

Soci t  Alzheimer Society

CHATHAM - KENT

VOLUME IV, ISSUE I

WINTER 2013

SPECIAL POINTS OF INTEREST:

- Let's talk about dementia.
- Get Involved & help raise money
- Need Study Participants
- Keep both Mind & Body Active

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See me, not my disease.

Imagine a close friend tells you she has dementia. Would you avoid her for fear of being embarrassed by what she might say or do? If you answered yes, you're not alone. According to a recent poll by Alzheimer's Disease International, 40% of people with dementia reported they had been avoided or treated differently after diagnosis. It's no surprise, then, that one in four respondents cited stigma as a reason to conceal their diagnosis.

That's why, this January during Alzheimer Awareness Month, the Alzheimer Society is launching a nation-wide campaign called "**See me, not my disease. Let's talk about dementia.**" The goal of the campaign is to address misinformation about the disease, shift attitudes and make it easier to talk more openly and honestly.

Stereotypes and misinformation are what prevent people with dementia from getting the help they need and stop others from taking the disease seriously. Stereotypes foster feelings of shame, rejection and embarrassment in people living with the disease—at home, at work and in the community. This fear of exclusion or being treated differently must be overcome because accessing support, resources and information early in the disease can positively affect the experience of living with dementia for those diagnosed and their families. Dementia is more than having the occasional 'senior

moment' or losing your keys. The truth is it's a progressive degenerative brain disorder that affects each person differently. It's fatal and there is no cure. Today, 747,000 Canadians have dementia. While dementia can affect people as young as 40 years of age, the risk doubles every five years after 65.

Dementia does not define the person. People with dementia are still people with unique abilities and strengths who deserve to be treated with respect and dignity. A diagnosis of dementia does not immediately require a person to give up their job or change their daily routine. In fact growing evidence shows that involving people with dementia in meaningful activities that speak to their strengths helps to slow the progression of the disease and will improve their well-being. Seeing the person and not their disease helps us to focus on what they can do rather than what they can't do.

He's having a senior's moment. She's lost her marbles. I forgot, it must be Alzheimer's. Statements like this are hurtful and perpetuate negative attitudes towards people with dementia and their families. We don't tolerate racial jokes, yet dementia-related jokes are common and trivialize the condition.

It's time we start looking at this disease differently. It's time to

change the conversation - and it starts with you. Talking about dementia openly and honestly helps to dispel inaccurate information, change attitudes and promote a better understanding of the disease. You can be part of the solution by participating in our test-your-attitude quiz and learning the facts. To take this online challenge visit www.alzheimer.ca/letstalkaboutdementia

- Learn the facts about dementia and help dispel inaccurate information and change society's attitudes towards people with the disease.
- Maintain relationships with people with dementia at home, in the community or at work, especially as the disease progresses.
- Share your story. If you or someone in your family has dementia, speak up. Your example could help someone else.
- Volunteer at your local Alzheimer Society to raise awareness or participate in an event.
- Invest in research to find the causes and a cure and better treatments.
- Raise your voice and tell our government to make dementia care a priority.

Only by understanding the disease and talking more openly about it, can we face our own fears and support individuals living with dementia.

2013 WALK FOR MEMORIES Alzheimer Society



**Join
us for the
Walk for
Memories on
Saturday,
January 26,
2013
Downtown
Chatham
Centre
(9:30 am -
12 noon)**

REMEMBER WHERE THE MONEY GOES

Every year, families and friends give 100 million hours of unpaid loving care and support for people with dementia. But by 2020, they will spend 140 million hours, an increase of 40% from today. The toll on their own health is severe. Every dollar you raise will help support the caregivers and the people they care about who are living with Alzheimer's disease and other dementias. All money raised through this Walk will remain in Chatham-Kent for our programs and services.

Activities include:

- A live band (The PUBCRAWLERS)
- Fun brain games and challenges
- A children's area
- A Fitness Zone for everyone presented by Goodlife Fitness
- Incentives and Door Prizes

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Day Program Christmas Party



Here's how to get involved:

ONLINE: Go to www.walkformemories.ca to register for our Walk. Set up your personal page and ask your family and friends to visit your page and support your Walk.

ON PAPER: Phone or visit our office to receive a pledge form (519-352-1043). Carry this form with you and invite everyone you meet to support your Walk.

TEAM UP: Have fun and raise even more money by asking friends, family and colleagues to form a team and raise money together.

MAKE A DONATION: If you are unable to attend the event, you can still help by making a donation at: www.walkformemories.ca.

For more information please call: 519-352-1043 or www.alzheimerchathamkent.ca



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Dementia with Lewy Bodies: A New 6 Month Study

Dementia with Lewy Bodies (DLB) is a neurodegenerative condition of the brain and is the second most common cause of dementia after Alzheimer Disease (AD). It may occur alone or together with AD. In 2008 it was estimated that about 110,000 Canadians were suffering from DLB with an annual cost of \$3.3 billion (Alzheimer Society of Canada). The history obtained from the person or family members is important to make the diagnosis and help differentiate DLB from primary Parkinson's Disease (PPD). The features necessary to make a diagnosis were refined and published in 2005 (Neurology 65;1863-1872). Progressive decline in cognitive abilities sufficient to interfere with normal social and occupational activities is the central feature necessary to make the diagnosis of dementia. Memory impairment may not be a prominent feature early on, but becomes more evident as the disease progresses.

There are three core features, two of which should be present to make a diagnosis of DLB. Seeing clear images of people that are not there (visual hallucinations) occurring during the daytime is one of the more obvious core features. Features of "Parkinsonism" such as an expressionless face, slowed walking with little arm swing and a stooped posture is also a core feature. Fluctuations in attention and alertness from being very alert to being quite drowsy in a very short period of time can be a more difficult feature to obtain on history from a relative. Other features which may be suggestive of DLB are new changes in sleep behavior with marked restlessness. People with DLB who are given major tranquilizers (neuroleptic drugs) for the visual hallucinations may experience an adverse response and develop marked symptoms of Parkinsonism and become sedated.

Besides the history and a detailed neurological examination, scans of the brain may help confirm the clinical diagnosis. A SPECT scan may show reduced activity at the back of the brain (occipital region). The symptoms of DLB often respond for a time to the cognitive enhancing medications: Rivastigmine, donepezil and galantamine (also known as Exelon, Aricept and Reminyl respectively).

A new clinical research project to better understand how to diagnose and treat DLB with the three cognitive medications will begin in 2013 at St. Joseph's Health Care, Parkwood Hospital. This will be the first research project under the new Centre for Cognitive Vitality. The Cognitive Neurology clinics from St. Joseph's Hospital are now consolidated with the Geriatric Medicine, Aging Brain and Memory Clinics at Parkwood to strengthen locally,

clinical research in and patient care for the neurodegenerative diseases causing dementia. The Lewy Body project will be done in collaboration with neuroimaging scientists from the Robarts Research Institute and St. Joseph's. It is anticipated that this collaboration will provide earlier and more accurate diagnosis and ensure that those affected by DLB and their families receive the care they need.

The neuroimaging studies will involve people with a diagnosis of DLB or PPD who are not already on one of the above 3 cognitive enhancing medications. The 6 month study will involve SPECT scans, and possibly PET and MRI scans before and after starting a cognitive enhancing medication. **Those interested in learning more about this neuroimaging study can contact Ms. Sarah Best, Team Leader and Clinical Trials Coordinator at Parkwood Hospital, London. (519-685-4292 Ext. 42567)**



As the New Year begins, we, along with our BSO colleagues, are hard at work implementing the BSO Action Plan to better meet the needs of older adults with responsive behaviours. As mentioned in our previous newsletter, a System Navigator has been hired in each of Chatham-Kent, Sarnia-Lambton and Windsor-Essex. A key component of the System Navigator position is to advocate on behalf of a client and his/her caregiver. Below, is a recent example of a System Navigator success story, provided by Jillian Heard, BSO System Navigator (Chatham-Kent). "A key component of the System Navigator position is serving as a "Guardian Angel" for caregivers throughout their care journey inclusive of advocating for those affected by

Behavioural Supports Ontario (BSO) Project Update:

responsive behaviours. Recently, I was able to advocate on behalf of a caregiver who felt that her husband was receiving care that was not considering quality of life for both her husband and her family. At the time I became involved, both the family and service providers were frustrated and could not agree on next steps. Given the complexity of responsive behaviours and the number of service providers involved in his care, I used my role as System Navigator to encourage a case conference to review the case. I provided support to the caregiver and educated both the caregiver and involved health care professionals about responsive behaviours and possible interventions specific to this case. By completing this process, a decision was reached and all

parties were satisfied. Most importantly, the caregiver and her family were afforded the dignity and respect that they deserve."

For further information pertaining to the BSO Project within the Erie St. Clair LHIN, please visit their website at <http://www.eriesclairhlin.on.ca>

Upcoming Learning Series Courses:
Care Essentials -
 January 25 and February 1
 At Ridgetown Senior Centre
Options for Care -
 February 8 and February 15
 At 36 Memory Lane, Chatham
 To register or for more information
 please call 519-352-1043

Société Alzheimer Society

CHATHAM - KENT

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Dr. Michael Borrie Addresses Chatham-Kent's Medical Community

There was a successful turn out as many Chatham-Kent physicians, nurse practitioners and others from the medical community attended the monthly "Continuing Medical Education" event held on Tuesday, November 20th, 2012.

Hosted by the Alzheimer Society of Chatham-Kent, the theme for the event was "Early Diagnosis of Alzheimer's disease: Case Findings in Family Practice". This significant subject matter is timely as the number of Canadians with cognitive impairment, including dementia, is sharply rising. According to a new study commissioned by the Alzheimer Society of Canada, the number of Canadians living with cognitive impairment, including dementia, now stands at 747,000 and will double to 1.4 million by 2031. This number represents almost 15% of Canadians 65 and older. It is because of these numbers that we are recognizing the importance of early diagnosis and intervention, increased funding for research, strengthened integration of primary, home and community care, enhanced skills and training of the dementia workforce, as well as recognition of the needs and improved supports of caregivers.

Dr. Borrie, Geriatrician and Professor in the Department of Medicine at Western University, educated listeners on how to best use screening tools when diagnosing



Dr. Michael Borrie (left) conversing with Dr. Will Saxena following his presentation.

Alzheimer's disease. Dr. Borrie obtained the interaction of the audience by discussing different case scenarios and allowing the attendees to contemplate the diagnostic outcome.

Dr. Borrie concluded the evening by addressing the importance that lifestyle has on the development and progression of Alzheimer's disease and related dementia. Keeping both mind and body active, as well as maintaining the Mediterranean diet can reduce the risk of acquiring a cognitive impairment. Studies have also indicated that beginning these positive lifestyle changes can slow down the progression of the disease after a diagnosis.

MISSION STATEMENT

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