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Finding support along the dementia journey

A diagnosis of Alzheimer's disease or another dementia can take you on a new path in life, leading to unique, challenging and unexpected life experiences. It can be helpful to know that you do not have to walk this path alone. There are people and resources in place that can offer practical help and emotional support if and when you need it. This issue of *Insight* highlights the importance of building a support team. People living with dementia also share how those in their support team help them continue to live well.

Living contently in Clearwater

Joyce, a physically active and spirited 73 year-old woman, was diagnosed with dementia a few years ago. Joyce lives in Clearwater, a rural community of 2,500 people located in the heart of British Columbia. Having lived in many cities across the United States and Canada, she eventually moved to Clearwater after purchasing a lodge which she ran for 14 years. After selling the lodge, Joyce decided to stay in Clearwater – a place she now calls home. In a recent conversation with the Alzheimer Society of B.C., Joyce shared some of her life experiences and offered insight into what it is like to live with dementia in a small rural community.

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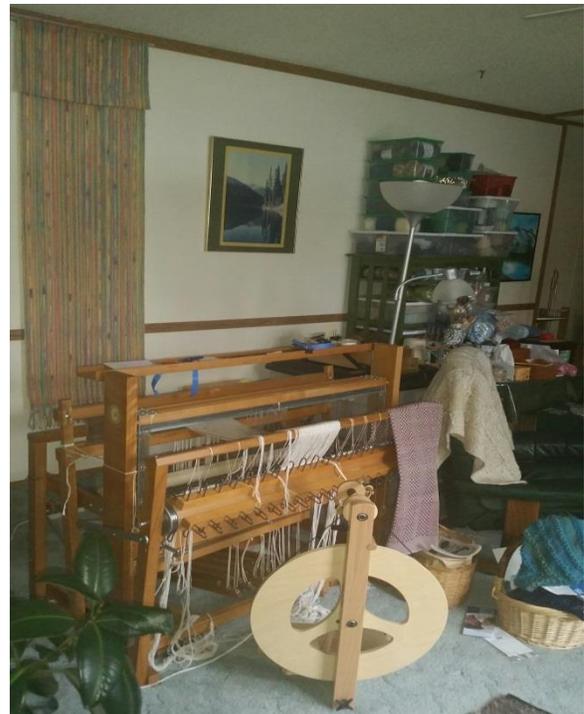
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I like living in a rural area very much. Clearwater is the longest place I have lived anywhere in my life. People here look out for each other and are community-minded. Over the years I have developed good friendships. There are also lots of things to do. I have friends who I join for activities like walking and cross-country skiing. It's also nice to be close to my daughter who lives nearby.

Along with her participation in various outdoor activities, Joyce keeps busy with her hobby of fiber arts – a style of art which uses textiles such as fabric and yarn.

When I was growing up my mom made all my clothes and got me into sewing – my mom also knitted. I carried on with it and I love it; I enjoy that you have to use your mind. Now I weave, spin, knit, and crochet and I create anything from rugs, blankets, sweaters, and scarves. Sometimes I sell the things I make, some I keep for myself, and some I give away.

There are a lot of people in the surrounding communities who weave. Every Thursday afternoon a woman in the area opens her door for people to come and participate in fiber arts, may it be weaving, knitting or spinning. It is really encouraging to be around all those people who are doing the thing that I like to do.



Joyce's loom and fiber artwork

Since her diagnosis of dementia, Joyce has made an effort to connect with the Alzheimer Society and attends a support group for people living with dementia. The support group nearest to her is located in the city of Kamloops – almost a 90 minute drive one-way from Clearwater.

I try to attend the monthly support group meetings in Kamloops. Going to the support group means I am with people who are in the same situation and it makes me feel a little better.

The others at the support group show me that they are just trying too and that helps me. We are all trying to keep our heads above water and carry on as best as we can and keep our brains as active as possible.

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Although Joyce hasn't experienced any difficulties living in a rural community since her diagnosis, she discussed some of the challenges she may encounter in the future.

I can't think of any challenges [of living in a rural area] right now, for the most part things are just kind of tripping along. However, it will be interesting to see what I do when it comes time for me not to drive anymore. I haven't really put a lot of thought into it because I am trying to focus on the positive of what is. My goal is to keep going.

Based on her experiences, Joyce offered some suggestions for people who have dementia and are living in a rural area.

One thing that comes to mind is getting involved with an Alzheimer Society support group as soon as people are diagnosed. The encouragement is helpful. I think it would be very easy to get into a depression and I think that it is tremendously uplifting for me to go to that meeting. It may become difficult for me to get there, but while I can, I definitely think it is worth doing.

Joyce also discussed some ways she has adapted to changes in her abilities and has been able to continue to live well with dementia.

The things that are affecting me the most right now are that I have to find ways to keep myself organized and not overdo it, but not stop doing the things that I like to do. I just have to keep going and contribute as much as I can in as many directions as I can because otherwise I will close myself up in a closet and that won't work. It's called 'get out there.'

I think it would be very easy to drop into a corner and stop doing the things that you loved to do. I don't succumb to 'oh I've got this problem and I can't do everything I used to do', I kind of ignore that and say, 'well, I can.'

Despite the changes that a diagnosis of dementia has brought to her life, Joyce continues to embody a positive spirit. "I don't think there is a point in anything else" says Joyce.



Sylvia Falls located in Well Gray Provincial Park, Clearwater, B.C.
Image courtesy of the District of Clearwater.

Building a support team

A support team is a group of people who you can partner with for help, care and connection throughout the dementia journey. Building your own network of helpers may support you to lead a more productive, active and engaged life. Consider establishing a plan to determine which people can help you with certain tasks. A plan will work better than trying to seek assistance in an emergency situation and can provide you – and those in your support team – with confidence that help will be there when you need it.

Who is part of my support team?

Family, friends, health care providers and community resources can all be a part of your support team. Start building your team by identifying a supporter you can trust – this person is often a family member or a close friend. Have a conversation with this person about the type of help you may need – such as cooking, housekeeping, and/or transportation. Below are examples of helpers you may consider asking to be a part of your support team.

Family and close friends: spouse, children, cousin, niece, nephew, neighbour – and more.

Health care providers: family physician, specialist, social worker, home support worker – and more.

Community Resources: Meals-on-Wheels, Alzheimer Society Resource Centre, HandyDART, local community centre – and more.

Your support team circle

To the right is an image of a support team circle. You are at the centre of the team, along with those closest to you. As you continue along the dementia journey your inner circle will expand as you tell others about your diagnosis. The additional circles will also grow as you become more connected with health care providers and community resources.

As you read this information, consider talking to your family and friends about the next steps you can take to become connected with resources in your community. Use the questions below to start the conversation.

- Who is a part of your current support team circle?
- How will your support team grow in the future?



Source: Alzheimer's Association.
Building a care team. www.alz.org.

People with dementia share their perspectives

Groups of people living with dementia around the province recently discussed the topic of support teams. Their comments and perspectives are shared below.



Who is a part of your support team?

- “My son who is just a phone-call away.”
- “My spouse.”
- “My children.”
- “Close friends.”
- “Alzheimer Society of B.C. staff.”
- “My family physician.”
- “Social workers.”
- “Educated communities [on dementia].”
- “The apartment manager.”
- “My caregiver.”
- “My church.”
- “Neighbours.”
- “Programs at the seniors’ centre.”
- “The tellers at the bank are very helpful.”
- “The Minds in Motion® program and the participants.”
- “Community nurses.”
- “Geriatricians, specialists, and neurologists – also a shout out to researchers.”
- “Previous work colleagues.”

What are the different ways those in your support team help you?

- “I meditate with peers.”
- “Understanding what I need and not making me ask.”
- “Moral support and being a buddy.”
- “We meet for great muffins and coffee and just to chat.”
- “My support team ensures I get out for a walk every day.”
- “Just being there.”



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- “Advocacy.”
- “They keep me busy and keep my mind active.”
- “Technological support (specifically helping with the TV when it is ‘acting up’).”
- “My medical team helped with medication and rehabilitation after experiencing a stroke.”
- “They make me laugh.”
- “If my friends or neighbours notice something, they are comfortable enough to talk to me about it. They are watchful.”
- “Being patient and considerate – for example, not telling me if I’ve already said something.”
- “Bringing me to places I need or want to be.”
- “By doing the banking, managing finances, and the legal stuff.”
- “By being proactive and learning about the illness so that they know more, can be more patient, and understand *me!*”

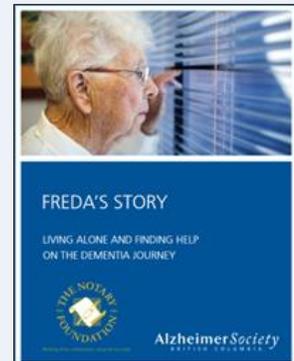
Freda’s Story: Living alone and finding help on the dementia journey

More seniors in B.C. live alone than ever before. Although many have family members or a “chosen family” of close and trusted friends who will help them if they experience health problems or need care, some live alone in the community without support from anyone.

Receiving a diagnosis of dementia is life-changing. Living alone adds unique challenges. The booklet “Freda’s Story” is about people with dementia who live independently without a close support network. It focuses on legal, financial and personal planning and is intended to help:

- People with dementia living alone without support.
- People living alone with some support.
- Long-distance caregivers.
- Community members who work with people who have dementia and live alone.

To view a copy of “Freda’s Story” visit, alzbc.org/Fredas_Story or call toll-free at 1-800-667-3742 to request a copy.



Poetry corner

A diagnosis of Alzheimer's disease or another dementia can generate thoughts, feelings and emotions you have not experienced before. Writing is a tool some people use to express their new outlook and sentiments. Consider whether writing anything from a journal entry, story, or a poem – like the one shared below – could be helpful to you.

I'm still me

By Norrms Mcnamara

Hello old friend, sit next to me,
I'm still the man I used to be,
Do you remember way back when?
We played with sticks and built a den?
And how we ran through cobbled streets,
Drinking Tizer and eating sweets,
The times we had without a care,
Times that I would like to share,
It's yesterday that troubles me,
I can't remember, do you see?
I can remember long ago,
But just last night it isn't so,
But even though my memory's fading,
Like winter leaves that are shading,
Recent thoughts inside my head,
Now gone forever, almost dead,
But look in my eyes and you will see,
I'm still the man I used to be,
Please old friend, sit next to me.



Norrms Mcnamara – an advocate for people living with dementia.

Contribute to Insight

Would you like to have your creative work included in the *Insight* bulletin?

Submit your:

- Poems or short stories
- Photographs, drawing or paintings
- Personal story
- Ideas for topics to be covered

See page 8 to learn more.

About Norrms

Norrms, who lives in Torbay, England, was diagnosed with Lewy body dementia at the age of 50. Since his diagnosis, Norrms has become a strong advocate for people with dementia. He helped organize the first Dementia Awareness Day in the U.K., and has co-founded the Torbay Dementia Action Alliance and the Purple Angel Dementia Awareness campaign. Most recently, Norrms is working on World Rock Against Dementia – a global music event taking place in March 2016 which aims to spread awareness of the disease. He has also written and published three books inspired by his experience living with dementia.

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 personal stories, photography or original poems?

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

- Email Insight@alzheimerbc.org
- Send mail to the address below, care of *Insight*.
300 - 828 West 8th Avenue
Vancouver, BC V5Z 1E2

All submissions 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.

Subscribe to Insight

Would you like to subscribe to receive your own copy of *Insight* in the mail or by e-mail at no charge? If you haven't already done so:

- Visit our **website** at alzbc.org/Insight-bulletin
- Call 604-681-6530 (toll-free 1-800-667-3742)
- 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 with dementia, their caregivers, family and friends, professionals and the general public.

- **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 persons with memory loss.

To subscribe:

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



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