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Communication & Celebrating the Holidays

This being our Winter edition of *Insight*, let me first wish everyone a very happy holiday season and all the very best for the New Year. Imagine 2012! It seems like only yesterday we were all concerned about the impending doom of ringing in a new millennium.

For many of us, this season includes families and friends and get-togethers often involving more than just a couple of people. I don't know about you, but I don't do well around a lot of people, especially with the associated noise.

And that is where the theme of this issue comes in: communication.

If you find yourself in a situation where you feel overwhelmed because of the noise level or the number of people, quietly excuse yourself to a quiet room. Explain to your partner why you need to retreat, even for a few minutes. Perhaps this will be a new reality for you and your partner, so a bit of patience will be in order.

I remember my first time when I was overwhelmed with the number of people and the noise and had to take leave to a quiet area. Frankly, I didn't know what was happening because I used to like talking with others and networking in a group of people. Not then and definitely not now.

Now I know what to expect and my wife and I discuss what might happen, and we look out for each other. If I have to find a quiet space, I know where to go and she knows my leaving isn't a bad thing.

So please enjoy the season and remember to pace yourself. Relish the time with friends and family, as well as the quiet time to refresh.

One last point: participate in the **Investors Group Walk for Memories** in your community on Sunday, January 29th. Visit www.walkformemories.com for details.

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.

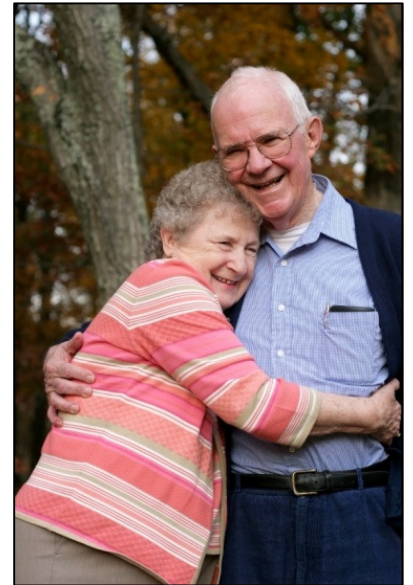


Communication: Challenges and Suggestions

Members of early-stage support groups across the province discussed the challenges they are experiencing with communication as a result of Alzheimer's disease or another dementia. They also discussed what caregivers, family members and friends can do to support people with dementia who may at times have difficulties with communication. Their perspectives and ideas are shared below.

Have you noticed any challenges with communication as a result of dementia?

- Sometimes I don't think before I talk.
- My husband is getting frustrated because he has to tell me things too often.
- I have difficulty following conversations in a group, so I simply stay quiet.
- I used to be a leader, but now I can't keep up.
- I'm struggling with words. I can see them in my mind and I know the word I want, but they're gone and I can't call them up. I'm reluctant to put myself in that position where I'm called on to say something and all of the sudden, I can't get the words out. I guess I'm struggling with my own acceptance of my diagnosis.



When communicating with you, what can others do that would be helpful?

- Have patience.
- Don't get upset.
- Remind me kindly.
- Don't nag.
- Take over if I lose my train of thought.
- They can be more clear about what they are talking about. It is not helpful when they talk too fast.
- Don't correct me – gently guide me.
- Not to be interrupted or have sentences finished...listeners must have patience..let me have my say.

What do you not find helpful?

- To not be acknowledged.
- When people get annoyed with me, or don't give me the time I need.
- Don't jump in too fast because I resent it. At the same time, give me the darn word if it takes me too long to remember.
- Don't remind me that I've forgotten something – it doesn't help.

Communicating with your Doctor

An individual who attended the Alzheimer Society of B.C.'s **Shaping the Journey: living with dementia™** program kindly shared the following tips for communicating and developing relationships with your doctor and other health care providers.



Preparing for a doctor's visit

- Book your appointment for the time of day when you are likely at your best.
- Write down any questions you have ahead of time.
- Consider taking a notebook or tape recorder to your appointment (ask for permission to make a recording).
- Ask a spouse, child or other supportive person to come with you.
- Your support person can help ensure that all of your questions are answered.

Communication tips

- Communication and a positive attitude are important.
- Speak freely with your doctor.
- Ask your doctor for explanations of anything you do not understand.
- Tell the doctor everything you are feeling.
- Be honest about your symptoms or situation.
- It is not uncommon to be angry, anxious or depressed.

Getting ongoing support

- Alzheimer's disease and other dementias are life-altering. Let your doctor know how dementia has affected your life.
- You shouldn't leave the doctor's office feeling that you don't have the answers to your questions.
- The Alzheimer Society of B.C. is an excellent resource to call upon in addition to the support and information you may be receiving from health care providers.
- There is comfort in seeing and meeting other people who are also living with dementia.
- It's good to talk about the disease.
- Your relationship with your doctor is important – make sure that it's working for you!

Holiday Traditions

We asked people who are living with dementia some questions about the holiday season. Below are the responses we received.



Does your family or friends have any special holiday traditions?

“Our family has many little traditions - one being a breakfast of mushrooms on toast on Christmas morning.”

“Most of our Christmas tree ornaments were handmade or brought from countries that we have travelled to in the past. They bring back a lot of good memories.”

What are you looking forward to this year?

“I am going away on a cruise.”

“I am looking forward to seeing my brother, nephews and nieces, and aunts and uncles as we do not see them very often.”

Are you worried about any challenges you may encounter during this holiday season?

“Recently I attended an event with a bunch of people who were all talking at the same time. Eventually, I gave up trying to participate because I just couldn’t do it. I find I’m reluctant to put myself in those social situations because it shakes up my confidence when I can’t do something that used to be so easy for me.”

“My grandchildren are always so excited to see me but I can’t keep up with them.”

“I enjoy going to local hockey games, but I can’t wander off like I used to because I get lost and then I start to panic. That affects my confidence when I panic – I used to be in control, but now I panic.”

Are you planning on adapting any of your holiday traditions?

“I will not participate in large family gatherings any more. I can’t do it. My sons are supportive – they get it and they’re so patient.”

“I find that I need to nap for 2 hours in the afternoon. Being around too many people can be exhausting.”

Living with Dementia: Holiday Tips

The holidays can be a stressful time of year for everyone. People living with dementia often find the holiday season draining on their energy levels and ability to concentrate. However, some people with dementia have found that by making a few adjustments and communicating their needs to family members and friends, they can continue to enjoy what the season has to offer. Here are some suggestions from people with dementia on adaptations that can make the holidays manageable and enjoyable.

Simplify things.

“I used to write a note in each holiday card, but that’s too hard now. This year, I’m writing one letter to everyone that I’ll make copies of and send out. I used to think they were less personal, but now I realize it’s a lot easier!”

Have smaller gatherings.

“My husband and I decided that I do better in smaller groups rather than the huge family gathering. We’re going to have a series of smaller events this year so we can spend special time with each section of our large family.”

Have a quiet space.

“I can easily feel overwhelmed at large family gatherings. In these cases, I will go to a bedroom or other quiet space to relax. It’s okay for those of us with dementia to feel the need to step away for a while and take some time for ourselves.”

Ask for help.

“I can’t manage holiday shopping anymore, so I asked my daughter to go with me. We wrote a list and did it all in one day. Couldn’t have done it without her!”

“I never ask for help. It’s just not in my nature. People will offer, but I never ask. In fact, living with this disease has really shown me that people are much better than I ever gave them credit for. They want to help, and they help without announcing it to everyone. They just do it quietly without recognition and expecting nothing in return.”

Focus on what’s important.

“Keep it simple and focus on what’s most important. Do something for someone less fortunate than you are. When you stop and think about it, there’s a lot to be grateful for.”



Sources:

Snyder, Lisa (2010). *Living your best with early-stage Alzheimer's*; Individual contributions from people living with dementia.

Notes and Events

THANK YOU!!!

Thanks to all who participated in the *Insight* reader survey. Your feedback and suggestions were truly valuable! We will be sharing a summary of our findings from the survey in an upcoming issue of *Insight*. Stay tuned!

DEMENTIA HELPLINE

1-800-936-6033

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



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.

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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*)

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Children and teens who have a parent or grandparent with dementia now have a website designed specifically for them. "*When Dementia is in the House*" has been developed to educate children living with someone who has dementia, with a focus on frontotemporal dementia. This website is based on research, as well as advice from other experienced adolescents.

Visit this new website at:

www.lifeandminds.ca/whendementiaisinthefhouse/