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Positive steps on the dementia journey

“Oh look, there’s a new *for sale* sign,” I say to Bhreagh... “and the fragrance of the roses grown at this other house is overwhelming!”

“Now that we’re walking by the park, why don’t you frolic in the water a bit? We’d better stop here as the fire truck is leaving the station with its lights flashing Okay, let’s go. Good girl.”

Walking with my dog Bhreagh is great fun and every time we go out for our walk we see new things, smell new flowers and say ‘hi’ to others walking by. And as long as there are no children playing around the water park, my chocolate Lab will take a moment to splash and run in the water. I love my walks with Bhreagh. It is good exercise, there is some socialization, and somewhere along the way it brings a smile to my face.

And the beauty of walking is it can be done alone, with another person or in a group. You can walk in your neighbourhood, around a sea wall or through a local park. Always, though, by walking you will see new things, brighten your day, and maybe even make new friends.

Just the other day I went for a walk on a new route with a new friend who also has Alzheimer’s disease. We were on a walk

along the water where we saw birds (I can’t remember the type he said), took lots of pictures, and took time to admire our city and talk about how it has changed over the years.

Of course walking isn’t the only way to get exercise, but for me it is a tonic I love taking. Whether you live in Bella Coola, Nelson or Nanaimo you can start your day feeling good with a smile or maybe you would prefer to end it that way. Either way, I hope the idea of walking, along with other suggestions and perspectives included in this issue of *Insight*, will be a positive step in our journey with dementia.

Jim Mann is the Honourary 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.



Spreading joy through his art

Werner Braun has been creating art since he was a young boy. Originally from Germany, Werner and his wife, Christa, immigrated to Canada in 1958 and have lived in Kamloops for almost 20 years.

Werner is living with a diagnosis of Alzheimer's disease and although he is experiencing some symptoms, he continues to paint and has an upbeat attitude. "I am not as fast as I was before, however I have several commissions pending," says Werner. "I am working on two right now."

The couple has a collection of over one hundred of Werner's unique paintings on display at their home in a downstairs gallery and art studio. "We have a two-storey property, so the lower level of our home is Werner's kingdom," says Christa. "When people come down and look and see what I do and what I have, it's great," adds Werner, who paints mostly in watercolour but also acrylics.

Werner's art has also been showcased in several exhibits. The most recent was an opportunity to show his collection titled "Travels in Europe" when another artist unexpectedly cancelled. The couple travelled throughout Europe, including Spain, France, Holland, Germany and Caledonia, taking photographs which Werner recreated as unique paintings. "We have paintings of windmills, old farmyards and beautiful landscapes," explains Christa.

Werner's previous exhibit in July was titled "Heritage Kamloops", and included intricate paintings of various heritage buildings located throughout their community.

Both Werner and Christa agree that letting people know about Werner's diagnosis, and making small adjustments, can make a big difference. "At the gallery shows I was worried because people speak too fast, and Werner might have problems responding quickly enough," explains Christa. "We went to Tara [from the Alzheimer Society of B.C. Kamloops office] and she gave us some small cards that read, 'Please be patient, I have Alzheimer's disease.' It took a while for Werner to adjust his thinking about them, but people are so good. They repeated themselves when needed and talked more slowly. Then it just ended up being a really great art show!"

Werner keeps active by participating in a weekly activity program at Ponderosa Lodge in Kamloops. "It's all about keeping busy and keeping positive," Werner explains. Last year he donated two of his paintings to the Lodge (shown in the photo above). This is one of many examples of how Werner spreads joy in his community through his art and his positive attitude. "It was a really good experience for everyone," says Werner.



Judi Dupont photo

“One thing that really helps us cope with this disease is a strong marriage,” says Christa. “We have had a great marriage for 53 years! That helps a lot. We have always been a team, and now we are even more so.”

Another way Werner and Christa receive the support they need is through a strong network of supportive friends that they have developed over the years. “The good friends stick around,” explains Werner. Their friends also understand the disease and as Christa says, “we can be relaxed around our friends.” Christa also attends a support group once a month to get information and insight.

“One day Werner came home from his activity group. He comes home at 4 p.m. and we usually have a glass of wine and chat,” Christa explains. “He told me about a new man in the group who said, ‘my life is over – I have Alzheimer’s disease.’ And it was so sad. Life doesn’t have to be over. Take in the joy that you have and try to take pleasure in every day!”

“It’s all about attitude,” says Werner. “You can’t just say ‘I’ve had it’.”

When asked if they have a message to share with other families in British Columbia living with dementia, Christa says, “I think it’s important to face the facts. Many people want to paint pretty pictures and don’t want it to be real. It doesn’t help anyone. Be hands on, make the best of it, and move forward,” she suggests. “Also, I make others laugh, and that helps a lot,” says Werner.

***Insight* readers – we want to hear from you!!!**

Since its inaugural issue in the Spring of 2005, the *Insight* bulletin has provided opportunities for British Columbians with Alzheimer’s disease and related dementias to share their stories, connect with others, learn strategies for living well and raise awareness about important issues.

Our goal is to continue to provide a valuable publication for subscribers. We want to learn more about our readers and how we can make *Insight* even better! That’s why we have developed a simple, confidential online survey for you to fill out. Give us feedback about *Insight* and pass along ideas for future issues – we want this to be **your** bulletin!

Click on the following link to complete the *Insight* survey:

www.surveymonkey.com/s/Insightsurvey2011

If you do not have internet access and would like to give your feedback, contact your local Alzheimer Society of B.C. resource centre to obtain a paper copy of the survey.

Consider signing up to receive future editions of *Insight* via e-mail. Visit our website at www.alzheimerbc.org and choose “News and Events” and then “Newsletter and Bulletins”.

Sharing our experiences

Members of the Kelowna Early-Stage Support Group discussed the symptoms they are experiencing as a result of Alzheimer's disease or another dementia. Although everyone is unique, these individuals found that they had some commonalities in their experiences. Here is what they had to share:



I often find that I am repeating myself

- *Sometimes my wife reminds me, "We've already talked about this. Don't you remember?" So what if I repeat myself?*
- *Between my husband and I, we're in a heck of a mess. He forgets, I forget. But somehow we just muddle through. We have a good laugh over me forgetting. There's nothing else you can do.*

Memory loss

- *I forget things I've learned. But I can remember things that happened years ago as if they happened yesterday.*
- *If I take an interest in something that somebody says, I can keep it. Otherwise it's gone.*
- *The significance of the event determines whether or not I will be able to remember it. Trivial things aren't remembered. I write things down to help me remember insignificant things like doctors' appointments.*

It's hard to find the right word

- *With a full vocabulary, it's easier to substitute words when you can't find the one you're looking for. It would be a struggle if my vocabulary was limited.*
- *If I have a long sentence to speak and there's sufficient flow, I'm okay. If I stumble for a word, I lose my concentration. I cover up by speaking a totally different sentence than the one I wanted to say in the first place.*

Through sharing with others who are "in the same boat," people living with dementia are often pleased to know that they are not alone.

Reach out and connect with other people living with dementia in your community – through a support group, educational workshop, or one-on-one. Contact your local Alzheimer Society of B.C. resource centre to learn more about opportunities to meet others who are on a similar journey.

Perspectives from a support group

Some people with dementia find that participating in a support group can help them cope with the symptoms and challenges they are experiencing. Support groups can also provide opportunities to explore the difficult feelings that come up throughout the journey with Alzheimer's disease or a related dementia.



Presented below is a discussion among four individuals who are members of an Alzheimer Society of B.C. Early Stage Support Group. They are sharing some ideas and perspectives that have helped them to live well with dementia.

Luc: "We get a lot of good ideas from the group."

Eddie: "We don't just sit at home and feel sorry for ourselves. We come to the group instead. I think it's a good idea for us to have a project to work on. I feel I need to accomplish something. If we decide we want to attain a goal and we can complete it, then we feel better about ourselves and it helps build our confidence."

"I don't feel ashamed. I think of it as a challenge to try to remember things. I realize I have Alzheimer's and that I have to work with it. I have a little book I carry with me and that helps me keep track of things too."

Bob: "Yes, coming to the group is helpful. Sometimes if I'm just sitting around the house I feel depressed. And sometimes I feel bored. I have found that going into a care facility and becoming a volunteer visitor for people, who hardly get any visitors, makes me feel better about myself."

Eddie: "When you're helping others, you're helping yourself, too. You feel better about yourself and what you can still do. It boosts your confidence. Volunteering is a good idea."

Luc: "I was watching a TV show and the guy on TV was saying how important a positive attitude is, and I think that he is right. Being positive is very important."

Wilf: "I agree. Don't put yourself down. You do your best and that's it. I try not to worry about what's wrong."

The Alzheimer Society of B.C. offers support groups for people experiencing early symptoms of dementia. Contact your local resource centre, visit our website: www.alzheimerbc.org, or phone the Dementia Helpline (604-861-8651 or toll-free 1-800-936-6033) to learn more.

In our own words

We asked people living with dementia some questions about continuing to live well despite the challenges that dementia can bring. Below are the responses we received.

What are some things that you still enjoy doing?

“Volunteering and participating in community events. These are great ways to spend time with others.”

“Getting together with friends to go hiking.”

“If you have difficulty doing something today, it still may be possible for you to do it tomorrow – try again!”

Have you developed any new interests or hobbies recently?

“Being a pet owner. Dogs are forgiving and they don’t care what you look like. Having a dog forces me to exercise. My dog loves me unconditionally.”

“I am a knitter and I have been experimenting with the use of new colour combinations and stitches to create unique patterns for toques. I knit an average of a toque a day and I donate them to various charities for children and the homeless.”

“Using my new walker so I feel safer on my morning walks along a busy residential thoroughfare.”

“Everyone is individual. Find what you enjoy doing – and do it!”

Do you have tips for others with dementia about how to live life to the fullest?

“When I meet people that I should know but have forgotten I say, ‘Listen. I’m sorry. I have memory problems and can’t remember your name or how we know one another.’ People open up when I explain my challenges and they are pretty good about it. This works far better for me than trying to hide my condition.”

“When I first got my diagnosis I was worried because I thought I should be. This is pretty serious stuff. But my wife helped me to not worry. She said, ‘don’t worry about it. Do what you have to do to stay well, like going to support group meetings’.”

Get involved!

Many people with Alzheimer's disease or a related dementia find that getting involved in their communities is a great way to stay active and live well with dementia.

Jim Mann, Honorary Editor of *Insight*, is involved in a variety of advocacy activities at the provincial and local level with the Alzheimer Society of B.C., as well as at the national level with the Alzheimer Society of Canada. Recently, Jim met with Vancouver Canucks legend Orland Kurtenbach in support of the annual *Coffee Break*[®] fundraising event for the Alzheimer Society of B.C. that helps raise awareness about the disease across the province. There are many ways to get involved with the Alzheimer Society of B.C. For example, volunteering at your local Alzheimer resource centre, participating in fundraising events, and getting involved in important advocacy work like Jim.

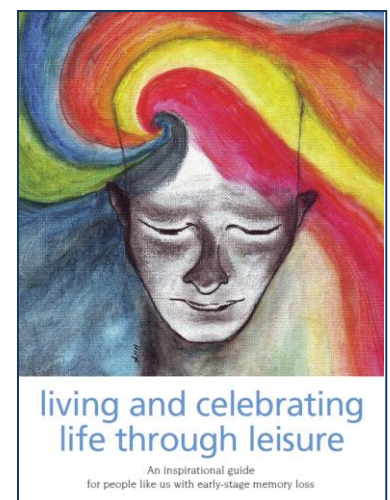


For more information about how you can get involved with the Alzheimer Society of B.C., visit our website at www.alzheimerbc.org or contact your local Resource Centre.

New By Us For Us[®] Guide

The *By Us For Us*[®] Guides are produced at the University of Waterloo by the Murray Alzheimer Research and Education Program (MAREP). What makes these guides particularly useful is that they are created by persons with dementia for persons with dementia. They are designed to equip persons with dementia with the necessary tools to enhance their well being and manage daily challenges.

The sixth *By Us For Us*[®] Guide, titled ***Living and Celebrating Life Through Leisure*** has recently been released.



The purpose of this new guide is to share with you some thoughts on living and celebrating life through leisure. Meaningful leisure can be a wide range of activities, from enjoying coffee on your deck first thing in the morning to being involved with other people in a more structured and challenging venue.

The new guide is available on the MAREP website at: www.marep.uwaterloo.ca (click on "Educational Tools" and choose "By Us For Us". Or call 1-519-888-4567.

Notes and events

DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033

(Lower Mainland 604-681-8651)
Tuesday to Friday, 10 a.m. to 4 p.m.

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.

Insight is published by:

Alzheimer Society
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Contribute to Insight!

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

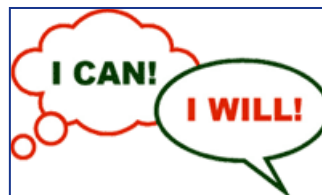
- Send us news from your support group. For example, what topics of interest or activities have you covered?
- Submit articles on how to live a full and meaningful life after a diagnosis of Alzheimer's disease or a related dementia.
- Drop off photographs.

Send your contributions to the Alzheimer Society of B.C. (Attention: *Insight*)

Fax: 604-669-6907

Email: info@alzheimercbc.org

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



Alzheimer's Disease International is pleased to announce the launch of a new website called **I CAN! I WILL!**

The website is a library of ideas to help people around the world stand up and speak out about Alzheimer's disease and related disorders. These ideas, which raise awareness about dementia and help to erase the stigma, have been contributed by people just like you so that you can learn from their experiences and they can learn from yours. Visit the new website and share your ideas at:

www.alz.co.uk/icanwill