



The Rising Tide

by Jim Mann

We continue to surprise.

We surprise people when we tell them we have Alzheimer's or a related dementia. We surprise ourselves on good days when we deal with our own diagnosis. And we really surprise ourselves on bad days, don't we?

And now everyone is surprised with updated statistics on the prevalence of dementia in Canada. And especially with the new statistics of people under the age of 65 who are living with the disease.

The Alzheimer Society of Canada commissioned a study – *Rising Tide: The Impact of Dementia on Canadian Society* – in order to get an updated picture (from one released in 1996) of the numbers of people with dementia across the country. From that they will be better able to project numbers and get a handle on the economic realities that this disease is having on society and on government and its services. The numbers, although not yet released in their final form, I suspect will be sobering.

The prevalence figures were higher than some would have thought. Do you know that half a million Canadians have Alzheimer's disease or a related dementia? Or that a startling number from that one is that 71,000 of those people are *under the age of 65*? In B.C., there are now more than 70,000 people living with the disease, and more than 10,000 of those people are under the age of 65.

This study made me feel good, even though the numbers were high. It showed me people were looking for the numbers to present to the federal and provincial governments so they could all be better prepared as we – those of us with a dementia and our care partners – move forward in our journey. Truly, we are all in this together.

“Why do I care?” you might ask, “I have dementia, so why is this of any personal concern?” The more people who know about this disease and the more people get involved, the better off we are. Governments will sit up and take notice, the public will notice and

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hopefully make contributions, many for the first time. Researchers may even be the recipients of increased interest and initiatives.

This is too important to ignore. We need to keep up-to-date with the progress of this report and its specific details. Take a look at the Alzheimer Society of B.C. website and the *Rising Tide* item specifically www.alzheimerbc.org/put_your_mind_to_it.php and check back for updates.

What would be really good is if we could now enlist you as an advocate in order to

educate those around you including your elected representatives. But that's another article – and you know one will be coming!



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.



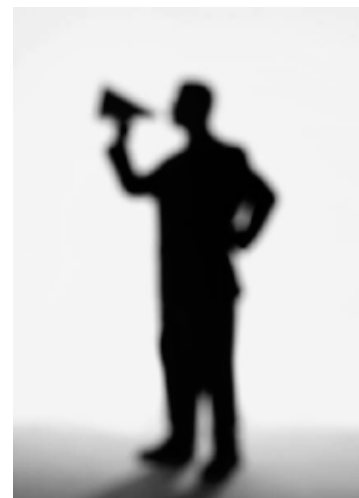
Raise your voice! Help make dementia a priority in BC. Check out our website for more details on how you can become an Alzheimer Advocate. www.alzheimerbc.org/advocate.php

Some thoughts about Advocacy

Comments from the Penticton Early Stage Support Group:

What do you think of the idea of advocacy – speaking up and speaking out?

- My children were in denial because I was 'too' young (only in my mid-fifties) – I had to keep sharing my 'story' until they understood. We need to share our story with others.
- One of my pet peeves is people who speak past me to my caregiver as though I'm not there. I have to say 'I am here' –please speak to me!



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Do you see yourself doing advocacy?

- I live on my own so I HAVE to advocate for myself – I have no choice!
- I have to live in a facility because I have no family nearby. I don't fit in too well in my dementia cottage because the rest of the residents are much older and most are unable to speak so I am very lonely. I ask every day if I can be included in activities in the main building and taken on the bus trips but I have to persist or they would just leave me in the cottage.
- I tell people to look at 'me' the person – not my disease

Has this been something you have already done?

- Yes, automatically – I didn't really think about it but just spoke up
- My friend has English as a second language and it is really hard for her now that she has dementia (to get her message across that is).
- Generally I am very happy with things but I definitely tell people when I am not happy!

Do you have anything that you would like to say? Contact us at info@alzheimerbc.org or contact us by mail (Attention: *Insight*):

Alzheimer Society
BRITISH COLUMBIA
#300 - 828 West 8th Avenue
Vancouver, BC
V5Z 1E2



Breakfast and Support

by Jim Mann

“Would you like coffee?” the waitress asks even before the “good morning” starts around the table. And so begins another get-together of the support group I attend a couple of times a month.

Breakfast and support: what a great way to start the day! I would encourage this for anyone.

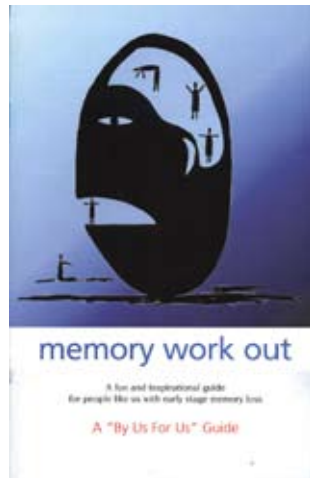
The atmosphere is different. We're like a family gathering with relatives, the in-laws and cousins. Some of us are more familiar than others, some are new to the group but we all gather around the table to join in a meal and good conversation.

And all of this comes together as we support and learn from each other. It is a very powerful and effective way to start our day.

Personally I prefer this relaxed and friendly arrangement and wanted to pass along this idea to others so they might consider this option.

By Us For Us© Guides

The *By Us For Us*© Guides are a series of guides created by a group of talented and passionate persons with dementia. These practical guides are designed to equip persons with dementia with the necessary tools to enhance their well being and manage daily challenges. What makes these guides particularly useful is that they are created by persons with dementia for persons with dementia.



All five guides are available through the MAREP website, or by contacting Janet Mooney at 519-888-4567 ext. 32920 (jmooney@healthy.uwaterloo.ca). Visit the MAREP website at www.marep.uwaterloo.ca. The BUFU guides are available to anyone for a nominal fee of \$1.00/guide.

Tele-Workshops



Upcoming Tele-Workshop

Life After Diagnosis

Thurs., May 28, 2009, 10am to 11am

This workshop for families offers an overview and the immediate strategies to be considered when faced with Alzheimer's or other illnesses that cause dementia. All family members can join in at the same time using the tools provided. Participation is reserved for family caregivers and people with early stage dementia residing in BC and the Yukon.

Health Link BC - Call 811

Speak with a nurse, consult a pharmacist, or get healthy eating advice from a dietician. This service is free of charge and available 24 hours a day and 7 days a week. Simply dial 811 for health information and answers to non-emergency questions. Information is also available online at www.healthlinkbc.ca.

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.

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Alzheimer Society
BRITISH COLUMBIA

#300 - 828 West 8th Avenue
Vancouver, BC V5Z 1E2
Tel: 604-681-6530
Toll-Free: 1-800-667-3742
Fax: 604-669-6907

Email: info@alzheimerbc.org
Website: www.alzheimerbc.org