Newsletter Society Winter 2012 Alzheimer Society CORNWALL & DISTRICT SOCIETY CORNWALL & DISTRICT

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A new Alzheimer Society survey reveals that Canadians are still dismissing symptoms of dementia as "just old age." Close to 50 per cent of Canadians lived a year or more with their symptoms before seeing a doctor. Of these, 16 per cent waited more than two years. A delayed diagnosis results in a huge treatment gap and prevents people from getting valuable information about medications, support and better disease management. This January, during Alzheimer Awareness Month, the Alzheimer Society is launching its **Let's face it!** campaign and asking Canadians to face dementia, get the facts and know for sure. To learn more visit: www.alzheimerletsfaceit.ca

From dementia to diagnosis: a couple's cautionary tale

Two years is a long time to wait between the first symptom of dementia and a diagnosis – precious time when 62-year-old Lou Grieve might have received medication and made plans for her future.

But the time lapse wasn't because she and her husband Wayne consciously put off seeing a doctor. It was because they did not understand that her mood and behaviour changes were classic symptoms of dementia.



The old Lou was chatty and engaged, says Wayne. She loved her job as a child and youth worker with her local school board and liked to talk things over at length with him. "It was a way she processed things," recalls Wayne, 64. "She was just a verbal person."

Alzheimer survey points to treatment gaps



According to an Alzheimer Society survey of 958 family caregivers released in January, close to half of respondents live more than a year with symptoms of dementia before seeing a family doctor or other health-care professional. Of these, 16 per cent waited more than two years.

In hindsight, three quarters wished they had been diagnosed sooner so they could have received medications to minimize symptoms. While the Grieves sought help early, their story is a cautionary tale for the more than half a million Canadians living with dementia - and those who may be at risk.

—Continued on page 2

812 Pitt St. #13 Cornwall, ON K6J 5R1 613-932-4914 250 Main St. East, Suite 210 Hawkesbury, ON K6A 1A5 613-632-4349 "You've got to take on the role of advocate yourself because your partner or parent can't do it themselves. Don't minimize their symptoms."

Memory loss isn't the only sign

When Lou began coming home from work exhausted, Wayne chalked it up to the stress of her job. He, too, was a social worker and understood how trying it could be.

But when Lou struggled to use her employer's automated phone system to call in sick, a red flag went up.

"There was a practical kind of problem-solving that wasn't happening. Lou was always really skilled on the computer. She was a whiz," he says. When the exhaustion wouldn't go away, Lou visited her family doctor.

She and Wayne saw him several times over the next two years as Lou's symptoms progressed - from extreme fatigue to mood changes. The doctor's assessment was depression, an illness whose symptoms include exhaustion, mood and

behavioural changes that can sometimes mimic those of dementia.

A tired Lou scaled down to part-time hours. By March 2008, she was still exhausted and less interested in things that once animated her. That's when Lou decided to stop driving. Then she stopped working altogether.

All the while, the Grieves sought counselling and nutritional advice from health professionals, hoping to bring Lou back to her old self.

"I felt we were continuing to miss something," recalls Wayne.

But they never suspected dementia. Like many people, the only symptom they associated with dementia was memory problems.

CAT Scan reveals brain atrophy

The turning point came when the doctor referred the Grieves to a psychiatrist in the fall of 2008 to ask about visual hallucinations Lou was beginning to experience, her increased anxiety and the fact she was being "coy" about not taking her medication. The psychiatrist ordered a CAT scan which showed frontal cerebral atrophy.

A referral to a cognitive neurologist followed soon after, along with MRIs and memory tests. In January 2009, they received a formal diagnosis. It was Pick's disease, a type of dementia also known as Frontotemporal dementia. But by this time, the illness had progressed too far along for Lou to make decisions about her care. Wayne, now retired, has been caring for Lou at home and plans to keep her there as long as he can.

Don't minimize symptoms

He receives 10 hours a week of help from a personal support worker through his local home care agency. He also attends monthly caregiver support sessions at his local Alzheimer Society.

Earlier detection could have given him these supports sooner and helped him understand what Lou was going through.

> Let's face it! Get the facts. Know for sure.

Changes in families



One of the many areas of life that dementia can cause significant changes to is the relationships among family members. Although only one individual may have received a diagnosis of dementia, it is likely that the whole family will be deeply changed by it. For example, if the person with dementia is your parent, you will face a

role reversal in caring for them. If you have siblings, you will all have to work together to share responsibilities and make important health care decisions for your

parent. If you are caring for your spouse, you will become responsible for someone who has previously been a partner. In addition, children and teens can be confused and upset by the changes they are seeing in a parent or grandparent with dementia. The changes and challenges that dementia brings can often ignite or magnify family conflicts, especially when people cope differently when it comes to caregiving responsibilities. Family members may deny what is happening or resent family members who live far away or are not helping enough. There may also be disagreement about financial and care decisions.

Here are some suggestions on how to work together:

- Have a family meeting. Talking about caregiving roles and responsibilities, problems and feelings can help ease tensions. You may want help from a professional counsellor or moderator to facilitate the meeting and keep things on track.
- Recognize differences. Some family members may be hands-on caregivers, responding immediately to issues and organizing resources. Others may be more comfortable with being told to complete specific tasks, such as mowing the lawn or paying the bills.
- Learn together. Register for an Alzheimer Society dementia education workshop and attend with other members of your family. Contact the Alzheimer Society of Cornwall & District, serving the 5 united counties, and ask about upcoming learning opportunities.
- Continue to communicate. Periodic family meetings or conference calls keep family members up-to-date and involved. Discuss how things are working, reassess the needs of both the person with dementia and the primary caregiver, and decide if any changes in responsibilities are needed.

Source: Alzheimer Society of British Colombia

Education Opportunities

Please contact Joëlle Perras, education coordinator, at 613-932-4914, ext. 22

Next Steps for Caregivers and Families

Workshops held in Williamsburg from 1:30-3:30

February 6th, 2012: What is Dementia? February 20th, 2012: Adapting to Change/

Creating a Circle of Support

Workshops held in Cornwall from 1:30-3:30

February 2nd, 2012: What is Dementia?

February 9th, 2012: Research/Legal &

Financial Matters

February 16th, 2012: Adapting to Change/

Creating a Circle of Support

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Safety

Winter months often get us thinking about safety, and the safety of our loved ones. Some adaptations around the home can help provide some peace of mind.

The following are some examples of adaptations that may be made to a home occupied by a person with Alzheimer's Disease (AD) to accommodate the pacing, wandering and confusion that are typical of AD.

Pacing & Wandering

- Move furniture back from the centre of rooms, remove all small pieces of furniture, and keep hallways clear of furniture and knick-knacks, to allow for pacing and circular wandering.
- Keep a solid armchair in the kitchen or the centre of quiet activity, so that the person can sit there and be part of things. This may discourage wandering.
- Move a bed or a sofa bed to the main floor of a two-storey house, so that the person can rest when weary without going upstair.

Confusion about whereabouts

- If the person is a rummage-and-hide person, lock away clothes in a separate bedroom and dole them out one outfit at a time.
- Allow the person with to carry out old habits (like watering the plants or having a nap after lunch or collecting the mail) as long as these habits do not put anyone at risk.
- Leave on all lights in the house if the person feels surrounded and frightened by darkness, and adjust lighting to reduce shadows. This may require adding more light.
- Remove carpeting if the person becomes confused about where to urinate.

Anxiousness and Restlessness

There are three main adaptations that can be made to private homes to prevent or decrease the anxiousness and restlessness of persons with 'Alzheimer Disease or related dementias'.

- Keep the television off, move it to a private caregivers's room, or watch only non-violent programs with the person.
- Play soothing music that is appropriate to the age and era of the person.
- Cover all mirrors in the house and keep the curtains drawn at night. Reflections can be very frightening to people with dementia when they do not recognize the people in the reflection
- Colour the water in the toilet bowl to assist a male patient's aim.



For apartment dwellers —mark the door of the person's apartment in a very distinct way, perhaps with a photograph, a wreath, or a flag of some sort.

Source: Canada Mortgage and Housing Corporation Please visit: http://www.cmhc-schl.gc.ca For information on adaptations for the home.

Public Policy blic Policy

Gravelle Tables Bill for National Dementia Strategy

Canada must plan for catastrophe coming for 1.1 million and their caregivers

November 24th, 2011, OTTAWA Nickel Belt MP Claude Gravelle introduced legislation for a national dementia strategy, invoking the memory of his mother and over 500,000 Canadians already ravaged by Alzheimer's disease and other dementias. Gravelle, joined by NDP Health critic Libby Davies (Vancouver East), NDP Seniors critic Irene Mathyssen (London-Fanshawe) and Alzheimer advocates, profiled his mother Leona's story, painfully familiar to Canadians whose numbers will double to 1.1 million plus their caregivers within a generation. "Long before her death at 83 in 2003, besides the first forgetting of appointments and things on the stove, it deteriorated to forgetting to take medication, to language loss, changes in mood and behaviour and loss of initiative," Gravelle recalled. "We were helpless watching a mildmannered woman at times turn aggressive and seeing part of her true self slip away. My dad was the partner who also suffers. learning to sleep with one eye open." "Existing federal programs, research funding, support and income assistance pale in comparison to the enormous and rapidly escalating health, economic and social impacts of this devastating disease," said Debbie Benczkowski, interim CEO of the

Alzheimer Society of Canada. "Dementia is a nonpartisan issue. On behalf of Canadians with dementia and their families, we urge all parties to work together to act on Mr. Gravelle's bill." "The Conservative government needs to take immediate action and provide comprehensive long term and community care options to support those living with chronic illness," stated Davies. "A national dementia strategy is desperately needed, and should be a cornerstone in guiding the implementation of long term and community care programs." "With a rapidly expanding seniors' population, 9.8 million Canadian seniors by 2036," investments for programs and research into seniors' health and well being must happen now" said Mathyssen. "Inaction is not an option. The federal government can and must take the lead." According to the Alzheimer Society's 2010 landmark report Rising Tide: the Impact of Dementia on Canadian Society, without government action dementia costs to the Canadian economy will increase tenfold, from \$15 billion a year to \$153 billion a year over the next 30 years. "Alzheimer's is not part of normal aging," Gravelle said. "Together, let's champion a national dementia strategy."

For further information:

Rick Prashaw, Legislative Assistant to Claude Gravelle 613-290-3238 claude.gravelle.a1@parl.gc.ca

Education Opportunities

Partnership in Transitional Care

Preparing for the move

Contact the education coordinator, Joëlle Perras, to register for upcoming sessions. 613-932-4914 ext. 22

Workshop topics:

- Common feelings at this time and ways to cope
- Discharge process from hospital
- Planning for the day of the move
- Preparing your family member for the move.

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Walk 2012



Cornwall

Our annual Walk for Memories is growing!!!!!!
Our annual Walk will be held on January 29th
2012 at the Cornwall Square. Registration is at 9
a.m. Walk begins at 10 a.m. Our theme is
Chinese New Year; please feel free to dress
accordingly. We hope to raise \$25,000.

Alexandria

New this year, we will be hosting a Walk at the Tim Hortons Dome 202 St. George St West, on January 29th 2012, registration is at 1 p.m. Walk officially opens at 2 pm. Many thanks to, Kim Gadbois and Danielle Hards, for helping to organize this event.

Rockland

On February 11th 2012 we are taking this event even further and are heading to Rockland. The Canadian International Hockey Academy, 8710 County Road 17, has opened their doors and is providing their Facility for this fundraiser. Registration is at 9 a.m. and Walk officially begins at 10 a.m. Thank you Nicole Ouelette and Denise Pigeon for helping to organize this event.

Donation

A big thank you goes out to the Drop in Quilters of Your Independent Grocers in Hawkesbury for the time and talent they have dedicated to their Touch Quilts and handbags donated to our Day Program clients and staff. Their generous donation is a great addition to our Day Program and brought smiles to many faces.



Drop in Quilters of Your Independent Grocer in Hawkesbury

Fundraising MOVESTING



The Fall has been guiet but successful with our annual Coffee Break Campaign. To date we have raised \$10,000. We sincerely thank all of our dedicated hosts. Caisse Populaire – (Casselman St. Albert, St Isidore and Embrun), Centre d'accueil Roger Seguin, Centre d'accueil Mon Chez Nous, Chateau Cornwall, Chateau Gardens, Giant Tiger Cornwall, Glen Stor Dun Lodge, J.W MacIntosh, Seniors Support Center, Glengarry Outreach Center, Lancaster Pharmacy, Sangsters Store, Les amis de I' HGH, Le Pavillon, McConnell Manor, Place Mont Roc. Seaway Gm, Angels Sanctuary, Foyer St Viateur, Royal Bank Pitt St. And East Court Mall Branch, Résidence Jardins Belle Rive, Ridgewood, Résidence Prescott-Russell, Résidence St. François, Sandfield Place, Scotia Bank Chesterville, Scotia Bank Morrisburg, Heartwood, Villa St. Luc and TSI ION KWA NOHN SO:TE.

New to our Coffee Break team this year is Bill and Joyce McAdam and Family, of Bulk Barn Cornwall. They raised \$1889 and for those who donated over \$5 their name went into a draw for 4 tickets to an Ottawa Senators game at the 100 level. The happy winner was Rachelle Sauvé.



Walkathon

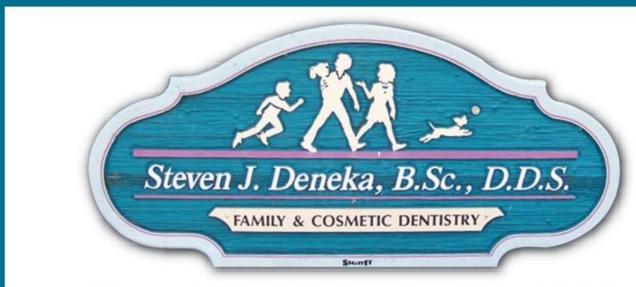
The Genesis Retirement Home Walk was held September 23rd in conjunction with Coffee break at St.Viateurs Nursing Home. This annual event was overseen by new Activities Coordinator, Suzanne Roy. We are so thankful for Suzanne who has taken on this challenge so new to her position. This event raised \$2614.

Thank you for helping us provide

Help for Today
Hope for Tomorrow...

Thank You

The 2012 Winter edition of our Newsletter has been sponsored by:



"Dental Health is a Family Affair"

New Patients Welcome

(613) 932-2058

26 Years Serving the Community

806 Pitt St., Cornwall

www.drdeneka.com

For information on newsletter sponsorship, please contact Joëlle Perras, Education Coordinator at 613-932-4914