



This fall, the Alzheimer Society of B.C. celebrates its 35th anniversary. Over the years, the Society has made great strides to reduce the stigma associated with dementia by showing that many people live meaningful, active lives after a diagnosis; the members of the B.C. Leadership Group of People with Dementia (pictured above) is just one great example.

This edition of *Insight* celebrates the ways people living with dementia continue to find purpose and joy in their lives, may it be through continuing to follow your passions ([page 1](#)), being able to share thoughts and feelings in a support group ([page 4](#)), or being a volunteer and dementia advocate ([page 5](#)).

FINDING A NEW LEASE ON LIFE

“My drug of choice is the violin. If I’m feeling anxious, I pick up my fiddle. While I’m playing, I don’t have Alzheimer’s disease.”

– Mary Gretsinger

Two years ago, Mary Gretsinger, a retired teacher, was diagnosed with Alzheimer’s disease at the age of 66. Recently, Mary shared how her love for playing the violin, walking and her family have helped her embrace a new attitude toward life.

Has your outlook changed since you were diagnosed with dementia?

When I was first diagnosed, I concluded that my life was over. I went to bed for four days and cried for about that long. But then I thought about my husband, children and grandchildren and realized that this was a defeatist’s thinking. I am not longer upset by a label.

The main thing for me was to get over the shame – to realize that’s just bologna.

Did anything else help you cope with your initial feelings?

I have played the violin since I was a child. One day after my diagnosis, I picked up my violin and played the very same concerto I had

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played at the Queen Elizabeth Theatre in Vancouver when I was just 16 years old. This experience showed me that I have a lot of living to do.

I read somewhere that music memory stays with you for a very long time. What good news to old musicians like me! Now, I am playing my violin more and my husband has even recorded tapes of me playing to share with friends and various dementia support groups.

I am enjoying life like I have never enjoyed it before. I consider my diagnosis a gift to me now, even though I sure didn't feel that way in the first four days after my diagnosis.

What other activities do you enjoy?

I still keep physically active. Walking is almost more important than music for me...but not quite!

I started walking for mood and fitness in 2006 and as of today, I've walked 10,852 kilometers! When I take my first step out the door, sometimes I start out thinking "I can't handle this disease" and about halfway out there, I start thinking "Boy it's a beautiful day."

How has your family supported you since your diagnosis?

After my diagnosis, we had a family meeting with my husband, my children and grandchildren. My family now knows it's okay to help me if I am having problems



remembering. It also doesn't hurt for the children to learn why granny might be trying to remember something and she can't.

My youngest grandchild asked me one day "Did you forget anything today granny?" Children are taught to be compassionate.

Do you have anything else you would like to share with people who have dementia?

Another great joy of mine is gardening. I've been trying to grow Shasta daisies forever, and yesterday, my first Shasta daisy arrived in my yard.

My message to others is to keep growing Shasta daisies – if you will. I want people to know that dementia is not the end of the world, it's just something that has been given to us.

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It hasn't destroyed my gardening, it hasn't stopped me from playing the violin, or playing with the grandkids, or going camping and doing all kinds of things.

I have a favourite line from a poem by Robert Browning that I have written down in my notebook, "For sudden the worst turns the

SPEAKING UP ABOUT DEMENTIA

A SIMPLE GUIDE TO RAISING YOUR VOICE

Everyone has a role to play in bringing attention to dementia issues. Speaking to others reduces the stigma associated with the disease, it also spreads knowledge and information about what is needed as dementia affects more and more people in B.C.

Recently, the Alzheimer Society of B.C. released *Speaking Up About Dementia: A Simple Guide to Raising Your Voice* to support people who are interested in making a difference in their communities. This resource includes information on:

- What advocacy is.
- How to speak to others about dementia issues.
- How to engage politicians through letter writing or in-person meetings.
- How social and print media can make a difference.

best into the brave." There are things I can't do with Alzheimer's disease, but that's not the end of the world, and it's making me brave.

The Alzheimer Society of B.C. would like to thank Mary for sharing her story with *Insight*.



SPEAKING UP ABOUT DEMENTIA

A SIMPLE GUIDE TO RAISING YOUR VOICE

Alzheimer Society
BRITISH COLUMBIA

To learn more about advocacy or to download the guide visit alzbc.org/become-advocate or call the First Link® Dementia Helpline at 1-800-936-6033.

INSPIRATIONAL INSIGHTS

A diagnosis of dementia impacts many areas of your life and it is common for people to experience a variety of feelings. To help people living with dementia strengthen their coping abilities, the Alzheimer Society of B.C. offers support groups for people who are in the early stages of the disease. These support groups are a place to exchange information, support and friendship with others whose lives are affected by dementia.

Recently, an early stage support group in Kamloops shared their insights with group facilitator and Society staff person Tara Hildebrand.

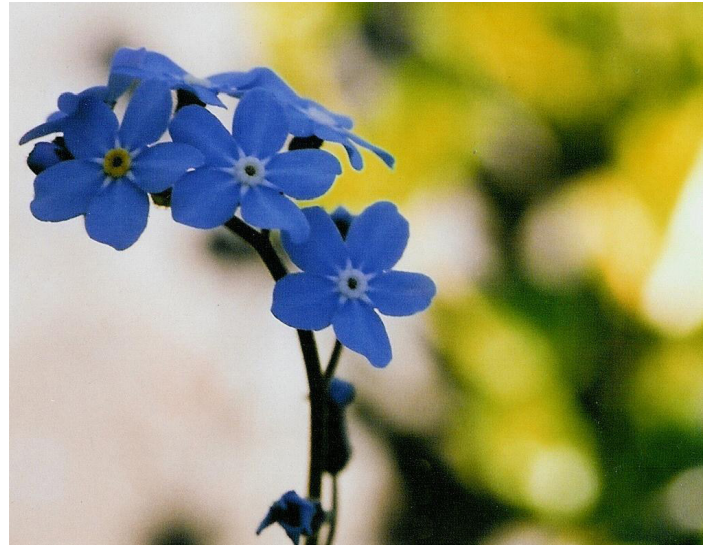
“The group inspires me to look at things differently and they continue to amaze me with their positive attitudes,” shares Tara. “There is always laughter in the meetings and they all give one another such a boost of confidence and pride in how they are maintaining their quality of life.”

Here’s what they had to say:

“This support group is a safe place, these are my sisters.”

“Being diagnosed and having the support makes life okay. I feel like I can do this.”

“At the beginning, when I heard my diagnosis, I thought ‘I’m going to go to bed until I’m dead’ and that’s so not true!”



“There are gifts that come from Alzheimer’s disease. It’s bringing my family closer together. My kids spend more time with mom – I think they think that we need to listen to her while she still has something to say.”

“At first I thought ‘Why me?’ and then, ‘Ok, this is happening’ and now, I have the support of a village. Literally! It makes me feel secure.”

“I try. It’s very scary but I’m doing ok. I really like coming here and seeing everyone else is ok. We feel at home with each other because we are all looking at the same thing.”

“The one thing about this disease is that your emotions are more ‘out there’ and I can’t hold my emotions in anymore. I let my husband know my feelings more and I think it has brought us closer together. I feel like he cares more and I’m more aware of it. We really need to communicate.”

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“This is a disease of reconciliation. I’ve let go of things, they don’t bug me anymore. Even people! I’ve learned to let go of a lot. I’m more patient with others too. I don’t care about things anymore. If I need someone to be patient with me, then I need to be patient with them too.”

“This is teaching my grandchildren patience. Granny forgets a thing sometimes, that’s ok!”

“There is life after Alzheimer’s disease.”

Do you have an inspirational quote or personal story you would like to share with readers of the *Insight* bulletin? If so, email Insight@alzheimercbc.org or call 604-742-4933 (toll-free: 1-800-667-3742).



For information about Early Stage Support Groups in your area, please contact your local Alzheimer Resource Centre or call the First Link® Dementia Helpline at 1-800-936-6033.

AN IMPORTANT VOICE IN THE DEMENTIA CONVERSATION

To celebrate the Alzheimer Society of B.C.’s 35th Anniversary, we have been interviewing people who have worked with the Society to support the thousands of British Columbians who are affected by the disease.

One of these important voices is that of Jim Mann, a member of the B.C. Leadership Group of People with Dementia and a long-time advocate for people living with the disease.

How did you first connect with the Alzheimer Society of B.C.?

My very first contact with the Society was to obtain brochures on Alzheimer’s disease during the early 2000s because my mother had dementia. My wife Alice and I needed helpful information.

For myself, I contacted the Society in mid-2007, a few months after my own diagnosis of Alzheimer’s disease, to investigate ways to volunteer.

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Is there something that stands out for you in your time with the Society that has meaning for you?

Many things, actually. I was honoured to be a board member for a full six-year term, which afforded me the opportunity to advocate for people living with dementia at the policy table.

This position gave me the platform to raise issues, to influence decisions and to reinforce my belief that the meaningful engagement of people living with dementia is indeed possible.

Over the many years I have been involved with the Society, I have been an active advocate at their side addressing the members of the B.C. Legislature, the Select Standing Committee of Finance and I was the face of the Jim's Push for a Plan campaign launched in 2012. And in 2012, I was proud to be the recipient of the Society's Clyde and Lanny Slade Leadership Award for volunteer leadership and contributing to the Society's mission through advocacy work.

What keeps you connected with the Society?

The people. My support group. The wide variety of excellent brochures and up-to-date information on Alzheimer's disease and other dementias, how to prepare for the journey, et cetera.

What do you hope the next 35 years will bring for dementia awareness?

Awareness that people diagnosed with dementia can live a full and productive life.



That the stigma of dementia is no longer an issue and there is no stereotype in people's minds of a person diagnosed with dementia.

What would you tell others about dementia or the Alzheimer Society of B.C.?

To approach the Society for information and for support. To offer to volunteer with the Society in any way that fits.

And what I would tell others about dementia? That you are not lost as a person. That the disease doesn't rob you of you. That you are very much still here, and there is life after a diagnosis of dementia.

And it's that last sentence that I emphasize and hope people take to heart.

CONTRIBUTE TO INSIGHT

Do you have a topic you would like to see covered in *Insight*? Do you have content you would like to publish in *Insight* such as a personal story, photography or an original poem?

If so, please contact the Alzheimer Society of B.C.

- Email Insight@alzheimerbc.org
- Mail to the address below, care of *Insight*:

300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

All submission will be considered based on theme and space. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.

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- Email Insight@alzheimerbc.org

CALL THE FIRST LINK® DEMENTIA HELPLINE

A confidential province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, professionals and the general public.

- Phone 1-800-936-6033
Lower mainland: 604-681-8651
Monday to Friday, 9 a.m. to 4 p.m.
- Email supportline@alzheimerbc.org

ARE YOU A CAREGIVER?

The Alzheimer Society of B.C. also publishes *In Touch*, a bulletin for caregivers of people living with dementia or cognitive impairment.

To subscribe:

- Visit our website at alzbc.org/In-Touch-bulletin
- Call 604-681-6530 or toll-free 1-800-667-3742
- Email In-Touch@alzheimerbc.org



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CELEBRATING **35** YEARS

Alzheimer Society
BRITISH COLUMBIA

300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

Phone: 604-681-6530
Toll-free: 1-800-667-3742
Email: info@alzheimerbc.org
Website: www.alzheimerbc.org