I Have A Voice!
By Jim Mann

Editor’s note: Jim Mann is a retired businessman and an active volunteer and Alzheimer’s advocate. He has been the recipient of numerous awards in Canada for his service to his community. Most recently, he was honored with the Governor General’s Caring Canadian Award for his efforts in raising awareness and reducing stigma around dementia.

I wear a lanyard (name-tag) with the Alzheimer Society’s card that reads: “Please be patient, I have Alzheimer’s disease.” I wear the lanyard to take control. If I get disoriented ordering a coffee, or if I am challenged at the counter trying to pay, the reason is clear, which hopefully lessens the clerk’s stress. It definitely lessens mine.

Some people—both with dementia and others—question why I wear the lanyard. It’s empowering. I wear it to engage people. If someone wants to talk to me about Alzheimer’s or has a question, ask me. Talk to me. Because, quite frankly, there isn’t enough of that happening around the subject of Alzheimer’s and related dementias. By not talking about it, dementia doesn’t go away. If we don’t ask questions about it, we won’t get answers. And the stigma won’t change. And the stereotypes will continue.

Let me give you an example. We meet for the first time. I introduce myself: “My name is Jim Mann. I live in the greater Vancouver area. I am 67 years old, and I have Alzheimer’s.” What do you see? Who do you see? What is your focus? Do you zero in on my Alzheimer’s as you look at me? Do you immediately think that my cognitive abilities are so limited that I couldn’t possibly have anything meaningful to say? Will you speak to Alice, my wife, to look for answers and ignore me? Do you even think I will be able to respond to you?

My mother had dementia and through that experience, I learned that we need to increase awareness of Alzheimer’s and related dementias. For example, not everyone is in their 90s and in the advanced stages of the disease. Unfortunately a lot of people in the field of medicine, personal care workers, and the public at large still think that to be the case. People need to be reminded of the early stages when ‘functioning’ and ‘capable’ are key words. An acquaintance of mine was told he has Alzheimer’s. The day before his diagnosis, he handled the money for his golf group of buddies. The day after, this responsibility was taken away from him. I recently heard how one family ignored their dad once he was diagnosed.
with Alzheimer's. They talked around him, over him, and about him in front of him.

You get the full-range from people - from being written off as soon as you're diagnosed to being challenged on the legitimacy of your diagnosis. Some will see me as a fully functioning person and will say I don't have Alzheimer's. However, I am routinely evaluated by a specialist affiliated with the Brain Research Centre at the University of British Columbia. I believe research projects are key to advancing therapies and diagnostic tools for people with Alzheimer's disease and other forms of dementia. Investment into research is critical to our struggle and offers us hope.

I am not content to sit on the sidelines, but this is a double-edged sword when you have dementia. Physically, I look good, but you don't see me disoriented. You don't see me asking for or needing assistance. You don't see me paying only with bills because often I can't determine the value of coins. You haven't seen me leave the stove on too many times. You don't feel my panic when I become lost at the grocery store or in my own neighbourhood. Dementia affects my daily life, especially my short-term memory. That's why I no longer drive. I recently purchased a watch with both a clock face and digital time so I wouldn't be confused by the numbers. Telling time is a problem for people living with dementia.

And what about family caregivers and others who are impacted? I don't know what I would do without the care and support of my wife. I can sound like I know what I'm talking about and speak convincingly on some things, but often, especially in company, I'm glad my wife is with me because I can be 100% incorrect. I'm certainly not always wrong though, and I feel confident in being an advocate about living with dementia. I have come to realize I have good days and I have bad days. I suppose the same can be said for all of us, except when I have a good day it means I get to exercise my independence, and when I have a bad day, when my mind is too muddled to do much on my own, it means I need support. For those around us, this is an ever-changing landscape of eggshells.

We can live positively and well after diagnosis. I have a voice – a legitimate voice – through which I can participate in life's daily routines and in the community. What do I mean? I write letters to the editor and they get published. I was a full voting member of the Alzheimer Society of Canada Board of Directors and was a board member at the Alzheimer Society of BC for the full six-year term. I serve as a member of the Leadership Group at the Alzheimer Society of British Columbia and am a former Honorary Editor of Insight their newsletter written for people with dementia. (Editor's note: See http://alzbc.org/Insight-bulletin to read and subscribe to this informative quarterly newsletter.)

I take my role seriously to make a contribution – to make a difference. I advocate to challenge peoples’ perceptions of dementia. It gives me a sense of purpose. It permits me to have and maintain a meaningful role in life – to be a full participant and not just an observer. And as for communicating, sometimes you can’t shut me up! I’m always ready to talk to an individual or a group. We’re not all victims. We have a life worth living. It may not be the life we would choose, but it’s still a life. So you know what? We’re going to make it ours and make it worthwhile. We’re going to make our mark in the world and be proud of who we are.
Dear friend,

We are a community of people living successfully with memory loss. We understand that you also have received a diagnosis of memory loss. We want to recognize your courage in finding out what is going on. It is normal to feel disbelief, anger, fear, and denial, but know that you are not alone. Our hearts go out to you.

You may want to hide your diagnosis. Many of us did too, but we have found that sharing what we are living with lightens the load and allows us to lessen stigma surrounding memory loss. We urge you not to hide. Connect with others who are living with memory loss, and encourage your family to get support. Acceptance is important. We are all in this together.

We have learned to live with our memory loss and still have productive lives with family and friends. We would like to give you hope that you too can live a full life. There will be obstacles to come, but you have an opportunity to give back to your community and yourself, and to experience beauty, happiness, and kindness.

Sincerely,

Walt, Mark, Bob, Sarah, Roger, Ron, Helene, Rick, and Midge

Members of the Gathering Place
Early Stage Memory Loss Enrichment Program
Greenwood Senior Center, Seattle, WA
Awakening and Maintaining Your Five Senses

Part One: SIGHT

We are all familiar with the five senses – sight, hearing, smell, taste, and touch. What may be less known, however, is the importance of the senses in coping with dementia and the ways in which dementia can affect the senses. In the next five issues of Perspectives, we will explore each of the senses and the steps you can take to make sure you are keeping them as finely tuned as possible. We begin with sight.

Vision changes may begin in childhood, but become more common as we age. Many people need better lighting and color contrast in order to read or identify objects, or may need glasses or other corrective measures to see clearly. But sight also involves the brain’s ability to interpret or make sense of what we see. With dementia, you may find that although your vision is sharp, you might not always recognize what you see. This puzzling symptom is called visual agnosia. Bea describes her experience: “Sometimes what I’m looking for will be lying right in front of me and I won’t see it. I don’t always misplace things; they’re right there, but I just don’t recognize them.”

Anyone can have a similar experience occasionally, but the problem can be more frequent for people with dementia and can sometimes include difficulty in recognizing people, too. Visual hallucinations – seeing things that aren’t there – or misinterpreting objects can also occur, and is often more common in Lewy Body dementia. For example a shadow on a wall could look like a person. Although these experiences can be upsetting, they are often temporary, are not uncommon, and can occur early on in dementia.

Some people experience other visual challenges. Three-dimensional objects may look flat so that a dark carpet looks like a hole in the floor. Or it may be hard to see cream-colored food on a white plate. Sometimes it is difficult to judge distance or depth. You may reach for an object and find that your hand lands inches away from it. The height of stairs or a sidewalk curb may be hard to determine and require greater caution when taking your steps. Tell your loved ones and your doctor about any changes in your visual abilities. You are certainly not alone if you have any of these experiences. Some tips for helping to maximize your sense of sight include:

• Use a walking stick to help better judge distance and depth while on outings.
• Have glasses or contact lens prescriptions reviewed annually and get checked for cataracts that can cloud vision.
• Use good quality sunglasses to reduce glare when outdoors.
• Make sure you have adequate indoor and outdoor lighting.
• Use color contrast to help identify objects and spaces. For example place yellow strips on the edges of stairs.
• Declutter as much as possible to make it easier to find and identify objects.
• Exercise your sight. Look at a work of art in a museum or in a book. Describe in detail what you see.
• Try to look for beauty in each day!

Explore your sense of sight by going outdoors and identifying all of the colors you see. You can stand in one place or take a walk and watch for different colors along the way.

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RESEARCH UPDATES
Alzheimer’s Disease Progress Report Available Online

A new online report provides an easy-to-read overview of recent National Institutes of Health-funded research advances and initiatives in Alzheimer’s disease (AD) and related dementias. Issued by the National Institute on Aging the annual report — 2014-2015 Alzheimer’s Disease Progress Report: Advancing Research Toward a Cure — discusses research momentum, describes research opportunities, and summarizes scientific advances in areas including:

- Understanding the biology of AD and related disorders
- Identifying genetic influences on risk for late-onset AD, the most common form
- Detecting the earliest Alzheimer’s-related brain changes, including further development of biomarkers to track the onset and progression of AD
- Understanding gender and racial differences in the impact of AD
- Stepping up research to enable the design and testing of new drugs
- Testing in clinical trials potential new therapies to prevent, delay, or treat AD
- Finding new ways to support caregivers

The report also includes searchable tables of NIA-funded clinical trials that are testing promising interventions for AD, mild cognitive impairment, age-related cognitive decline, and other dementia-related symptoms. To read the report, see: http://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/introduction

Evaluating the Effectiveness of Brain Imaging in Diagnosis

The Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study will assess the impact of amyloid positron emission tomography (PET) imaging on outcomes in more than 18,000 Medicare beneficiaries across the United States who have mild cognitive impairment (MCI) or dementia of uncertain origin. Researchers seek to demonstrate that amyloid PET brain imaging can help clinicians more effectively and accurately diagnose the cause of cognitive impairment (changes in thinking abilities), provide the most appropriate treatments and recommendations, and improve health outcomes. In addition to assessing the impact of amyloid PET on management of patients with mild cognitive impairment or dementia of uncertain cause, the study will compare medical outcomes for study participants with matched patients not in the study. It is anticipated that the evidence obtained by the IDEAS Study will support insurance reimbursement of amyloid imaging by Medicare and other third-party payers.

The IDEAS Study is being conducted by a team led by Dr. Gil Rabinovici, neurologist and professor at the University of California, San Francisco. These dementia specialists nationwide will team with trained radiologists and nuclear medicine physicians at PET facilities to order, conduct, and interpret the amyloid PET images. A physician must refer you for enrollment in this study.

For more information concerning eligibility and the study site locations, see: http://www.ideas-study.org
To Whom I May Concern
An Innovative Theatre Project Gives Voice to People with Alzheimer’s or a Related Disorder

By Maureen Matthews

To Whom I May Concern® is an interactive theater program designed to give voice to people who have recently been diagnosed with a progressive brain illness such as Alzheimer’s disease. Using their own words and scripting, these individuals share their stories and experiences with audiences made up of family members, peers, friends, care partners, and professionals. Working with a professional moderator and writer, in groups online or in person, clients are able to create their own narrative, expressing their fear, anger, frustration, hope and determination—often with humor and love.

Ten years ago the first participants in To Whom I May Concern took the stage in New York City and shared their experience of living with dementia. Reading from a script based on the stories that the men and women themselves had shared in their Alzheimer’s Support Group, they captured the attention and empathy of the audience that filled the auditorium. A standing ovation followed by a lively Talkback session ended the performance. It was only the beginning of a powerful project that has changed the conversation about dementia for many people.

Since that first performance in 2006, many more people with dementia have taken to the stage in churches, senior centers, assisted living residences, retreat centers, and conference rooms with audiences of 25 to over 600 people. We have also begun meeting with people online using video conferencing software and have “staged” their stories in webinars and, most recently, on a DVD called This Is My Voice, accompanied by a Discussion Guide to assist community groups in developing their discussions.

And what difference has To Whom I May Concern made? Lots! For the individuals diagnosed, it is an experience of empowerment that comes when they feel that people are listening:

“To Whom I May Concern really helped my confidence, it helped me explain what was going on in my mind to my family, it gave them, my family, an insight I could never have achieved on my own.”
–Chris Roberts (Wales, United Kingdom)

“A diagnosis of dementia can be very lonely. To Whom I May Concern gives people with dementia a voice and a sense of being part of something bigger—a chance to belong during a time when one feels adrift. Even though we have our struggles, the members of our group are still friends two years after our performance.”
–Mary (Salt Lake City, Utah)

“When I first read the lines of To Whom I May Concern, it brought tears to my eyes. I was so moved by it... It tells a story from the eyes of people who have been diagnosed with the disease. It lends us a voice.”
–Scott Russell (Connecticut)

For the audience, the opportunity to hear about living with dementia from people
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To Whom I May Concern
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diagnosed can be perspective-changing. As one attendee stated: “This is the first time I have heard people speak so freely and explain what it’s like [to live with dementia]. They have changed my attitude... Thank you!”

The theatre performances and message can have a powerful impact on students and professionals, as well. A social worker in tears once apologized to the performers for all the times she had been insensitive to the people in her care. The husband of one of the performers stood up and told her how proud he was of her. A doctor responded: “Doctors need to see this!” After a different performance before an audience of college students, a young woman who attended shared a comment with the performers:

“Thank you for your courage to share your experience. I’m about to go home for Thanksgiving break and I will see my grandmother. Now I will know to go a bit slower in our conversation at the table so that she will stay included.”

People living with dementia are often silenced long before the brain cells die because of the stigma and sidelinging that comes with the diagnosis. Participating in To Whom I May Concern helps them find their voice and continue living the next chapter of their lives.

What’s next? A Facilitator Training Program will soon be available so that more communities can create performances of To Whom I May Concern. For more information about how to bring this theatre program to your own community, I hope you will visit our website at http://www.towhomimayconcern.info/ or “like” us on Facebook to stay in touch!

Question and Answer

With the warmer weather coming, I know it would be good to get out more, but I don’t really know what to do. Do you have any suggestions?

Sometimes you don’t have to travel far from home to find a new adventure or a stimulating activity. One man and his wife are exploring their own community: “Even though we’ve both lived in our city for many years, my wife and I have decided to try to visit a new site in the area each week. It’s good for both of us. It’s amazing how many parks, little museums, exhibits, and odd off-the-beaten path places there are to see. We’re having lots of fun.” Part of the couple’s enjoyment is in reading the local newspaper each day to look for these new places or events. Although their outing is usually once a week, each day they discuss new possibilities and enjoy making plans.

If you live in a small town or rural area, don’t be discouraged by seemingly limited opportunities. You can walk the same walk or visit the same park, but create a different experience. Count the number of birds you see or make a point to smell and identify the names of flowers or other blooming plants. Visit a local nursery or farmer’s market to take in the colors and smells. Take a camera, look at life through the lens, and take some photos! Warm weather may bring outdoor concerts to your area. Open your ears to some new sounds or simply take a walk or sit outside and pay special attention to all of the different sounds you hear. Spring provides countless ways to engage your senses. Let us hear from you about your own ideas!

Some content for this column is from the book Living Your Best with Early-Stage Alzheimer’s. Available in bookstores or online at amazon.com.
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