

In this issue...

Some Thoughts about Driving

Giving up Driving

Principals for a Dignified Diagnosis

What's One of My Best Qualities?

A Celebration of Summer

Suggested Readings

Some Thoughts about Driving

by Jim Mann

The magic of a car. The open road, wind's fingers through your hair. The feeling of independence.

Screech! Think again.

For me now it is the magic of a bus. And that independence? I get that around a fixed timetable along with everyone else on the bus or SkyTrain.

How did this change happen? "Surely it wasn't voluntary," might be a thought popping into your mind.

Events ganged up on me and forced the decision, so yes, in a way it actually was voluntary. I decided my actions were not as safe as they needed to be so I decided to stop driving before I had an accident and possibly injured someone.

Like so many young men, I learned to drive at the age of 16. Talk about a rite of passage. With Dad's car I felt like I could go anywhere. I had taken a huge step forward in life's journey.



Now this particular journey has taken an unexpected turn. I have ceded my transportation needs to others. Is that frustrating? You bet.

Before this I could go to the store on my own. I could hop in the car and visit White Rock's Farmer's Market on Sunday. I could venture out just because.

Now it's "Where are you going?" or "Why do you want to go?"

On a good day, that seems unnecessary and personally intrusive. On a bad day, it seems totally justified and safe.

That's the split personality of dementia: good day = independence, bad day = support. For our partners-in-care, this is an ever-changing landscape of egg shells! »

(continued on page 2)

(continued from page 1)

At the end of the day I believe “safety first” is the best motto for any driver, especially a person with dementia.

Having used public transport since high school for getting to and from work, I am comfortable using the bus and accessing schedules online.

Some people lose their license and feel like their right arm has been severed. They view the loss in a negative light, with no redeeming factors.

It is frustrating, I agree, but public transport puts a smile on my face when I watch my fellow riders. A cross-section of humanity playing computer games, texting, listening to their ipods and others talking with their neighbours. And then there is the view from the window: new construction, neighbourhood changes and viewscapes that are new. It's a window on the city and I love it.



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.

Giving up Driving

an interview with Tony Marchand

When Tony was a young boy in Switzerland, his family did not need a car. That changed after his family immigrated to Montreal. Tony first learned to drive when he was a young boy and received his driver's license when he was 13. Because his father did not drive, it was up to Tony to drive the family around.

Driving was a major part of Tony's life in other ways. He, his wife Sandy, and their three children used to spend a lot of time camping, driving their trailer all over Canada and the United States. Earlier this year, Tony made the decision to sell both his car and his trailer.

Tony and Sandy have lived in Vernon for the last 21 years. For many years, they lived just outside of town, making driving a necessity. After Tony was diagnosed with Alzheimer's disease in 2007, they decided to move closer to town. Now they often walk to where they need to go. They also use local transport to get around the city.

Tony is impressed with the city's bus system. He says, “The buses are clean and the drivers' personalities are absolutely fantastic!” Tony also found out through the Alzheimer Society of B.C. that people »

(continued on page 3)

(continued from page 2)

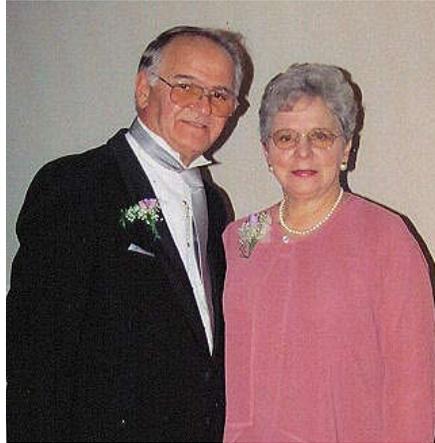
with Alzheimer's disease are eligible for taxi discounts through HandyDART. In addition, he has a good network of friends who often call to offer him rides.

The fact that Tony no longer drives has not limited him from experiencing other modes of transportation. He and Sandy are planning on taking an Alaskan cruise this summer to add to their past cruises to exotic places such as Panama, across the Pacific, Australia, New Zealand and the Amazon.

Now retired, Tony keeps busy by helping out his friends whenever he can and going to the gym three times a week. He has also returned to outdoor gardening.

Tony attends the monthly Alzheimer Society of B.C. support group meetings for people in the early stages of dementia. He says that he is grateful for the support. "There is a wonderful group of dedicated leaders at the Alzheimer Society."

Tony says that he did not give up his driver's license because he was concerned about his driving abilities; he gave it up in part because of his wife's concerns. It was a decision that both he and his wife made together. Tony also felt that the time was right. He had never gotten a ticket, nor had he ever been in an accident. He says that he does not want to take the risk of hurting anyone. Sandy is



Tony and Sandy Marchand

impressed and very proud of Tony for retiring his license with such grace.

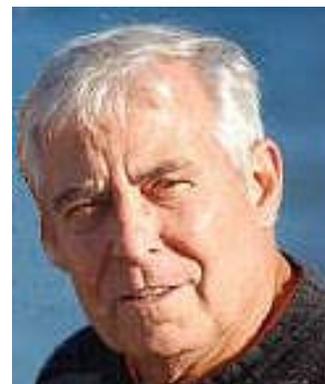
When asked what advice he would give to people about driving, he says that he would encourage people to investigate the alternatives to driving. He is a proponent of being realistic about driving. He realizes that for many people, driving is something that is hard to give up. "I chose not to be angry or upset about it. I am satisfied in knowing that I will not be a danger on the road."

Tony is a member of the Vernon Early Stage Support Group. For more information about support groups, please contact your local Alzheimer Resource Centre. To locate an Alzheimer Resource Centre go to www.alzheimerbc.org and click on **In My Community** or call 1-800-667-3742.

Principles for a Dignified Diagnosis thoughts from the Vancouver Early Stage Support Group

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience. It is produced by the Alzheimer's Association in the United States.

The Vancouver Early Stage Support Group (we meet on the 2nd and 4th Tuesday of each month) decided to discuss each of the points. Over two meetings, we went through the principles and the group commented on each one. Each principle is highlighted in bold with our group's comments summarized underneath.



1) Talk to me directly, the person with dementia.

When you don't, I feel cut out, like I have lost my personhood.

2) Tell the truth.

This is self-evident. I have the right to know what is happening to me.

3) Test early.

Most of us waited months and months (and sometimes years) for a diagnosis, and were given inappropriate tests. This added to our frustration.

4) Take my concerns seriously, regardless of my age.

Many of the members of this group are young, so we know firsthand that too often, our symptoms are brushed off by others.

5) Deliver the news in plain but sensitive language.

Don't just give me a diagnosis and show me the door.

6) Coordinate with other care providers.

Things are taken away from me with this disease. Too often, people get the diagnosis and nothing is put in place of what is missing. Everyone who gets this diagnosis should be pointed towards the Alzheimer Society.

7) Explain the purpose of different tests and what you hope to learn.

I have the right to know what you are doing with me. »

(continued on page 5)

(continued from page 4)

8) Give me tools for living with this disease.

As with #6, I need help learning how to cope.

9) Work with me on a plan for healthy living.

And recognize that I am an individual, with my own individual needs.

10) Recognize that I am an individual and the way I experience this disease is unique.

Yes!

11) Alzheimer's is a journey, not a destination.

(Other dementias should be included here.)

To view principles for a dignified diagnosis, go to www.alz.org/national/documents/brochure_dignified_diagnosis.pdf.

Contribute to the newsletter!

We really want you to feel part of this newsletter.

- Send us news from your support group
- 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*)

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

What's one of my best qualities?

In the December 2008 issue of *Insight*, the North Vancouver Early Stage Support Group shared with us the qualities that they liked about themselves. They also wanted to know what other early stage support groups felt were their best qualities. Below are some comments from an early stage support group in California.

- "I'm always steadfast."
(a retired nurse)
- "I have stick-to-it-ness."
(a retired advertising rep)
- "I have the ability to make and repair things."
(a retired mechanic and welder)
- "I am fairly level headed."
(a retired journalist)
- "I try to look at things from other people's perspectives." (a retired nurse)
- "I am caring. I like people."
(a retired social worker)
- "I am persistent and discerning."
(a retired engineer)

Early Stage Group, Santa Rosa Office
April 2009

The Santa Rosa, California group is interested in hearing comments from other support groups. They also mentioned that they would love to have pen pals. If you are interested, write to info@alzheimercbc.org and we'll help to connect you to them.

A Celebration of Summer

with the Kelowna Early Stage Support Group

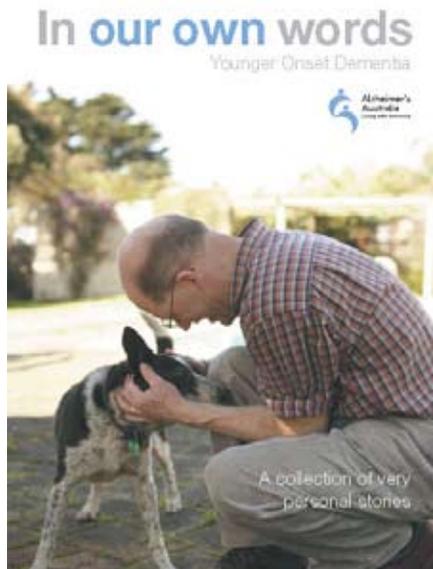
Summer is a wonderful time for people to get together to enjoy the warm weather. This is exactly what the Kelowna Early Stage Support Group members did on June 9th. The group got together with their family and friends to enjoy the 9th Annual Picnic and Bocci Ball Tournament. Despite the small turnout, the weather was lovely and a good time was had by all.



What is Bocci?

Bocci is a kind of lawn bowling. The object of the game is to get your ball as close as you can to the smaller ball, or jack. The name bocci is from the Italian word *boccia*, which means “bowl.”

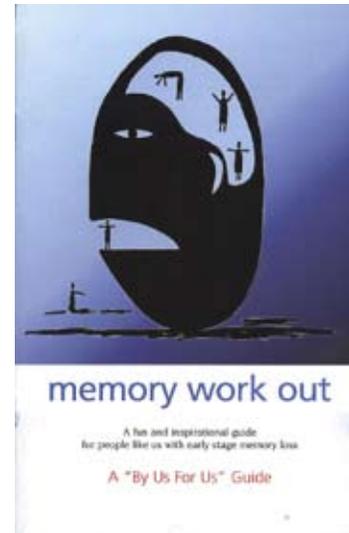




Produced by Alzheimer's Australia, *In our own words: Younger Onset Dementia* is a collection of stories from people who have been diagnosed with early onset dementia. These personal stories give others insight on how life changes after being diagnosed. To view this document, go to: www.alzheimers.org.au/content.cfm?infopageid=5472

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. To order guides for a nominal fee of \$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.



Thursday, September 17, 2009

Coffee Break is a simple initiative where people gather over a cup of coffee at home or at work to help raise money for the Alzheimer Society of B.C. Participating stores and restaurants around the province will be selling coffee cup cut-outs by donation this fall to support the more than 70,000 people in B.C. who are living with Alzheimer's disease and dementia. To learn more, visit www.alzheimerbc.org and click on **Get Involved**.



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.

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.

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.

Insight is published by:

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