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To advocate is to educate

Advocacy. To some that is another word for "boring". Others think it is related to government. So, again, it's boring. It's certainly a waste of time in the minds of some. Still others' vision of advocacy involves marching out of control in the streets. Actually advocacy can be all of that. But it can and should be more.



Advocacy can be done by one person or by a group. It can be done quietly in the background or through loud demonstrations. It can involve meeting after meeting or it can be one meeting or one telephone call or even one letter. For you – for us – it can and should be personal. Above all, advocacy is a necessary part of democracy.

For us as people with dementia, and for our care partners, I believe the primary purpose of advocacy, and our role as advocates, is to educate. To advocate is to educate. To tell our story. To tell others who we were, but more importantly who we are today. To tell our hopes and dreams. And our expectations.

This issue of *Insight* focuses on advocacy. It provides information to help you understand what advocacy is and introduces some tools to help you begin to engage in advocacy. There are many forms of advocacy, and I hope that after reading this edition of *Insight*, you will be inspired to become an advocate, in any shape or form that works for you.



Jim Mann is the Honorary Editor of Insight. He is an active volunteer who advocates on behalf of and for people with dementia. Diagnosed with Early Onset Dementia in February 2007 at the age of 58, Jim is determined to help make a difference in the lives of people who are affected by the disease. As an experienced public policy professional, Jim provides critical advocacy advice to the Alzheimer Society of B.C. and the Alzheimer Society of Canada.

Introduction to advocacy

What is advocacy?

The dictionary definition of advocacy is: “the act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support.” In general, advocacy can be simply defined as ‘speaking up’. There are several different forms of advocacy. **Self-advocacy** and **system advocacy** are two types of advocacy that individuals with dementia can engage in to improve their lives and the lives of others affected by the disease.



What is the difference between self-advocacy and system advocacy?

Self-advocacy means advocating on one's own behalf. Exercising self-advocacy skills can empower you and allow you to gain control over your own life.

System advocacy can be used to change “systems” – for example, the health care system. Additionally, it can be used to promote causes, such as finding a cure for Alzheimer’s disease.

What are some examples of advocacy that I can do now?

Examples of system advocacy:

- Write a letter to your local MLA or MP about your experience as someone with dementia in your community.
- Join the Alzheimer Society of B.C.’s Advocacy Committee - see the section “Be an Alzheimer Advocate” on page 6 of this bulletin for details.
- Tell your story - be interviewed by your local TV or radio station.
- Tell the Alzheimer Society of B.C. something that is really important to you that needs to change in order to improve the lives of people with dementia in B.C.

Examples of self-advocacy:

- Take some time to think about what is important to you, and what you need in order to live well with the dementia. This is the first step in the process of advocating for what means the most to you.
- Help reduce the stigma associated with dementia by being open with others about your diagnosis and sharing your experience in any way that you can.
- Participate in Alzheimer Society education programs and support groups to learn more about the disease and empower yourself as a self-advocate.
- Read the tips and strategies included in the following pages which can help you become a successful self-advocate.

Self-advocacy: Working with health care providers

Health care providers, such as your family physician, home care workers, case managers, and others, are important sources of support and information throughout your journey with dementia. One way to engage in self-advocacy is to let health care providers know what your expectations are during your interactions with them. Below are some principles developed to educate health care providers who are working with people with dementia. You may find it helpful to use these principles as a self-advocacy tool by sharing them with health care providers as needed.



Talk to me directly, the person with dementia. I am the person with the disease, and though my family is also affected, I am the person who needs to know what to expect as I live with this disease.

Tell the truth. Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

Test early. Helping me get an accurate diagnosis as soon as possible gives me more time to plan and live to my fullest potential and to get information about appropriate clinical trials.

Coordinate with other care providers. I may be seeing more than one specialist — it is important that you talk to my other health care providers to ensure you all have the information so that changes can be identified early on and I don't have to repeat any tests unnecessarily.

Explain the purpose of different tests and what you hope to learn. Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease. Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer Society and other resources in my community.

Work with me on a plan for healthy living. Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience dementia is unique. Dementia affects each person in different ways and at a different pace. Please be sure to explain how this disease may change my life with this in mind.

Dementia is a journey, not a destination. Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with dementia.

Adapted from: "Principles of a Dignified Diagnosis" – Alzheimer's Association of the U.S.A.

Increase your power as a self-advocate

Here are some tips for dealing with bureaucrats, officials and other people whose assistance you want:

- ✓ Explain what you want briefly and clearly. You may want to write down an explanation ahead of time and read it aloud.
- ✓ Don't hesitate to ask people to wait while you write notes. Repeat back important information to confirm that you got it right.
- ✓ Write down names and titles of whomever you talk to or meet with, and include the date.
- ✓ It's OK to remind people to be patient and to repeat things.
- ✓ Write yourself reminders for follow-up activities.
- ✓ Don't feel pressured to answer every question put to you or to make decisions immediately. Ask for time to think about things and consult friends or family.
- ✓ Make official requests in writing. Letters should be brief, polite and contain all the vital information.
- ✓ Ask a friend to be with you when you make a phone call or have a meeting to attend. They can take notes and provide you with support.



In our own words

We asked people living with dementia a series of questions about their views on advocacy. Below are some of the responses we received.

1) What does “Advocacy” mean to you?

“Advocacy is about acknowledging (to ourselves and others) what we're dealing with and taking action to do something about it, including speaking out about our experience of living with it.” – Jay Smith

“Putting it out there – what you want people to know. Not being afraid to put it out. There is fear around it.” – Richard

2) Why do you think it is important for people with dementia and their families to engage in advocacy?

“Advocacy is important because it empowers and energizes us to keep on living fully. It's also important because advocacy creates an avenue for awareness and knowledge that are agents of change to improve the situation.” – Jay Smith

“People like us, those affected by Alzheimer's disease, sorely need the support of the kind that lets people know what it is like where we are and what they can do for us to help us out. We who are afflicted and the rest of us affected, are not only victims of this disease but suffer equally from society's oversight.” – Mike Donohue

*“By trying to improve ourselves, we find that others become more understanding.”
– Support group member*

*“Telling our stories can help both people with dementia and our care partners.”
– Support group member*

3) Do you have a success story to share which demonstrates the power or importance of self-advocacy for people living with dementia?

“I do have a success story, mine. Advocating in all ways for all matters of Alzheimer's disease has brought me acceptance of my disease, a wonderful way to cope with having it and a sense of fulfillment I am doing some good with my disease.” – Mike Donohue



Advocacy questions and answers

Q: *What if...the person I want to speak to isn't available or won't answer my calls?*

A: Ask when the person you are trying to contact will be in his/her office. Arrange to call back then. If you say you are going to call at a specific time, make sure that you do. If the person does not call you back, or seems to be avoiding you, ask for the name and phone number of the supervisor and let him/her know about the problem.

Q: *What if...the person I need to speak to uses a lot of technical terms or jargon and I don't understand what they are saying?*

A: You have a right to be spoken to in a way that you can understand. However, if you don't understand what is being said, or if it is not clear to you, you have a responsibility to ask the person to use other words.

Q: *What if...the person I have to deal with makes me feel inferior or as if they are doing me a big favour?*

A: If it is a service-providing agency, you have the right to ask for service. Services wouldn't exist without people to use them. Remember that every person has equal worth and value, no matter what side of a desk they are sitting on.

Q: *What if...I suspect that I am being discriminated against because of my ethnicity, political beliefs, religion, physical or mental disability, gender, age, sexual orientation, marital status...*

A: You may be able to deal with the matter directly at the agency level by letting supervisors or managers know your concerns. However, you may also wish to contact the BC Human Rights Tribunal to see if a formal complaint is appropriate.

Source: The AdvoKit: A step-by-step guide to effective advocacy. Penticton Advocacy Network

Be an Alzheimer Advocate!

Advocates are people who have been diagnosed with dementia, care partners, or friends and family who support a person with dementia. As an Alzheimer Advocate, you can join us by speaking up about the disease, drawing the public's attention to this important issue, and directing decision-makers towards a solution. As an advocate you might:

- Educate your local MLA and your community about dementia issues
- Share your personal story in your local media
- Tell others how they could raise their voice to help advocacy efforts
- Keep the Alzheimer Society of B.C. informed about what matters to you and your family

For more information contact Barbara Lindsay, Senior Manager of Advocacy and Public Policy for the Alzheimer Society of B.C., at blindsay@alzheimerbc.org or 604-742-4918.

Advocacy tools

MLA Finder

You can find the name and contact information of your local MLA through a special website. Access the MLA Finder by visiting: www.leg.bc.ca/MLA/3-1-1.htm or call 604-660-2421 (Vancouver), 250-387-6121 (Victoria) or 1-800-663-7867 (elsewhere in B.C.).



Seniors Advocacy & Information Line (SAIL)

Operated by the BC Centre for Elder Advocacy and Support, SAIL is a safe place for older adults (age 55+) to speak to a trained professional about situations where they were abused or to ask legal questions about their rights in regard to a particular situation where they were mistreated. Call 604-437-1940 or toll free 1-866-437-1940.

Dementia Advocacy and Support Network International (DASNI)

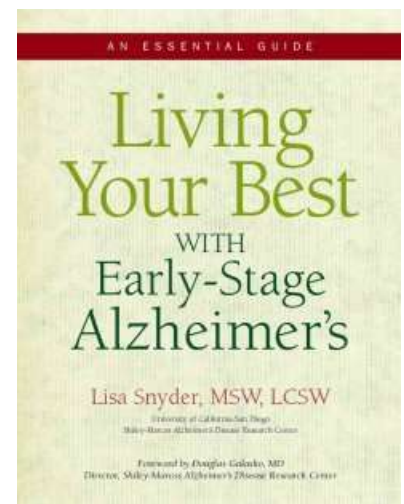
DASNI is an internet based support network for people with dementia. Since its founding in 2000, DASNI has evolved as an international group of people with dementia that empowers individuals to actively participate in their own care and treatment. For more information, visit www.dasninternational.org.

Nidus Personal Planning Resource Centre and Registry

Planning for the future is an important component of self-advocacy for people living with dementia. The Nidus Personal Planning Resource Centre is a non-profit, charitable organization. Nidus provides information about personal planning and operates a centralized registry for personal planning documents. For more information phone 604-408-7414 or toll-free 1-877-267-5552 or visit www.nidus.ca.

Book review: *Living Your Best with Early-Stage Alzheimer's* by Lisa Snyder

This is an excellent new resource written specifically for individuals experiencing the early stages of Alzheimer's disease or a related dementia. The book includes clearly written information on the disease, creative tips and suggestions, as well as quotes and personal stories about the challenges and successes of people with dementia. For the reader it is both informative and encouraging. *Living Your Best with Early-Stage Alzheimer's* can be purchased by calling Sunrise River Press at 1-800-895-4585 or by visiting www.sunriseriverpress.com. A \$23.95 shipping and handling fee will be added to each order. You can also find the book online at www.amazon.ca.



Notes and Events

DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033
(Lower Mainland 604-681-8651)

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.



Our Vision

Our ultimate vision is to create a world without Alzheimer's disease and related dementias.

Our Mission

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementias, to promote public awareness and to search for the causes and the cures.

Contribute to Insight!

We really want you to feel part of this bulletin. You can contribute in the following ways:

- Send us news from your support group. For example, what topics of interest or activities have you covered?
- Submit articles on how to live a full and meaningful life after a diagnosis of Alzheimer's disease or a related dementia.
- Drop off photographs.

Send your contributions to the Alzheimer Society of B.C.

(Attention: *Insight*)

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Get Walking!

Sunday, January 30, 2011

www.walkformemories.com / 1.800.667.3742