want to ask if it is okay that you take a picture of you and your MLA so that you can post it on Twitter or Facebook. Politicians often like to demonstrate that they are meeting with constituents and hearing about their concerns.

It’s also helpful to re-tweet, like, or share interviews, news stories or posts related to dementia issues.
WRITE A LETTER TO THE LOCAL EDITOR

The most effective time to write a letter to the editor for publication in your local newspaper is when a story has been written about dementia, or when a related event appears in the news. Take this as your opening to write to your editor about dementia.

In the first few sentences of your letter quickly note the topic of the news story, where you read it and why it was (or wasn’t) helpful. For example:

“The news article *Just a Little Walk* in the May 4 edition of *News Daily* brought attention to the important issue of wandering and dementia. I was so sorry to hear about this horrible situation”

If possible, note a personal connection to the story and use the next few sentences to bridge from the article to your issue:

“I’ve been a caregiver for my mother for three years. I know how challenging the dementia journey can be and how responsive behaviours like wandering can make it even more challenging to continue caring for a person at home. Respite programs can be a very valuable way to keep caregivers energized so they can continue to provide the care the person needs. I would like to see an increase in access to respite across the province…”

Letters to the editor should be kept to 150 words. There are often opportunities to submit your letter online through the newspaper’s website.

We like to hear about what dementia advocates have been doing in their local communities!

Drop us a line to let us know how your meeting with your MLA went or send us a copy of your letter by mail:

Attention: Advocacy & Education Department
Alzheimer Society of B.C.
300-828 West 8th Avenue
Vancouver, B.C.
V5Z 1E2

Or by e-mail: advocacy@alzheimerbc.org
MEETING PLAN TEMPLATE

Time:

Location:

Called by:

I. Attendees
(Write the name of your MLA, your name and the name of anyone attending with you)

II. Agenda
1. Introductions
2. My story
3. My ask
4. Next steps

III. Goals
(List the top three goals for your meeting)

1.

2.

3.