

It's not just their disease - it is ours too

By **DEBORAH BARKER**
Executive Director Alzheimer Society of Grey-Bruce

This year, the Alzheimer Society of Grey-Bruce is recognizing 30 years of service to our community. During those 30 years we have provided support and counselling for thousands of persons with dementia and for their caregivers.

We have played, and we continue to play a vital role in the lives of the growing numbers of individuals we support.

Each year, 25,000 Canadians hear the words, 'you have dementia.' But dementia is more than just numbers. Friends, families and members of our communities all experience the personal and social impact of dementia. For our health-care system and economy this means higher demand for services and soaring costs. It's not just their disease. It's ours too.

That's why the Alzheimer Society of Grey-Bruce is pleased to join Alzheimer Societies across Canada in asking Canadians to be **#InItForAlz** and support the programs and services that are offered to affected individuals, their families and their caregivers.

Through this campaign, the Alzheimer Society also hopes to change the conversation about a disease that continues to be shrouded in silence.

Dementia doesn't discriminate and can affect anyone. It's one of the fastest-growing diseases of our time, but still has no cure or effective treatments. It can only be beat if



everyone takes action.

The gratitude expressed by our clients is a reflection of the profound effect that providing hope, support and

relief has for them.

The difficult news is that the number of people affected is growing at such a significant rate that it challenges our ability to keep up. Over the last two years, our active client list increased 24% to more than 1,100 people, and our education and training services increased 36% to 2,600 persons.

Last year we participated in a yearlong study funded through the Ontario Brain Institute. The results were significant. Our

clients reported we helped them increase their understanding of dementia, increased their skills and abilities to cope, assisted them in times of need and helped them access other resources in the community.

We need to continue to raise awareness and understanding to alleviate the stigma of the disease, And we need to encourage those affected to seek early diagnosis and support in order to maintain the highest quality of life possible through the course of the disease.

You, too, can be **#InItForAlz** and make a difference right from your computer.

Visit our website www.alzheimer.ca/greybruce to learn more and to read the personal stories of other Canadians impacted by dementia. You can also use the hashtag **#InItForAlz** to spread the word that "it's not just their disease. It's ours too."

Alzheimer's or dementia – what is the difference?

A common question we hear at the Alzheimer Society is one that involves the confusion over Alzheimer's disease and dementia. Aren't they the same? Is one worse than the other? What is the difference?



In actuality, dementia isn't a disease at all but an umbrella term of symptoms that describe a variety of brain disorders involving memory loss and behavioural changes.

Alzheimer's disease is the most common of these disorders and according to the Alzheimer Society Canada, accounts for almost 65% of all dementias in Canada. There are other types of dementia, including (but not limited to) Vascular dementia, Lewy body dementia and Frontotemporal dementia that impairs brain function and associated behavior.

Dementia is NOT a normal part of aging. That said the biggest contributing factor in Alzheimer's disease and other dementias is aging.

The reason for those contrasting but similar sounding

statements is that with age comes a higher incidence of risk factors. These risk factors, which include high blood pressure, stress and obesity, are implicated as contributors to the presence of dementia.

Like dementia, these risk factors also shouldn't be considered as a normal part of aging. All of which speaks to the current thinking regarding dementia prevention and brain health where the concept of an overall healthy lifestyle with active exercise, socialization, diet and intellectual stimulation can play an important role in staving off or delaying the onset of dementia as well as providing a richer and healthier life.

The other reality of dementia is that it is a multi-victim type of illness. It not only changes the life and livelihood of the person

afflicted, it also profoundly affects others around that person. The circle of influence that dementia radiates includes family, care partners (likely family members), friends and work colleagues (depending on age of onset).

All will be affected by the disease, some to a lesser extent and others in a way that could be easily described as all consuming. The theme for the 2017 Alzheimer's awareness campaign captures this concept in fewer than ten words. **It's not just their disease. It's ours too.**

At the Alzheimer Society, we are seeing more awareness and openness about the disease but it isn't enough. There needs to be less stigma associated with it. With a willingness to face the realities of dementia and not run from it, comes hope. More hope than ever before.

Yes, we are still searching for the basic answers but over the last twenty-five years we have seen important developments in support programs, services, clinical care and research.

WALK FOR ALZHEIMER'S
MAKE MEMORIES MATTER



Walk for Alzheimer's May 13

The Alzheimer Society of Grey-Bruce will be holding our second annual Walk for Alzheimer's this May.

Supporters are encouraged to register online either as an individual walker or as part of a team.

We will be holding two Walks simultaneously, at Kelso Beach Park in Owen Sound and at Sulphur Spring Conservation area south of Hanover.

Registration at both locations opens at 9 a.m. and the walks officially begin at 10.

Last year was our first outdoor Spring walk and the results were fabulous – Grey-Bruce was one of the top regions in Ontario receiving more donations than all but five societies!

Please mark your calendar for:
Saturday May 13, 2017
Owen Sound and Hanover
Online registration is now open at:
www.walkforalzheimers.ca

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We spoke - the Senate listened

In 2012, Mary Beth Wighton of Southampton was diagnosed with Frontotemporal Lobe Dementia at the age of 45. Since her diagnosis, Mary Beth and her family have dedicated themselves to living well with dementia and to advocating for others with the disease.



**By: Mary Beth Wighton
Person With Dementia**

There are few times in the average Canadian's life where the opportunity to influence a nation presents itself. I am one of the fortunate few to be able to capitalize on such an opportunity. In May, 2016 the Ontario Dementia Advisory Group (ODAG) had been invited to Ottawa to present before the Standing Senate Committee on Social Affairs, Science and Technology.

As people living with dementia we were to be witnesses for the Senate's study on dementia in Canadian society. Using video conferencing technology I was presenting from my home in Southampton while our other three board members: Phyllis Fehr, Bill Heibin and Bea Kraayenhof were seated in the Senate room in Ottawa.

ODAG considered it a victory just to be in front of the Senate. We had worked hard to get there. We pushed for our rights as Canadian citizens with disabilities to obtain concessions which allowed us to be better presenters.

In my speech I stated a very

important fact: "My story is like most other people living with dementia. It is our desire to live life fully and utilize our remaining skills that help us remain strong. We reject the notion of going home to die. The time between diagnosis and end stage dementia can be many years. In the meantime, we have the ability to live life well."

After ODAG finished its presentation, we congratulated ourselves, partners and supporters. We, Canadians with the true experience of living with dementia, had done our work, now it was time for the Senate to do theirs. The question was, did the Senate hear us?

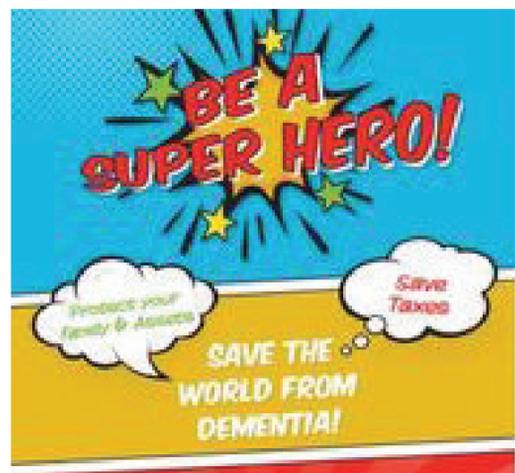
The answer came this past November. In an extensive report release titled "Dementia in Canada: A National Strategy for Dementia-Friendly Communities. It stated "A fully funded National Dementia Strategy is urgently needed to support caregivers, research efforts and Canadians living with dementia." Within the report, there is a chapter called "The Patient Perspective." My answer to the question on if we were effective was answered: "Of all the expert testimony offered

throughout this study, none was more compelling than that which was given by members of the Ontario Dementia Advisory Group.."

We had done it! Four average Canadians living with dementia had managed to communicate our perspective. The Senate had not only listened but truly embraced our words and did their best to make sure all of Canada also heard us.

I felt like a superstar as congratulations poured in. I'm so proud of ODAG and our very important partners. This moment has negated the many times when I have shouted out in rage and despair. It is the moment that I will keep near and dear to my heart and pull out when I need to remind myself that I, a person living with dementia, had made a difference.

The Ontario Dementia Advisory Group (ODAG) is a group of people living with dementia. Formed in 2014, ODAG's mandate is to influence policies, practices and people to ensure that people living with dementia are included in every decision that affects their lives. For more information about ODAG visit their website at www.odag.ca. If you are a person with dementia, ODAG invites you to become a member. For more information, contact the group by email: ontariodementia@gmail.com



Be a superhero Leave a legacy

Preparing your Will is not a subject most people talk about easily. We certainly don't wake up in the morning thinking 'Ah yes, today is the day to confront my mortality and get that document done!'

We avoid, ignore and put off to another day. More than 50% of Canadians do not have a Will.

Even among people who have already made a Will, many do not have it professionally reviewed every few years to make sure it reflects current tax and family law.

The only way to ensure that your assets - the things that you have worked hard all your life to acquire - will be passed on in a timely, tax-effective manner, according to your wishes, is to have a valid, up-to-date Will.

What does this have to do with being a Superhero? Completing your Will and Powers of Attorney takes care of your family, protects your assets and can support causes that are meaningful to you.

In fact charitable bequests to registered charitable organizations like the Alzheimer Society of Grey-Bruce can help reduce taxes after death.

Having the courage to protect what's important, put the needs of others first and make the world a better place - now that sounds like a Superhero.

Making a Will and planning your estate is important for everyone, not just the wealthy. Dying without a proper estate plan in place may leave your family with needless tax and legal problems, at an extremely stressful time. What's more, your property may not be distributed as you intended. Having an up-to-date estate plan with a valid Will is essential to ensure your wishes are carried out.

Consequences of not having a written Will

1. Your savings, investments and property will be divided according to provincial law, allowing the province to decide the distribution of your estate for you.
2. You will have no say in who benefits from your lifetime of effort. Provincial law will determine who your heirs will be.
3. Your estate's assets may be depleted by taxes and unnecessary administration costs.
4. The settlement process will likely be drawn out and your family could undergo financial stress.
5. You will not have the opportunity to express your choice of a guardian for your young children.
6. You will not have a choice of Executor/ Trustees, the individual or institution who will act on your behalf and carry out your wishes.
7. There can be no donations or gifts to your favourite charitable organizations.
8. And finally, if you do not have a spouse or any next of kin, the province will take all of your estate into its own treasury.

As you consider making or updating your Will, always seek professional advice to ensure your financial goals are considered, your tax situation reviewed and your charitable giving tailored to your circumstances.

Caregivers: Are You Burning Out?

Caregiving is often physically and emotionally stressful. In an effort to provide the best care possible, you might put your loved one's needs before your own. In turn, you could develop feelings of sadness, anger and loneliness. Sometimes these emotions can trigger depression. It is not unusual for care partners to develop depression as a result of the constant demands placed on them while providing care. In an effort to provide the best care possible for their loved one, caregivers often sacrifice their own emotional and physical needs, which can take a heavy toll - even on the most resilient person.

Here are some tips to prevent burnout.

- **Ask for help:** Is there another family member or a friend you can ask to be more involved. You may also consider seeking out respite services or caregiver support groups. The Alzheimer Society offers caregiver support groups in several communities. Visit our website www.alzheimer.ca/greybruce for more information.
- **Remember other relationships:** Showing loved ones and friends you care about them can give you strength and hope, it's important to make time for all those you care about and care about you.
- **Start a journal:** You may have

ditched your childhood diary long ago, but keeping a journal can help you gain control of your emotions and improve your mental health.

- **'You' time:** Taking time for yourself every day, even just a few minutes, is one way to help you recharge. Reducing your stress will make you a better care partner.
- **Stay positive:** Despite the endless pressures placed upon you, caregiving allows you to make a positive difference in your loved one's life. It's good for your happiness and health to find ways to stay positive. At the end of the day, it's about believing in the power of good, not bad.

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