



## THE POWER OF YOUR VOICE

Everyone has a role to play in being an advocate about dementia issues. Advocacy refers to the actions a person can take to create change.

The upcoming provincial election is a great time to advocate for dementia issues that are important to you on a larger platform. By speaking out, people with dementia can help others understand what it's like to live with the disease. This often encourages people to learn more about dementia and what they can do to help.

From time to time, you may also need to advocate for yourself. Self-advocacy simply refers to the things we do to improve a situation for ourselves or a family member, like seeking support from the Alzheimer Society of B.C.

In this issue of *Insight* we highlight the different ways people with dementia are great advocates for themselves and for others who are affected by dementia. Do you have questions about advocacy and dementia? Email us at [advocacy@alzheimerbc.org](mailto:advocacy@alzheimerbc.org), call 1-800-667-3742 or [download](#) the Advocacy Guide today.

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## A LETTER FROM GEORGE – SHARING MY DIAGNOSIS WITH OTHERS

Born and raised in Alberta, retired teacher George Glasier and his wife Sally now live near the small town of Mill Bay on Vancouver Island. After experiencing memory problems for a couple of years, George was diagnosed with Alzheimer’s disease at the age of 72. Shortly after, George and Sally decided to write a letter to their friends and family to let them know about his diagnosis. George shares some insights into his life and why it was important for him to write the letter.

### WHEN DID YOU FIRST MOVE TO B.C.?

After retiring from teaching, Sally and I wanted a place to garden – so we moved to a two acre property close to Mill Bay. It was a good decision. We have some of the best neighbours around and have enjoyed the past 19 years here in our paradise.

### HOW WOULD YOU DESCRIBE YOUR RELATIONSHIP WITH YOUR WIFE SALLY?

Sally and I have always had to be aware of each other’s needs and wants. I’m an outside person who enjoys fishing, hiking and overnight camping in the mountains. Sally is a people person and does not like getting dirt on her hands, so she does volunteer work in our area. We are each other’s best friend.

### HOW DID YOU BECOME CONNECTED WITH THE ALZHEIMER SOCIETY OF B.C.?

Our neurologist asked us if it was okay if he gave our name to the Society. We said yes and are glad that we did.

### WHY DID YOU DECIDE TO WRITE AND SHARE A LETTER ABOUT YOUR DIAGNOSIS WITH YOUR FAMILY AND FRIENDS?

I struggled for a few years with things like remembering someone’s name, where I put the hammer and whether there was gas in the van.



George with the truck he has had for over 35 years! His truck has moved furniture, wood, rocks, soil and all kinds of garden supplies for his family and others.

As the gap with my memory grew larger, we decided it was time to let folks know what was happening with my health. This was a good decision. Our daughters and their husbands have been an excellent support. We also have a very understanding church group, friends and relatives.

Life is a journey and we never know how that journey might play out.

[READ THE LETTER GEORGE WROTE TO HIS FAMILY AND FRIENDS ON PAGE 3](#)

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## GEORGE'S LETTER

Sally has been saying to me for a while to write you a letter, whenever I was comfortable in doing so. I wanted to also, but just never quite got it done. So, turn your back to the wind, look at the moon and stars (yes I know they are not out now but you have to do a little dreaming).

I am going to send some short notes to you which you may reply to if you would like to, but keep in mind that my mind is beginning to wear out in earthly terms.

Another way to make an explanation about things is that my brain is beginning to operate somewhat like the old trucks and tractors I grew up with in Coronation, Alberta in the mid-50s. It misses a spark now and then, and I am informed it will get worse, not better.

The name attached by the medical profession to my brain is known as Alzheimer's. Ongoing break down of the nervous system in the head will continue, meaning that as time goes by the brain will be less and less able to function in a normal way. Perhaps my brain will function well for a couple to six years, as the current wisdom by the medical folks was passed on to me, but who knows for sure what will really happen.

I am currently experiencing short-term memory loss which translates into: I may see you and recognize your features, but I cannot put a name to you. Actually, for a lot of you, I don't find a lot of difference – "you" all are still as cute as you were.

If I can ask a favour of you, please keep Sally in mind. She is doing very well but she does have her down times. God, I love that girl.

The only rough time I am having is seeing the tears in her eyes and wishing I could brush them away forever.

The best to you all.

– George



## TELLING PEOPLE ABOUT YOUR DIAGNOSIS

Each person reacts differently to the idea of telling people about their diagnosis of dementia. Some people want everyone to know, while others want to tell only a few people.

Knowing who to tell, what to tell, how and when can be challenging. Receiving one-on-one support from staff at your local resource centre or talking to others who have been affected by the disease may help you begin the conversations with people in your life.

Below we share some tips if you are considering sharing your diagnosis with others.

### WHO TO TELL

- Most people choose to tell the people who are closest to them first. A spouse or partner, children, other family members and close friends are examples of the people who may know you best. You would likely want these people to be aware of this change in your life, just as you would with any major illness.



### WHAT TO TELL

- Tell people as much as you are comfortable with.
- Let people know how you want to be treated.
- If you need support, ask for it.
- Let friends and family members know if you need some space.
- Encourage people to learn more about the disease.

### GET SUPPORT

- Whether you choose to tell people about your diagnosis, or whether you prefer to be more private, the Alzheimer Society of B.C. is here to support you.
- For more information connect with your [local resource centre](#) or call the First Link® Dementia Helpline at 1-800-936-6033.



## HOUSE RULES – PEOPLE WITH DEMENTIA SHARE WHAT’S IMPORTANT TO THEM

Over the years, many myths about dementia have emerged that add to the stigma associated with the disease. For example, sometimes people assume that a diagnosis of dementia means that the person can no longer participate in activities in a meaningful way.

This is just one of the myths that the Alzheimer Society of B.C. and people with dementia from across the province are working hard to dismiss.

The reality is that it's possible to live well with dementia. In their own way, people with dementia remain engaged, active and able to maintain meaningful relationships, even as the disease progresses.

At a recent Early Stage Support Group in Victoria, the group shared concerns that friends and family who are coming to visit for the first time in many years may not appreciate or understand that the person with dementia remains capable of making decisions and choices for themselves.

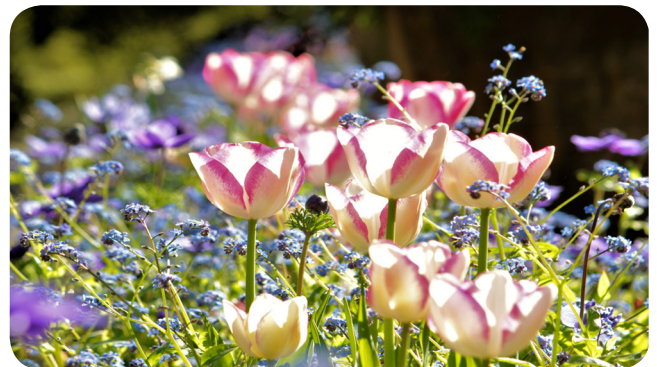
The group decided to create their own “House Rules” (to the right) as a fun way to share the feelings, thoughts and capabilities they have, while living with dementia.

“The support group members are amazing advocates for themselves and others with dementia,” shared the facilitators of the support group.

### House rules

I know that you care and you want to help, but please remember...

- I do not wish to only talk about my dementia. I prefer to have a normal conversation and want to hear the news you bring.
- I am still in charge of my life. I can and will make my own choices. I have feelings, preferences, likes and dislikes.
- Please ask me, don't tell me.
- I have dementia. Don't get upset if I don't remember everything you tell me.
- I am choosing what is important to me right now. I may do things differently, so it works for me. This might mean I do less baking, cooking, gardening or shopping. I am working within my new capacity.
- Wait until I ask for help even if it takes me a little longer to finish a task.
- Let's do something fun. Music is great!



## MAKING YOUR MEMORIES MATTER

The *Investors Group Walk for Alzheimer's* is British Columbia's biggest fundraiser for Alzheimer's disease and other dementias. It's a fun and family-friendly way to create new memories while sending a message of hope to the estimated 70,000 people living with dementia in B.C. and their families.

Every year, a person is honoured in each of the 22 communities that host a walk across the province. Marilyn Van Dongen is the 2017 *Walk* honouree for the city of Kamloops. We are pleased to share her story.

### ABOUT MARILYN

Marilyn is a very expressive, social and lively woman. She is a wife, mother, grandmother and friend. The fact that she is a Life Member of the Catholic Women's League of Canada (CWL), a national organization representing Catholic women across the country, is a true testament of her sincere commitment to something she believes in.

Marilyn was born and raised in New Westminster and met her husband Casey at midnight on New Year's Eve 1972. She had been working and made it to the dance just in time for the New Year's Eve kiss. In Marilyn's words, "He came for a kiss, and then came back for seconds. We have been married 43 years!" The couple's home grew to include four children, and now five grandchildren.

Raising four children and all the responsibilities of maintaining a home didn't stop Marilyn from becoming very involved with all aspects of the CWL, her passion and source of joy for many years.

Marilyn now attends a Society-led Early Stage Support Group. She appreciates the support she receives from that group because she feels like other members can relate to the feelings associated with the changes they are experiencing.



Marilyn and her husband Casey.

Regarding her diagnosis, Marilyn says, "It's important to let people know. Other people started noticing I wasn't myself anymore. Casey and I had "the talk" and he said, 'I love you even more and I will always be there for you.' I felt instant relief and so secure."

Join the Alzheimer Society of B.C. on Sunday, May 7, 2017 at one of 22 *Walks* taking place across the province.

Visit [www.walkforalzheimers.ca](http://www.walkforalzheimers.ca) to read your local honouree's story and to learn how you can participate, or call 1-800-667-3742.

## SHARE YOUR EXPERIENCES ABOUT HEALTH-CARE CONSENT!

In collaboration with the Alzheimer Society of B.C., the Canadian Centre for Elder Law has launched a new project that seeks to help people living with dementia better understand their right to consent to health-care treatment and medication. The project arose from a concern that people living with dementia, family members and the people who make decisions on their behalf are not always consulted on treatment options and medication.

Jim Mann a passionate advocate for the rights of people living with dementia and a member of the project's Advisory Committee, shares his thoughts on the importance of this work.

### WHY DO YOU THINK THIS PROJECT IS IMPORTANT?

I think the outcome of this project will force everyone to reflect on their perception of, and how they in fact see, a person living with dementia. Does that person have a voice? Should they have a voice?

We know there is a stigma around dementia and society will often fall into the trap of thinking once a person is diagnosed with the disease their voice is or should be lost. And nothing could be further from the truth!

### WHY DID YOU JOIN THE ADVISORY COMMITTEE?

The issue of consent is an extremely important and sensitive issue for every individual living with a diagnosis of dementia. Quite frankly, consent goes beyond health-care and I'm hoping to gain a broader understanding of consent in order to possibly influence policy change in other areas.

I was honoured to be asked to join this committee, ensuring the voice of a person living with Alzheimer's disease has a seat at the table, is involved in the committee's deliberations, and is influencing the discussion and outcome.



Dementia advocate, Jim Mann.

### SHARE YOUR EXPERIENCE

In April and May the Alzheimer Society of B.C. will be holding discussions in communities across B.C. to learn about people's experiences around consent to treatment and medication.

To find the date and time of the meeting in your community, please contact Lee Segall at 604-742-4938 (toll-free 1-800-667-3742) or email [lsegall@alzheimerbc.org](mailto:lsegall@alzheimerbc.org).

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- Subscribe online at [alzbc.org/insight-bulletin](http://alzbc.org/insight-bulletin)
- Call 604-681-6530 or toll-free 1-800-667-3742

## CONTRIBUTE

We welcome contributions, such as personal stories, photography or original poems, from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

- Email [Insight@alzheimerbc.org](mailto:Insight@alzheimerbc.org)
- Call 604-681-6530 or toll-free 1-800-667-3742
- Mail to the Alzheimer Society of B.C., care of *Insight*:  
300-828 West 8th Avenue  
Vancouver, B.C. V5Z 1E2

## 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](mailto:supportline@alzheimerbc.org)

## ARE YOU A CAREGIVER?

*Connections* is a quarterly print and digital publication produced by the Alzheimer Society of B.C.

To subscribe:

- Visit our website at [alzbc.org/connections-newsletter](http://alzbc.org/connections-newsletter)
- Call 604-681-6530 or toll-free 1-800-667-3742



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