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Finding and Accepting Help

In a previous job I learned a lot about the province of British Columbia, including that what happens in Vancouver or Kelowna, for example, does not necessarily represent the reality in Prince Rupert or Nakusp. With that in mind, when I signed on as Honourary Editor of *Insight*, I wanted to reach out to others with dementia around the province.

Complementary to that intent is the Alzheimer Society of B.C. - not only their resource centres located across the province, but their website (www.alzheimerbc.org), brochures and educational opportunities. Do you know what the Alzheimer Society offers? Are you taking advantage of these resources and information?

There are more than 70,000 people in B.C. with dementia and many of those are fairly recently diagnosed. The message for you is, "*you are not alone.*" To reinforce that, there are many support groups where you can meet others, gain insight and new friends. No support group in your area? The Society has the next best alternative with helpful information and services for you, the details of which are included in this edition of *Insight*.

I know how easy it is to retreat from activities after hearing the diagnosis, and avoid talking about what is going on. But that's not what we should be doing. *There is life after diagnosis and it is our journey of a lifetime.* When we travel, we research where it is we're going and avail ourselves of the services of a travel agent. For our dementia journey we should practice the same technique. There are a variety of services available in communities throughout B.C. Every one of us with dementia benefits from information gathering and from socializing. I encourage you to read this bulletin and take advantage of what the Alzheimer Society offers. And strap yourself in for your trip of a lifetime!



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I want this bulletin, *your* bulletin if you have a dementia like I have, to be a must-read whether you live in Abbotsford or Bella Coola. Hopefully the messages are uplifting, informative, helpful and encouraging. Remember the phrase that was so popular in the 60s: *today is the first day of the rest of your life.*



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.

Tips for accepting help Source: Alzheimer's Europe

- ✓ Open up to others.
- ✓ Accept help from others (even if you think you may be troubling them).
- ✓ Let people know how they could help you.
- ✓ Ask whenever something is unclear to you.
- ✓ Let people know if you are finding it difficult to understand or follow what they are saying.
- ✓ Remember that letting people help you can give them the chance to show you that they care.
- ✓ Avoid letting people completely take over a task if it is not necessary. Apart from being demoralizing for you, this can lead to a more rapid deterioration of an existing skill or ability.

Words of wisdom

"People with serious memory problems can go through an identity crisis as they come to terms with changes in their abilities. Over time I came to realize that I was the same person as before, but I now have a disability that I have to work around and I may need help from others in expressing my ideas and getting my needs met. Believing that you are the same person as before is important to having a full life."

— Early Stage Support Group member

"Don't just tell me what to do. Help me to make choices."

— Person living with dementia

"We need support and care just as all others do and our care partners are of enormous importance and we value them greatly. But we also need empowerment and independence."

— Person living with dementia

How do I know when I need assistance?

Sometimes it is hard to know when to ask for help and when to try to stick it out on your own. It may also be hard for others to know when and how to help you. One man with Alzheimer's says, "A good caregiver doesn't enforce help. They offer, but then back off until I ask."

One of the first steps in accepting help is to acknowledge that some of your symptoms may interfere with your ability to accomplish certain tasks. Others might observe changes in your abilities that you may not notice. For example, you may think you are managing your bills and finances just fine, but a family member notices that some of the bills are going unpaid or cheques are not being recorded accurately in the chequebook. It can be hard to accept that someone else is concerned about you when you don't think you have a problem.

The following signs indicate when accepting help may be practical, supportive, or necessary:

- You are repeatedly frustrated, angered, or discouraged when trying to complete a task. With help you could accomplish the task without wasting valuable energy.
- You are making mistakes that could be dangerous to yourself or others, such as errors in bank accounts or burning pots on the stove. With assistance, you may be able to accomplish these activities safely.
- You are held back from doing one thing because you are unable to accomplish another. For example, you don't have company over for dinner because you can't make the whole meal yourself, or you no longer enjoy a hobby because you can't remember all of the steps. With assistance, you may be able to continue these activities.
- There is a time constraint requiring quick action. For example, if you need to be out the door for a morning appointment, you may feel less pressure and can be there on time if you allow your care partner to make breakfast for you.



Sometimes it is strategic to accept help. You may think that you are losing control, but in fact you may be taking control of the situation by deciding to partner with someone else.

Adapted and reprinted with permission from: Snyder, Lisa (2010). *Living Your Best with Early-Stage Alzheimer's*. North Branch, MN: Sunrise River Press. www.sunriseriverpress.com
1-800-895-4585

Resources to look for in your community

Throughout the journey with dementia, people can benefit from support, information and services available in their communities, whether it's through family members, friends, their local health authority, or organizations such as the Alzheimer Society of B.C. Below are some examples of the types of resources to look for in your community.



Alzheimer Society of B.C.

The Alzheimer Society of B.C. has 19 resource centres located throughout the province. Through these resource centres, services are provided to many communities in the surrounding area. Connect with the Alzheimer Society of B.C. resource centre nearest you to find out about support groups, education programs and other services available in your community. More information about Alzheimer Society of B.C. programs can also be found on page 5 of this bulletin.

Local health authority

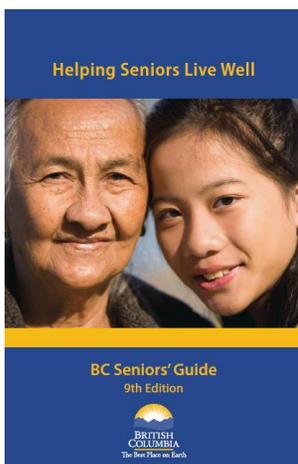
In B.C. there are five health authorities that govern, plan and coordinate services. For information on how to contact local health services, call Service BC at **1-800-663-7867** or visit the Ministry of Health's website at: <http://www.health.gov.bc.ca/socsec/>.

Community organizations

- Seniors centres offer a variety of programs, and many even offer meals and transportation. Check your local phone book for the centre nearest you.
- Consider having some of your meals delivered. Check your phone book for the number for Meals on Wheels or other meal services in your community.

Friends, family members and neighbours

- One person said, *"My next-door neighbour is a real help. He drops off my newspaper every day and sometimes even picks up one or two things from the shops. It's great to have someone close by that you can rely on."*



B.C. Seniors' Guide

This resource provides information about the many programs and services available to seniors throughout British Columbia. Available in English, French, Chinese and Punjabi, it is a good starting point when learning about what is offered in your community, and a great resource for helpful phone numbers and websites.

To get a copy of the Seniors' Guide:

- Call **1-800-663-7867**
- or visit www.seniorsbc.ca

Alzheimer Society of B.C. offers help across the province

For over 30 years, the Alzheimer Society of B.C. has played an important role in the lives of people with dementia, their families and care partners. The Society is dedicated to helping families build the knowledge, skills and confidence to live well with dementia. We offer several programs accessible to you no matter where you live in the province. The list below contains descriptions of services available throughout B.C. and information on how to access them.



Dementia Helpline

A province-wide information and support service for people with dementia, their caregivers, family members and friends. A trained, caring team will answer your call and provide information and support about living with dementia. Hours are Tuesday to Friday from 10 a.m. to 4 p.m. Call 1-800-936-6033 or 604-681-8651.

Support Groups

The Alzheimer Society offers support groups for people with dementia in many B.C. communities. Participating allows you to meet others who are on a similar journey, and can strengthen your ability to cope with the disease. To learn about support groups in your community, contact your local resource centre.

Website (www.alzheimerbc.org)

If you have access to the Internet, visit the Alzheimer Society of B.C.'s website at www.alzheimerbc.org. Here you will find information about dementia and tips for living well with the disease. You can also download past issues of *Insight* (located under "News and Events"). Check regularly for notices on upcoming educational opportunities in your area.

Minds in Motion™

A fitness and social program for people experiencing early memory loss due to Alzheimer's disease or a related dementia and a friend, family member or care partner. A certified fitness instructor conducts the fitness portion of the program, and a facilitator ensures participants are welcomed and involved in activities or just enjoying social time and light refreshments in a relaxed atmosphere. Currently available in Greater Victoria, North & Central Okanagan, Northern Interior & Skeena and Greater Vancouver. Contact your local resource centre for information.

Shaping the Journey: *living with dementia*®

A six-session education series designed for people experiencing the early symptoms of Alzheimer's disease or a related dementia, as well as a care partner, family member, or friend. It is for people who want to explore the journey ahead in a positive and supportive environment. To register for *Shaping the Journey*, contact your local Alzheimer Society of B.C. resource centre.

Note: Not all programs are available in every community. Check with your local resource centre.

In our own words

We asked people living with dementia a series of questions about their experiences with finding and accepting support and services in their homes and communities. Below are the responses we received.

1) Where do you turn to in order to get the support and services you need?

Alzheimer Society of B.C. support groups, family, friends, church groups, community classes at my local rec centre like swimming and aquafit, libraries, HandyDART, seniors centres, hiking group, informal coffee group at the mall, Minds in Motion™.

2) Was it difficult for you to accept the help you are now receiving?

“At first I was mad and frustrated. I didn’t want any help.”

“The help I receive from my husband has been gradually increasing, allowing me to ease into the changes and making it easier.”

“It was very difficult for me to lose my role as a caregiver, wife and homemaker. What am I if I’m not these things? I always did the cooking and I don’t like having to give it up.”

“The back-up of my friends makes me feel fantastic. When we get together to discuss my situation they make it like a party, and this helps keep me independent.”

3) What steps are you planning on taking to prepare for your future?

“Making a will, designating a Power of Attorney, doing a Representation Agreement and making funeral arrangements.”

“I have a file of all my important information, such as banking information.”

“I told family about my diagnosis early on in the disease.”

“Choosing a care facility ahead of time.”

4) Were there any challenges you faced while navigating the health care system?

“Getting medications covered by ADTI [Alzheimer’s Drug Therapy Initiative].”

“Sometimes you have to be aggressive with the system in order to get what you want.”

Having a camera for a memory

Submitted by Betty Kellogg

An almost 80 year-old woman, I have been carrying Alzheimer's around with me for several years. I have been carrying, also, my trusty little Canon "Power Shot" camera, which slips easily into my pocket, and comes close to being a simple "point and shoot" device, although it is capable of much greater achievements. It has recorded magnificent as well as gentle sunsets, family activities and festivities, amusing and handsome shots of our now 11 year-old beloved coal-black cat, our kayak journeys, wilderness scenes, wondrous clouds, whales up close, stray shots out our car window as we ride along to "somewhere", a pretty flower in the garden, as well as the glowing red globe of a tomato about to be plucked, interior views of our home, our children, grandchildren, friends...and on and on.

A key part of the process, for me, is to edit and print selected photos that are captioned with subject, date, and even sometimes the time of day, and insert them into albums. Fortunately my camera keeps track of dates and times, for I would be muddled without that capability. The results have become my memory, and a happy reminder of what my husband and I, and the rest of our family, have accomplished and enjoyed. As has been said, "a picture is worth a thousand words". In my case that is an understatement—it is my memory!

Some people may be able to deal with photos stored on a computer, but I enjoy snuggling down on an evening with an album in my lap. Having such a "memory machine" might help someone else, and I would recommend it highly as a simple tool.



General suggestions for living well with dementia

- Keep your sense of humour.
- Communicate your needs to your partner, friends and family, and ask for and accept help.
- Don't be ashamed – talk openly about your disease.
- Check out transportation resources in your own community, including organizations that offer volunteer drivers for medical appointments and grocery shopping.
- Stay engaged; for example, volunteer in your community.
- Attend a support group.
- Create a memory box and start writing or taping your life story – this is a good way to share with others what is meaningful to you and what you want them to know about you.

Source: *By Us For Us – Tips and Strategies*, Murray Alzheimer Research and Education Program, University of Waterloo.

Notes and Events

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.



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.

Health and Seniors Information Line

Offered by the Ministry of Health, this service is "one stop" location to obtain information on both health and non-health related federal and provincial government programs and services for British Columbian seniors.

Monday to Friday 8:30am - 4:30pm
 1-800-465-4911
 (Victoria 250-952-1742)

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@alzheimerbc.org

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

Healthlink 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

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 BRITISH COLUMBIA

#300 – 828 West 8th Avenue
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Tel: 604-681-6530

Toll-free: 1-800-667-3742

Fax: 604-669-6907

Email: info@alzheimerbc.org

Website: www.alzheimerbc.org