

Help for Today. Hope for Tomorrow...®



## Celebrating Women Affected by Dementia



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**W**omen are most affected by dementia, and this month we want to celebrate the strength they show in their dementia journey. On average, women live longer than men, which makes women more at risk of developing the disease. Statistically, women are also more likely to take on a caregiver role than men. Although women seem to carry the bigger burden of dementia, women like Tanis Rummery and Debbie Jones are embracing it and continuing to live life at its fullest.

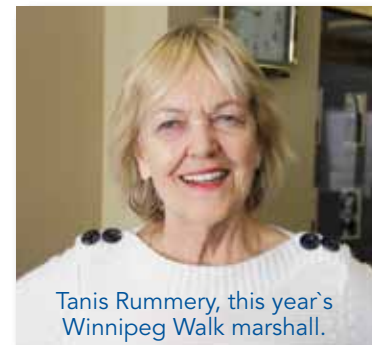
### Living Life Bravely

If you sit down and chat with Tanis Rummery, she'll tell you

that life is good. She loves her friends, has few complaints and is eager to advocate for anyone with dementia.

Tanis has vascular dementia, a type of dementia caused by problems in the supply of blood to the brain. A few years ago, Tanis started to have signs that something may be wrong. She visited the neurologist and discovered she had dementia. Rather than let this stop her from living her life as she wanted, Tanis has found a way to change things for the better.

"I feel like I'm on a one person crusade to change people's perspective on any type of mental illness. There's a great



Tanis Rummery, this year's Winnipeg Walk marshal.

stigma attached to dementia and I don't want people to think that way," says Tanis.

In order to break any stigmas, Tanis is not afraid to make mistakes. For example, she can often become confused while shopping in a store. Rather

See "Celebrating" on page 3...

## Investors Group MEMORY Walk

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people who care

## STEP IT UP!

Register online today!  
[alzheimer.mb.ca](http://alzheimer.mb.ca)

### WINNIPEG WALK:

Thursday, June 12, 2014  
5 pm at The Forks

Visit our website to find a walk in your community.

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## Walking for Mom

**A**t this year's Memory Walk, Tannis Evans plans to proudly hold her sign that says she's walking for her mom. She and thousands of Manitobans will step it up for dementia to raise funds that support valuable programs and services for people affected by dementia and the search for a cure. After having to learn about dementia at a young age, Tannis hopes to recruit more team members and keep educating others.

Tannis' mom, Norma, was diagnosed with Alzheimer's disease in 2008 at the age of 52. Soon after her diagnosis, Norma's husband decided to take her to Hawaii for a trip she'd always dreamed of.

See "Walking" next page...

"Walking" continued from page 1...



Tannis Evans (R) & her mom, Norma Evans

Around the same time, Tannis, then age 20, started doing some research to learn about her mother's disease and look for a way to help. Tannis soon discovered the Alzheimer Society's Memory Walk and quickly knew she wanted to start a team. "When I found out about the Walk, I thought it would be a good way to

support something that affected my family and me," she says.

When it was time to come up with a team name, Tannis asked her mom what her favourite memory was. She replied that her favourite memory was her trip to Hawaii, and their team name has been "Team Aloha" ever since. This year will be Tannis' seventh year as captain of Team Aloha.

At her young age, Tannis says there are times when balancing her caregiver role and living as a young woman are difficult.

"My friends still find it hard to understand," says Tannis. "When you're 20, you're in a different part of life. My friends were going to parties while I was home bathing and feeding my mom, and acting as a mother figure. It's hard to describe this disease to younger people because we

often assume someone with dementia is elderly."

Tannis and her mom have always been close, and Tannis visits every other day at her mom's nursing home. Although her mom can't remember Tannis' name anymore, she still smiles, sings and hums to let Tannis know she's happy.

In their dementia journey, Tannis says she's learned a lot about herself and how close she holds special moments and memories with her family. She commends her dad for his selfless love and care, and says she's learned so much about love from watching him care for her mom and their family.

"I can't control this disease," says Tannis. "But leading a team for Memory Walk is something I can control. I need to do it every year - for my mom, myself and others." ❀

Join us for the  
Alzheimer Society of Manitoba's

## Annual General Meeting, Volunteer Recognition & Tree of Memories Ceremony

Wednesday, June 25, 5:15 pm  
10-120 Donald Street  
Mezzanine Level  
Winnipeg, MB

Help us celebrate our accomplishments,  
recognize our dedicated volunteers  
and honour those who have lost their  
lives to dementia.

### Tree of Memories Ceremony

For a gift of \$250 to the Alzheimer Society of Manitoba, you can honour your loved one by placing an engraved brass leaf on the Tree of Memories. For information, please email [tmattey@alzheimer.mb.ca](mailto:tmattey@alzheimer.mb.ca) or call 204-943-6622.

## It's Leave a Legacy Month. . . Plan to Give!

Many people receive life-changing assistance from the Alzheimer Society of Manitoba. Some of these individuals are people who are living with dementia. Others are family caregivers and friends who provide support to the person affected.

As a non-profit organization, the Alzheimer Society absolutely depends on its donors. While the government provides a small operating grant, a large portion of our revenue (45% in 2012-2013) comes through donations. Without our donors, the Society could not continue to offer the programs and services that are so valuable to those in need.

Anyone can enrich the lives of those struggling with dementia by becoming a donor. Planned giving allows you to make a future gift to the Society in a way that will have minimum impact on your current income while

allowing you to obtain tax and estate benefits.

### **Planned Giving Options**

**Charitable Bequest:** The truth is, you don't have to be rich to leave a bequest. Even a donation of \$100 from your estate can have a lasting impact on the Alzheimer Society's ability to continue providing services into the future.

**Life Insurance:** Did you know that you can buy a life insurance policy – as large or small as you like – with the Alzheimer Society as the beneficiary? Once again, the donor can set up the policy for the amount that he or she can afford.

**Residual Interest:** You might want to consider leaving a gift of residual interest from real estate or another item of value (such as art) to the Alzheimer Society. This method of giving allows you to enjoy

the property while you are living. As well, you receive a charitable tax receipt for the value of the property at the time the gift is made. When you pass away, the Society receives the deed to the property.

The methods of planned giving outlined here are only a few of the many you may want to consider. Others include annuities, charitable remainder of trusts, and gifts in memory of a loved one or in honour of someone. You can also give cash or securities, RRSPs or RRIFs.

To investigate the best option for your circumstances, check with a financial advisor, who will help you to understand the tax implications for your individual situation.

Whatever the amount and method you decide on, your gift is greatly appreciated and will improve the lives of those affected by dementia. ❀



"Celebrating" continued from page 1...

than be afraid in these moments, she'll bravely walk up to a clerk, tell them she's been diagnosed with dementia and simply ask for some help. Almost always, the clerk will smile and lend a hand.

"I walk away from those situations thinking, if I have planted a seed so that others don't dismiss people like me as 'crazy' or 'odd', then I've done a good thing," says Tanis.

Tanis has attended the Alzheimer Society's weekly Support Group for people with dementia for the past three years. She says the other people in her group aren't just her friends, they're her family.

"We have such a good time and we giggle a lot," says Tanis. "I want people to know that you can talk to someone with dementia. They're the same person they always were. I'd hate to see people in my Thursday group being mistreated."

Tanis keeps busy by volunteering at Hospice and Palliative Care Manitoba and at a no-kill pet shelter. She says as long as she's able to do the things she loves, she'll continue to do them.

"I've never been afraid of this disease," says Tanis. "Who knows when life is going to end? And I'm not afraid to try new things. Maybe one day I will be, but not at the moment."

Her bright blue eyes are wide as she talks, and her determination to stand up for people with dementia conveys her beautiful inner strength.

### **Loving Mom and Dad, As Always**

Debbie Jones' dad, John Hamm, was diagnosed with dementia in 2009. The following year, her mom, Léa, was also diagnosed with dementia. Debbie is the primary caregiver for both her mom and dad. Despite being in a role that may at times feel overwhelming, Debbie has found that the best solution to their situation is to cherish her parents the same way she always has.

"My parents have always been awesome people and would see you through any troubles. I see this as my time to return the favour," says Debbie.

Debbie's parents are still living in their family home. Home care frequently comes to check in and Debbie visits three to four times a week. And one thing remains constant: Sunday dinner.

"My mom always wanted to have family over on Sundays, so I've kept up with the tradition. It relieves a lot of stress for her and makes her happy," says Debbie.

Although she plays the role of caregiver, Debbie also acts as her parents' secretary, taking them to their various appointments

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Mother's Day  
gift all  
wrapped up!*



Visit [alzheimer.mb.ca](http://alzheimer.mb.ca) to view and order these special gifts:

- A Forget Me Not silver pendant necklace by Hillary Druzman (part of the proceeds go to the Alzheimer Society of Manitoba)
- A Touch Quilt
- Or make a donation in honour or in memory of your mother

**THANK YOU!**

and maintaining their interests. Debbie and her father often grab an omelette for lunch and she makes sure to take her mom shopping.

Although her parents are progressing in their disease, Debbie says she chooses to look at all the good things each of them has in their life. This includes her dad still being able to joke around like he always has.

"We all have to learn how to embrace this," says Debbie. "There's still that same person inside and you have to love and cherish them." ❀

## **UPCOMING EVENTS**

### **Mind Your Matter: Brain Health and You**

Thursday, May 15, 2 to 3 pm  
St. James Library, 1910 Portage Ave.,  
Winnipeg, MB

### **Living Well & Living Alone with Dementia**

Wednesday, May 21, 7 to 8:30 pm  
The Parkway Retirement Community, 85 Paget St.,  
Winnipeg, MB

### **Mind Your Matter: Brain Health and You**

Friday, May 23, 2 to 3 pm  
Fort Garry Library, 1360 Pembina Hwy.,  
Winnipeg, MB

### **Living with Alzheimer's Disease Workshop**

Saturday, May 31, 10 am to 4 pm  
Life Office at TBJ Mall, Ashern, MB

### **Speak Up: Advocacy Skills for Caregivers**

Wednesday, June 18, 7 to 8:30 pm  
The Wellington Retirement Residence, 3161 Grant Ave.,  
Winnipeg, MB



2014  
**care4u**

*A conference for family  
and friends caring for  
a person with dementia*

## **SAVE THE DATE!**

**Saturday, November 1**  
**9 am to 4 pm**  
**Canadian Mennonite**  
**University,**  
**500 Shaftesbury Blvd.**  
**Winnipeg, MB**

Cost: \$40 (includes lunch)

## **GET YOUR MOTORS RUNNING!**

**19th Annual  
MOTORCYCLE POKER DERBY**

**Saturday, August 16**  
**9 am to 7 pm**  
**Brandon, Manitoba**

To register or for more information,  
contact [mloewen@alzheimer.mb.ca](mailto:mloewen@alzheimer.mb.ca)  
or go online at [alzheimer.mb.ca](http://alzheimer.mb.ca)



**QUESTION: Much of what I hear and read in the media describes people with dementia as violent or aggressive. I am distressed by this. Could you shine light on this issue?**

#### HAVING DEMENTIA IS NOT EASY.

As the disease progresses it becomes more difficult for the person with dementia to interpret the things happening around them. At times, the person may become fearful or anxious because they are uncertain whether they are safe. It is at times like this that a person with dementia may react in a manner that is not characteristic. When this occurs, it is a response caused by the impact of dementia on the person and is not an action chosen by the person.

The key to averting emotional, physical or psychological outbursts by people with dementia is found in person centred care that focuses on the person, their needs and individualized interventions that are a fit for the person. For example, if a person becomes distressed by an environment that is noisy, rather than having the person become distressed by the noise, plan for their living space to be restful.

Giving the person with dementia meaningful choices is also important. If the person is indicating they do not wish to do an activity at the time their caregiver may request, allow time and ask again. Pressing a person to do

something when they are not ready can cause them to resist. Effective caregivers empower people with dementia by respecting the person's choice.

When assisting a person with dementia in their activities of daily living, plan to break down the task and give instructions one step at a time. Knowing what comes next will set the person at ease and help them to remain calm.

When people with dementia receive supportive care it helps them to feel secure and respected and to live with dignity. ✿

– Norma Kirkby, Program Director,  
Alzheimer Society of Manitoba

## Easing the Transition into Personal Care

Moving is never easy, as anyone who has ever done it can attest. It's no different for an individual with dementia when a move from their home in the community to personal care becomes necessary.

"There are things family members can do to help ease the transition," says Joyce Klassen, Dementia Care Education Coordinator at the Alzheimer Society of Manitoba. "It's a matter of knowing how the person might react, then deciding on a plan that is right for that individual."

### Planning in Advance

Before the move occurs, a little pre-planning can be valuable. For example, an advance visit to the care home may help the person become familiar with the new environment. Both the individual and the family member can meet staff members, participate in a social activity, and perhaps have lunch.

It's also a good idea to talk to staff at the facility beforehand about what happens on the first day. Who will greet you upon arrival? What personal items can you bring so the new room will feel home-like? Is it necessary to arrange for a cable hook-up? Answers to these questions, explains Joyce, provide family caregivers with information

about what to expect so moving day will go as smoothly as possible.

### Moving In

Family members can tailor the actual move to suit the needs of the person. It may be possible to delay the move by one day so there is time to set up the room with personal items, such as a quilt or photos. In other situations, the person with dementia may appreciate having more control and may want to participate in arranging the room.

"There is no right or wrong way to make the move," says Joyce. "Do things in the way that works best for your family's circumstances."

### Feeling at Home

After moving day, the person with dementia may find the change to be overwhelming, while others may quickly feel comfortable. In any case, the next step is to ensure that the person settles in and starts feeling secure.

Joyce has some concrete advice that may assist the person to adapt to the new environment. First of all, studies show that both music and laughter reduce the levels of the stress hormone, cortisol. Sharing a funny story and a song can go a long way!

As well, individual attention from both family members and staff can help



Odele Kaplun's mom, Martha Balharry

make the person feel welcome and comfortable. Odele Kaplun recently experienced just how important this can be. Her mother, Martha Balharry, moved to a care home where staff members showed, by their actions, that they understood her mother's dementia. "Mom carries around a stuffed dog that she treats like a baby," she says. "The staff completely accepted this and petted the dog. Mom loved it!"

Finally, make sure that staff members at the care home are aware of the person's life history and interests. Do they have children and grandchildren? Where did they work? What are their hobbies? Other details, such as knowing that the person likes to watch the news before bed – and allowing that habit to continue – will make all the difference in ensuring that the individual truly has found a new place to call home. ✿

## CEO Message

# Working Towards a Better Future for People with Dementia



Wendy Schettler, CEO

As I look back and reflect on my first year as CEO with the Alzheimer Society, I feel proud to be part of an organization dedicated to making a difference for Manitobans impacted by dementia. I have seen first-hand the commitment of the incredible volunteers, supporters, board and staff who give of

their time and generosity to support the work we do.

Over the past year, I spoke with Manitobans diagnosed with dementia, caregivers, donors, sponsors and health care professionals. As a result, I have been getting to know the Alzheimer Society better and learning as much as I can about what *you* think we should be doing.

There were many comments about the need to do more of what we currently do – family education, regional workshops, and awareness about the programs and services we offer. There was a desire for the Society to continue helping caregivers navigate the health care system and access community resources.

Concern was voiced that many individuals are diagnosed with dementia, yet comparatively few are accessing our support. People need to know that the Society offers services not only for those with Alzheimer's disease, but also for individuals with other forms of dementia and their family members.

Numerous people mentioned the need for more research dollars and the importance of supporting research without compromising our programs and services. Others discussed the need to continue our advocacy efforts including: responsive and appropriate services, government focus on the importance of a dementia strategy and the need for a better system to get the information and help that is necessary to care for their family member after a diagnosis is made.

I have listened to what you want done and learned from what you told me. The challenge lies ahead in determining how to meet the ever growing needs. I am ready to move forward with your support.

I look to the year ahead with optimism as we adapt and grow to best serve every Manitoban touched by this disease.

I thank everyone for the warm welcome and am excited about the difference we will make as we work towards improving the quality of life for those affected by dementia. ✿

## Did You Know?

**The Alzheimer Society provides services for people affected by Alzheimer's disease and for those affected by other forms of dementia. This is the third in our series of articles designed to provide information about other types of dementia.**

### Frontotemporal Dementia (FTD)

FTD tends to occur at a younger age than Alzheimer's disease. This type of dementia resembles Alzheimer's disease in that it also involves a progressive, irreversible degeneration of brain cells.

A person with FTD may have symptoms such as behaviour changes, or difficulties with speech and movement.

Unlike Alzheimer's disease, which generally affects most areas of the brain, FTD is an umbrella term for a group of rare disorders that primarily affect the frontal and temporal lobes of the brain – the areas generally associated with personality and behaviour. FTD disorders include:

- Pick's disease
- Semantic dementia

- Frontal lobe dementia
- Primary progressive aphasia
- Corticobasal degeneration
- Pick's complex

In the early stages of FTD, behaviour changes and/or problems with speech (language) can appear separately. As the disease progresses, these two areas will overlap. Unlike Alzheimer's disease, a person with FTD often remains oriented to time, and memory is not a problem in the early stages. In the later stages, general symptoms of dementia arise (e.g., confusion and forgetfulness), motor skills are lost and swallowing difficulties occur.

Changes in behaviour may include becoming either withdrawn or disinhibited (e.g., losing the ability to restrain one's behaviour and actions). The person may

lose interest in personal hygiene, become easily distracted or repeat the same action over and over again. Overeating or compulsively putting objects in the mouth may occur. Sometimes incontinence is an early symptom. People with FTD may also become indifferent toward others or may experience abrupt, frequent mood changes.

Problems with speech (language) can range from speaking less to total loss of speech. They may have difficulty finding the right words and may use circumlocution (i.e., talking around the words or describing what they mean). Echoing what has been said by others and stuttering are common symptoms. The person may have difficulty sustaining a train of thought or maintaining a conversation for any length of time. Writing and reading are also affected.

For more information about FTD or any other form of dementia, contact the Alzheimer Society at 204-943-6622 (Winnipeg), 1-800-378-6699 (Manitoba) or the Regional Office nearest you. Help is just a phone call away. ✿



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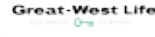


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