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Stigma and Dementia

Excerpt from "Why are We the 'Untouchables,'" a presentation by Lynn Jackson and Christine Bryden delivered at the Alzheimer's Disease International conference in the Dominican Republic in 2003. Included are some comments from the Vancouver Early Stage Support Group in 2009, with permission from Lynn.



Why does the stigma arise? What can we do to combat it? The perspectives of people with dementia, their families and friends, and the professionals who care for them are all sources for this discussion.

We were transformed at that terrible moment of diagnosis from valued members of society into "untouchables." We were labelled with the stigma of dementia. Why is this so? What is the problem? Is it our self-perception of being no longer valued? Of being a lesser person? Of being someone without a future of hope and possibilities?

Alzheimer's Disease International (ADI) compiled a Global Alzheimer's Disease Charter, with input from those living with dementia. It stresses six principles, including "Respect the human rights of people with the disease." But the issue of stigma remains. We face stigma from the public, even from doctors, as we face the diseases that result in dementia.

So how do we change the public's attitude about dementia? How did the AIDS/cancer movements do it? First of all, there is still too much stigma associated with giving and receiving a dementia diagnosis. Doctors too often are unwilling to give their patients a diagnosis. So we need to improve the education of medical doctors for early diagnosis and treatment.

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To name an illness usually gives a feeling of greater control. But naming dementia can have a very different impact. Misunderstanding of medical terms, and conflicts between medical concepts and cultural beliefs, can lead to an increase in stigma. The Big “S”(stigma) leads to a whole load of other “S” words, such as secrecy, shame and silence. Shame leads to isolation, brought about through making no new friends and the loss of old friends. Silence adds to this isolation and leads to family tension from within and without. Secrecy has an impact on health because people with dementia feel less empowered, are fearful, and see their doctors later rather than sooner. This reduces their chance for available therapeutics to be beneficial. Informed people do better. There are plenty of treatment options, but we need to avoid denial if we are to take advantage of them.

People with dementia are increasingly seen as having the right to be heard and taken seriously. Personal accounts of the onset of dementia, along with research into the experience of developing dementia, present a picture of people trying to find meaning in what is happening to them. They are attempting to work out ways of living with dementia that allow them to retain useful roles and interpersonal connections. Hopefully by developing a “voice”, banding together around the world to help one another through mutual support and collaborative activity, the stigma associated with dementia will lessen over time.

To read the full article, visit our website at www.alzheimerbc.org, go to News and Events and click on [newsletter and bulletins](#) and look under *Insight*.

Travel Tip

from Jim Mann



I flew from Los Angeles to Vancouver and told the flight attendant that I have Alzheimer’s. I asked her if she needed to know and would prefer to know. The answer was yes. She suggested I should pre-board in order to let the in-charge flight attendant know about my diagnosis and where I would be sitting. I thought this was interesting and valuable information to share with readers.

Patricia's* Journey:

(*name has been changed by request)

When Patricia* noticed changes in her memory and began to have difficulty at work, she suspected that something was wrong. Because of her family history and her former profession as a nurse, she was not surprised when the neurologist diagnosed her with Alzheimer's disease about a year ago. The disease is present in her family; both her father and her aunt were also diagnosed with Alzheimer's disease.

Patricia rarely tells people about her diagnosis unless it's relevant for them to know, such as a doctor or other medical professional. If she is having difficulty with a task, she may tell people that she has short-term memory problems. From past experience, she has found that when people learn that she has Alzheimer's disease, their attitude changes. Often it makes people feel uncomfortable. "There are a lot of people who have the idea that Alzheimer's is a crazy person's disease." Rather than risk being treated differently, she prefers to tell people who need to know and who are likely to be more understanding about the disease. Despite wanting to remain anonymous, she agreed to do this interview because she wants to share her experience with others.



About eight months ago, Patricia learned that the Alzheimer Society of B.C. offered Early Stage Support Groups for people with early symptoms of dementia. Since joining the Early Stage Support Group, she realizes the benefits of having a support system. "The support group makes you feel less alone, less isolated," says Patricia.

In Patricia's support group, people are comfortable with each other and find it easy to relate to others who are going through the same journey. "You feel like you're with a group with similar issues and are at the same level of the disease." In the support group, which meets twice a month, people talk about what they've been doing and share their thoughts about how the disease is affecting them.

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Members also learn about the disease, share tips and strategies, and find out how to access additional community resources. “Sometimes we talk about general things. It’s sometimes better than only talking about the disease, but at the same time, you kind of have to because that’s the point of the support group.”

Asked if she had advice for other people faced with dementia Patricia says, “They need to go through the process. Go to your doctor, get access to support groups and other support systems that are available. Support groups can improve quality of life and allow you to be independent longer. It’s valuable to get into support groups. Trying to go through the disease by yourself is very difficult.”

Everyone’s journey with dementia is unique. We would like to hear from other people about their experiences, whether good or bad. Contact us if you would like to share your story.

E-mail us at info@alzheimerbc.org or by mail:

Alzheimer Society of B.C.
Attn: *Insight*
#300-828 West 8th Avenue
Vancouver, BC V5Z 1E2

You Asked Us...

This is a new column where we hope to answer some of the questions that you have for us. Below are some questions asked by the Surrey /White Rock Early Stage Support Group.

Q: How many Early Stage Support Groups are there in B.C.?

A: Currently, there are 19 support groups. The newest Early Stage Support Group began meeting in January 2010 in Surrey.

Q: Is the government putting any money into research to find a cure for Alzheimer’s disease? If so, do they put money into research on a regular basis?

A: The provincial government doesn’t put money into research on a regular basis, but has done so in the past. The B.C. government does fund research organizations that do dementia research. The federal government also funds organizations which do this research.

If you or your early stage group has a question that you would like to ask the Alzheimer Society of B.C., please forward them to us. (← See our contact address on the left).

Kelowna Early Stage Support Group Update

by Norma Selbie (Early Stage Support Group Facilitator)



What is needed to add a magically fun evening to your Christmas Holiday?

In Kelowna, the Early Stage Support Group hosted what we hope will become an annual event. A group member offered her social room, which had been attractively decorated by the condo residents. Then an excellent caterer was booked, and the tickets sold. Now how easy is that?! Add a few Christmas carols, some warm apple cider, punch and 32 caring people who know one another well and you have all the ingredients for a wonderful holiday evening. If it sounds like fun...it was. I can't remember a nicer Christmas party ever!

“ALZHERISM”

(Pronounced...*Alz-er-is-m*)

by Dave Fost

Sometimes how we feel isn't always socially acceptable. When you have Alzheimer's this is more often the case. Such as, "I don't want to see the grandkids, I just want to watch TV," or "I don't want to go out for dinner, I want to stay home." Sometimes this upsets the plans of those who might not understand our situation. This is when we could use the word "Alz-er-is-m." This is derived from the root of "Alzheimer."

It can be used to avoid upcoming frustration or socially awkward situations, such as, "I don't want to see the grandkids, I seem to be coming down with Alz-er-is-m," or "I am having a bout of Alz-er-is-m so I don't want to have coffee with Earl today." Alzherism can cover it all for us who have the disease...like you and me. It is IMPORTANT to have as much fun as we can in this wonderful life. Well, as long as it is legal!



Dave Fost was diagnosed with Early Onset Alzheimer's disease in 2002. He keeps busy by co-facilitating his local Early Stage Support Group and speaking at public forums. He is a spokesperson for both the Alzheimer Society in Alberta and the Alzheimer Society of Canada. Dave currently lives in Edmonton.

The Rising Tide

speech by Jim Mann

The Alzheimer Society of Canada released a report called the Rising Tide Study with information about the projected economic and social costs of dementia. To deliver these statistics, the Alzheimer Society of B.C. hosted a press conference on January 4, 2010, which was attended by major media and key speakers, including Jim Mann. Below is an excerpt from his speech.

An early diagnosis of Alzheimer's or a related dementia can offer early treatment that may stabilize or slow the rate of decline. You get a chance to be educated on the disease and learn, for example, that socialization and physical activity – like walking – are excellent programs.

Some of us will also use this opportunity to educate. We can increase awareness of Alzheimer's and related dementias and what it is like to live with this disease. You know, there is a lack of awareness and even a misunderstanding in the community-at-large about Alzheimer's and the related dementias. There is even a stigma associated with our disease in some quarters.

So this is our chance, to share our story and to educate. We know this story but others don't. And if we don't tell the story – our story – who will? If we don't advocate to educate then how do we shatter the myth or break the stereotype?

Who listens? Well our family, friends

and neighbours do. We also spread the net of awareness to the broader community. And government can't help but hear that.

Who cares? We all do, or at least we all should. Everyone needs to hear about Alzheimer's and the related dementias. They need to be inspired to learn about brain health and the things they can do for the good of themselves and, of course, their brain.

Hearing our stories will hopefully lead to wanting more information on research and how the course of this disease might be altered. Perhaps by our actions government will be encouraged to invest significantly more into this critically important activity. We can hope. And we can keep educating by taking advantage of what I call teachable moments. Like this. Today. For me.

So thank you all for attending this press conference and listening to my story as a 61-year-old person with Alzheimer's.

Visit www.alzheimerbc.org and click on [newsletter and bulletins](#) to read the full speech.



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.

Alzheimer's Drug Therapy Initiative

PharmaCare continues to provide coverage for cholinesterase inhibitors (ChEIs) until March 2012, within specific guidelines.

People are encouraged to share their experience with the Centre on Aging at the University of Victoria by participating in the Seniors' Medication Study and Caregiver Study. What PharmaCare learns about these drugs over the course of the Alzheimer's Drug Therapy Initiative will affect PharmaCare's decision on whether to include these medications in its formulary.

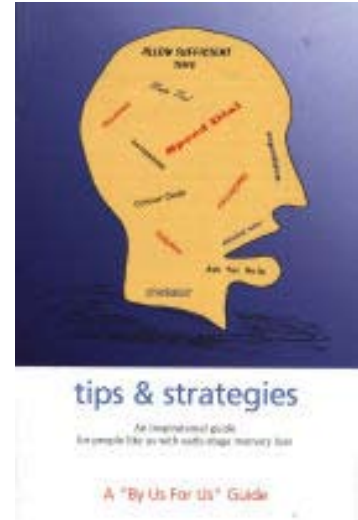
To find out if you are covered, speak to your doctor. Further information can be found on this website www.health.gov.bc.ca/pharmacare/newsletter/09-014news.pdf on page 5 of the newsletter.

You can also contact the Centre on Aging directly at 1-866-511-2594 or e-mail sms@uvic.ca.

By Us For Us® Guides

The *By Us For Us*® Guides were created by a group of talented and passionate persons with dementia.

They are designed to equip persons with dementia with the necessary tools to enhance their well being and manage daily challenges. These guides are particularly useful because they are created by persons with dementia for persons with dementia. To order guides (\$1 each) contact Janet Mooney at 519-888-4567 ext. 32920 or e-mail jnmooney@healthy.uwaterloo.ca. Visit the MAREP website at www.marep.uwaterloo.ca.



Suggested Websites

Dementia Advocacy and Support Network International

www.dasninternational.org A worldwide organization by and for those diagnosed with dementia, working together to improve quality of life.

Alzheimer Society Canada – Creative Space

www.alzheimer.ca/english/creativespace/writingroom-intro.htm A writing and art space where persons with dementia express their experiences with the disease.



Shaping the Journey

This six-session educational series is designed for people experiencing the early symptoms of Alzheimer's disease or a related dementia, as well as a care-partner, family member, or friend. It is this joint learning environment that makes the program unique.

Contact your local Alzheimer Society of B.C. Resource Centre to find out when it will be taking place in your area. Go to www.alzheimerbc.org for more information.



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 cure.

HealthLink 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.

The Alzheimer Society of B.C. relies on the generosity of individuals and the community to ensure families have access to the knowledge, skills and tools they need to live well with dementia. Your donation will help make the journey easier for families impacted by Alzheimer's disease or related dementias.

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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