

Staying Connected



A Newsletter from Alzheimer Society of Durham Region

CEO Chris Braney soared to new heights recently as he reached the summit of Mount Kilimanjaro during a trek to raise money and awareness for Alzheimer's disease.

Alzheimer Society Durham CEO Chris Braney says climbing Mount Kilimanjaro was the most difficult thing he has ever done in his life – but he wouldn't have had it any other way.

On January 18, at 7:38 a.m. in minus 18 degree celsius weather, Chris succeeded in his quest to summit the world's tallest freestanding mountain in Tanzania, Africa at 19,341 feet above sea level. "It was unbelievable, and words can't describe how incredibly big the mountain is." Chris lost an additional 15 pounds while climbing the mountain in addition to the 40 pounds he lost before the journey.



Chris is now one of a small group of around 130 Canadians who have climbed mountains in the fight against Alzheimer's disease, a release from the society states. "The one thing you can't plan for when climbing is the mental frame of mind," Chris says. "You're always thinking of what lies ahead of you and keeping a positive attitude."

Braney says some people get what's called 'summit fever,' where you think the summit is closer than it actually appears. "You completely disregard what your body and mind are telling you," he says. "The western breach of Kilimanjaro was the most difficult thing he's accomplished." "I'm glad to be back home with my family and Alzheimer Durham staff team," he says. "We are so fortunate to be Canadian and have a great health care system. The greatest gift we can give to our families and caregivers is hope, and that's what our Alzheimer Durham team provides."

Chris raised \$23,000 for Alzheimer Society Durham, which will help support programs and services across Durham to those living with dementia and their caregivers. But it was the awareness he raised and the support he received along the way that truly meant the world to him, he says. "It's changed me as a person. I think of the simplicities in life," he explains.

"Everyone has mountains to climb."

In This Issue

Education

Special Events

Family Support

Support Group Listing

Meeting dates
How to contact us

Mark your Calendar

21st Annual

Chocolate Lovers'

Luncheon

Sunday May 6th

Ajax Convention Centre

Call today for your tickets

905-576-2567



DEMENTIA-Friendly Design Considerations

Architects have long suspected that the places we live in can affect our thoughts, feelings and behaviours. In recent years behavioural scientists are unearthing tantalizing clues about how to design spaces that promote creativity, keep students focused and alert, and lead to relaxation and social intimacy. This is no surprise to care providers of people with Alzheimer's disease or related dementias, who are acutely aware that the physical and social environment has the potential to further impair or better yet, enhance the abilities of people living with dementia.

Did you know...

- Overall, lighting in long term care homes is well below the required level for normal age related changes.
- Daytime noise in healthcare settings can range from 65 to 95 dB or higher which can be as loud as the sound of heavy traffic (80dB) within the residents' living space. Not understanding the components of sound can contribute to inaction or lack of urgency when action may be required.

In Ontario through the Alzheimer Knowledge Exchange Design and Dementia Community of Practice, researchers and practitioners have been examining research evidence and best practices to highlight how we can assist persons with dementia to make sense of their environment and improve their sense of well-being. They created 3 useful documents which offer practical advice about modifying doorways, lighting and noise in long term care homes. Visit the AKE website to view or download the presentations and resource documents which feature DEMENTIA-Friendly Design Considerations <http://www.akeresourcecentre.org/Design>

Doorways are an important design feature to the quality of life for persons living with dementia who are no longer able to navigate safely on their own. Redirecting attention away from doorways can:

- reduce anxiety
- reduce exit-seeking behaviour
- promote feelings of freedom and control
- promote exercise and restorative functions
- decrease boredom



Dementia-Friendly Design Recommendations for Doorways offers strategies in the following areas:

- | | |
|----------------------------------|--|
| 1. Camouflage Restricted Areas | 5. Doorway Entrance Seating |
| 2. Therapeutic Redirection | 6. Limitations to Doorway/Elevator Traffic |
| 3. Enhanced Access to Safe Areas | 7. Door Code Redirection |
| 4. Positioning of Prompts | 8. Enhanced Privacy |



Simple ideas can be effective, like having an open door beside a closed door or offering sensory cues like the smell of freshly baked breads, vanilla, or coffee.

Research tells us that it is possible to adjust lighting in order to:

- dissipate shadows
- reduce mood disturbances
- positively affect eating
- optimize communication opportunities
- encourage well-being



Finally, environmental factors affect noise and noise affects behaviour. The evidence is clear and compelling that unwanted and excessive noise increases stress which in turn has health impacts such as higher anxiety and confusion, increased heart rate, blood pressure and fatigue, delayed wound healing, decreased weight gain, impaired immune function and impaired hearing. The effect of noise on medical and behavioural health is magnified for a person with dementia. While recommendations about dementia unit layout and design, conducting noise level assessments, reducing noise echoes, maintenance of noise producing equipment, monitoring and minimizing background noise may seem obvious, they are not always addressed. Managing noise is a balancing act between code and quality of life.

Here are some suggestions for encouraging appropriate noise and positive sound:



- Decrease meaningless noise as much as possible and be mindful of noise generated by staff
- Consider a commercial masking noise system to minimize other intrusive noises (e.g. which can be programmed to change level of intensity dependant on time of day)
- Use positive sounds such as music which is appropriate for age/ culture/ faith/ language.
- Ensure noise levels do not exceed guidelines
- Consider and balance the needs of persons with dementia with other persons with and without hearing loss both in activity (television) and safety (fire alerting device)
- Develop lists of bothersome noises for each person
- Turn off the television / radio when not being used
- Use music therapy and positive stimulation sounds when appropriate (e.g. multi-sensory space)

People who work in long term care homes are invited to take a walk through your facility and think how you might be able to improve design for the benefit of the people who live there.

Bill's Corner

Bill is a person living with Alzheimer's disease. He is sharing excerpts from his personal journals to increase awareness of the disease and its impact.

This is for all of our wives & husbands that do not have this disease. They are the caregivers, the unsung heroes that look after us. My wife is an angel to me. I love her and she puts up with my nonsense. Here are some of the things she helps me with:

- She does all the driving.
- Helps me with names.
- Does all repairs in our house for example: assembling furniture, electrical, plumbing, painting, finances, appointments, packing for holidays.
- Helping me in conversations when I slip up.
- Making phone calls.
- Matching my clothes.
- Operates the T.V. or tape machine.

Bernice is my guiding light and also helps me when I get depressed or angry with myself. I know I am slipping with this disease, my angel is always there to help me calm down.

All caregivers are angels.

~ Bill

2012 WALK FOR MEMORIES

Alzheimer Society



A huge thank you goes out to all who helped raise over \$30, 000
at Alzheimer Durham's Walk for Memories.

Thank you to all of our sponsors

Home Instead Senior Care
Chartwell Senior Housing Retirement
The Edwards Family Charitable Foundation
107.7 CKDO Radio
Pfizer
Veridian
Oshawa Centre Mall
Ontario Power Generation
Proper Home Care

Thank you to all of our prize Donors & a Special Thank you to:

Abbeylawn Manor
Wynfield Retirement Homes – Oshawa
Smile Makers – Melissa Landry

Also, thank-you to all of our volunteers

Bflat5 Jazz Band (O'Neil Collegiate)
Boston Pizza

We could not have done it without you!

Congratulations!



We would like to congratulate Taunton Mills Long Term Care, who was the top team bringing in over \$3,000 and also to the top individual, Harry Vanderbelt who raised over \$2,000!

Alzheimer Society

DURHAM

Presents the 21st Annual

Chocolate Lovers' Luncheon

Sunday May 6, 2012

11:30 a.m. – 3:30 p.m.

Ajax Convention Centre

550 Beck Crescent, Ajax

Gourmet Lunch

Scrumptious Chocolate Dessert Buffet

Auctions, Raffles, Door Prizes

Cash Bar, Entertainment

Welcoming back:

Dan Carter, Author, International Speaker,

Television Producer and Host



Tickets \$50/pp

Call today

(905) 576-2567 or

1-888-301-1106

info@alzheimerdurham.com

Talking About the End of Intimacy

Everyone has a need for companionship and physical intimacy. People with Alzheimer's disease or a related dementia are no different. They may fill this need through marriage, partnership or friendship. Whatever the relationship, it will be affected by the changes brought on by the disease, including changes in the need for companionship and physical intimacy.

Below is an article about intimacy and Alzheimer's disease written by Barry Peterson, author of "Jan's Story: Love Lost to the Long Goodbye of Alzheimer's"

My wife, Jan, was diagnosed with early-onset Alzheimer's disease in 2005 at age 55. Our love life, our intimacy, was one of the things the disease stole. I am all for talking about it, so much so that I included it in my book: "Jan's Story: Love Lost to the Long Goodbye of Alzheimer's." "She had faded," I wrote, "until she no longer seemed to feel the pleasure or have the interest in our togetherness." And there was uncomfortably more as Jan faltered and I, as her caregiver, began making every decision from what we would eat for dinner to what clothes she would wear.

"There was my increasing sense of being a parent watching over her like a child," I wrote. "This can be numbing and repulsive to one's desires, no matter how much love is involved, or for me, the remembrance of what our love had once been." Past tense. "Intimacy slipping away until it was finally gone". I am sure this causes depression in many caregivers—as it did with me, but this is also about what Alzheimer's disease takes away. The caregivers who do their best in the blizzard of tears that is this disease seem to be the ones who open up, who talk about it, who confront it. And intimacy is one area that needs much talking.



This is a frightening loss, and having those to whom you go for help turn away just fuels more fear. Am I doing something wrong? Did I make some terrible mistake even asking about this? Am I a bad spouse or a terrible caregiver for having these desires that were once so normal, so important between us? Let us remember that spousal caregivers usually have no training, no years of medical study and very poor roadmaps available for what is coming at them. We were accidentally picked as caregivers because, in so many cases, we were the nearest person to the one we love who has the disease. And that is all the more reason why professionals who have the training and who can offer guidance should not avoid this discussion. If there is reluctance, then consider the many things we would not talk about in years past, and today we don't think twice about the conversation.

In 1932, America elected a president who was in a wheelchair. But news photos never showed that. Being a "cripple" in that era was considered a sign of weakness and might have cost Franklin Delano Roosevelt the election. When he appeared in places like the Democratic convention, he was shown standing upright. Or when he met with other heads of state, he sat in a regular chair just like they did.

When I started in television news in the 1970's, you couldn't say "breast" on television. Now we have grunting, hulking N.F.L. linebackers wearing pink shoes to raise awareness of breast cancer. The words "colon cancer" were not polite dinner table conversation until my colleague, CBS Evening News Anchor Katie Couric, made it acceptable. Her colonoscopy shown on the "Today" show sent thousands to their doctors to have the same procedure.

It is proof that perceptions of a disease and how we deal with it can change, depending on how open we are. In this case, some professionals who are counselling spousal caregivers are a bit like FDR and the wheelchair. Keep it hidden. Loss of intimacy tearing you up...take a pill for depression. I've been a journalist all my working life, and have always had an irritated reaction when I am told not to report something. There are some experts who have told me not to talk about intimacy (which, they explain, in an embarrassed whisper, means sex). That triggers my journalistic rebellious streak, making me all the more determined to speak out.

But here is a far better motivation, which came as a surprise to me. When I talk about Alzheimer's disease, I make a point to read the part of my book about intimacy that I shared above. I can only guess that a few people are uncomfortable. But I know for sure that others are relieved when someone discusses this out loud. In truth, I did not know when I wrote about this how many of those trapped by their loved one's disease felt these things—and how deeply it hurts.

They come to me and, like the woman with the story to tell, they desperately want someone to listen. I am not a professional counselor or support group leader or doctor.

I am just a guy whose wife has early-onset Alzheimer's disease. But I have a lot of experience seeing people suffering loss from war and disease. And on the topic of intimacy, there are many out there suffering in silence.



Alone, they cry themselves to sleep at night in desperation and guilt. If you are someone who helps spousal caregivers, if you are a support group leader or counselor or doctor, you can change this by asking the caregiver a simple question: How are you coping with the loss of intimacy? Maybe there is embarrassment at first talking about this. But I believe that the best of those who help caregivers have patience and insight. Use it here. Don't shy away. Ask again, if need be. If you are a spousal caregiver, then let me share the one constant that kept me sane as a caregiver: the knowledge that I was not alone. Someone else ahead of me had made this sad journey. And that included seeing lovemaking fade and die. I needed to know I was not the only one suffering as the disease ended the touching and the pleasure, the caress that was once natural and wonderful and wondrous. Spousal caregivers need to understand about these losses and these feelings. And we need people who will listen and respond and make sure we know we are not alone. On this issue, silence is our enemy.

For further information on this topic please visit our resource library for material or to sign out Barry Petersen's Book "Jan's Story: Love Lost to the Long Goodbye of Alzheimer's ."

Source: Spring 2011. care Advantage

ALZHEIMER SOCIETY OF DURHAM REGION SUPPORT SERVICES

AJAX-PICKERING <i>(4th Wednesday evening)</i>	EAST DURHAM <i>(3rd Tuesday evening)</i>	OSHAWA-WHITBY (Oshawa location) <i>(1st Wednesday afternoon)</i>
March 28 April 25 May 23 Time: 6:30-8:30p.m. Orchard Villa Retirement Residence Victoria Harbour Lounge 1955 Valley Farm Road, Pickering	March 20 April 17 May 15 Time: 6:00 p.m. – 8:00 p.m. Lakeridge Health Bowmanville 47 Liberty St. S. Lambert Conference Rm., Bowmanville	March 7 April 4 May 2 Time: 1:00 p.m. – 3:00 p.m. Alzheimer Society of Durham Region Oshawa Centre Mall 419 King Street W., Ste. 207, Oshawa
AJAX-PICKERING <i>(2nd Wednesday morning)</i>	NORTH DURHAM <i>(last Tuesday afternoon)</i>	OSHAWA-WHITBY (Whitby location) <i>(3rd Wednesday afternoon)</i>
March 14 April 11 May 9 Time: 10:00 a.m. – 12:00 p.m. Pickering Village United Church 300 Church St. N., Ajax	March 27 April 24 May 29 Time 1:30 p.m. – 3:30 p.m. Trinity United Church 20 First Ave., Uxbridge	March 21 April 18 May 16 Time: 1:00 p.m. – 3:00 p.m. St. Andrews Presbyterian Church 209 Cochrane Street, Whitby

NORTH DURHAM SATELLITE OFFICES – March 19, April 16, May 21

Port Perry – West Shore Village, 293 Perry Street, Port Perry 9:00a.m. – 12:00p.m. ****Booked appointments preferred****
Beaverton – Lakeview Manor, 133 Main Street West, Beaverton 1:00p.m. – 4:00p.m. ****Booked appointments preferred****

EARLY STAGE SUPPORT GROUP

For person with early stage Alzheimer’s disease or related dementia and their care partners.
 Offered at scheduled times throughout the year. Call the Society for more information.

MEN’S BREAKFAST

3rd Wednesday of the month
 A social breakfast meeting for male caregivers at Denny’s Restaurant in Whitby from 9:00a.m. to 10:30a.m.

Alzheimer Society of Durham Region

Oshawa Centre (Executive Centre)
 419 King Street West, Suite 207
 Oshawa, ON L1J 2K5

To Contact Us

Phone: 905-576-2567 Toll Free: 1-888-301-1106
 Fax: 906-576-2033
 Email: info@alzheimerdurham.com
 Web: www.alzheimerdurham.com

Office Hours

Monday to Thursday 8:00 a.m. - 5:00 p.m.
 Friday 8:00 a.m. – 4:00 p.m.

Our Vision

To be a leader in the Alzheimer movement
 and recognized by our community as an
 essential provider of dementia-related
 services and supports.

Our Mission

Alzheimer Society of Durham Region’s
 mission is to improve the quality of life of
 people with Alzheimer’s disease or a related
 dementia and their care partners.

*The printing of “Staying Connected”
 is generously sponsored in part by*



Thank you for your support

*Alzheimer Society of Durham Region
 gratefully acknowledges funding from the
 Central East Local Health Integration Network and our donors
 who show their generosity in so many ways.*