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CLICK ON INDEX ITEMS TO GO TO THE ARTICLE.



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INSIDE THIS ISSUE

- [Walk for Alzheimer's](#)
- [Annual General Meeting, Volunteer Recognition & Tree of Memories Ceremony](#)
- [Volunteer Profile](#)
- [Upcoming Events and Programs](#)
- [Celebrate Mother's Day!](#)
- [Ask an Expert](#)
- [Meaningful Giving](#)
- [CEO Message](#)
- [Anything for Alzheimer's](#)
- [Thanks to our Gala Sponsors!](#)

Caregiving and Young Onset Dementia

How the "Outside Guy" Learned to be the "Inside Person"

Deric Balagus and his wife of 33 years had a playful and succinct way to sum up their approach to marriage.

"We always joked that I was the outside guy and she was the inside person," he says. "I looked after everything outside of the house, and she kept things running inside the house."

When Anni was diagnosed with young onset dementia six years ago, at 56, it completely shook up their world.

For the first two years the change in Anni's function was gradual. But by 2013, she was no longer able to drive, and a year after that, no longer able to plan and prepare meals.



"I hadn't cooked since I was single," Deric recalls. "Now I was making meals and driving Anni everywhere. If it weren't for Google, I would have driven my friends and relatives crazy asking for advice."

One place where Deric sought out guidance was the Alzheimer Society, but he admits that part

of him had a hard time relating to other caregivers.

"A lot of the events I was going to were for people who were caring for someone in their eighties, and I didn't feel a lot in common with them," he says.

One of a Kind Support Group

Then last fall, Deric began attending the Society's Support Group for Caregivers of People with Young Onset Dementia. The group, hosted at Deer Lodge Centre, is the only one of its kind in the province. Its goal is to provide support to those dealing with the unique

[See "Outside Guy" on back...](#)



WALK FOR ALZHEIMER'S
MAKE MEMORIES MATTER™

Presented by: Investors Group

Bonnie Thiessen (story at right) will be walking at the 2017 Walk for Alzheimer's.

Join her to show your support for all people affected by dementia!

Shifting Sands: A Caregiver's Story

– By Bonnie Thiessen

A few years after my husband Abe and I retired, the ground started to shift – so slowly and almost imperceptibly, at first, that Abe didn't realize what was happening. But I knew! My once brilliant husband began to lose his words – common, simple words.

We still had good times, but in subtle and sometimes not so subtle ways, our relationship was changing. As he lost awareness, I became protective. I'd fill in words and generally help him look and function as normally as possible. But Alzheimer's is unrelenting!

[See "Sands" next page...](#)



Bonnie Thiessen with husband Abe.

THE WINNIPEG WALK TAKES PLACE ON JUNE 13TH AT THE FORKS.

"Sands" continued from page 1...

One day, for instance, when he was still driving, he offered to take our tax payment to City Hall. Off he went with the envelope, but within half an hour he came back telling me that City Hall was gone; all he had found was a great big hole in the ground!

What to do? It would've been easy to tell him he was wrong – and prove it. It would've also been cruel! It would've crushed his sense of who he was.

Truth and honesty had always been our way, but now I chose a different path. With a puzzled look I said, "Hmm, that's peculiar! Let's go check it out."

Of course, when we got there, City Hall was still where it had always been.

Abe hopped out of the car and went in to pay our taxes. I sat there in shock! This was no longer the Abe I knew.

I was no longer the same either! I could no longer challenge fuzzy logic or point out errors in judgement – that would crush his spirit. I had to find a new way! I began listening carefully to him with the hope of finding ways to connect. His truth was no longer anchored in the here and now. He saw and heard things that I

did not. I had to improvise! And improvising became my way of saying "Yes," "I'm with you" and "Tell me more." So began our journey into a whole new way of being together.

As his intellect released its hold, other ways of relating shone through. A new and freer Abe began to appear as his feelings took centre stage. I no longer knew what he was saying, but I could relate to the feelings he was expressing. "That sounds good. I'm glad you're happy!" Or "That sounds sad. Let's talk about something else."



Abe and Bonnie

Abe's emotions now speak loud and clear. Because of this, I am often able to understand what he needs and what will make life more comfortable for him.

Another long buried talent that has come to the surface is music. His voice is richer and fuller than ever before. Also, more than ever, he is comforted by physical touch. Hugs and holding hands often bring out a big smile.

This is obviously a story of my husband's changing identity. But it is also the story of my changing identity. I have found

Thanks to Bonnie Thiessen (story at left) for supporting the Walk for Alzheimer's! Join her in the nation-wide movement!
Register your team today!



WALK FOR ALZHEIMER'S MAKE MEMORIES MATTER™

Presented by: JG Investors Group

WINNIPEG WALK
The Forks – Festival Stage
Tuesday, June 13th, 5 pm

Register online today!
alzheimer.mb.ca/wfa2017

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Winnipeg Free Press



a deeper appreciation of emotional connections, the way we communicate without words, and the absolute need to meet a person where they are. I'm a better listener and a much more compassionate person.

And, I know, that life isn't quite finished with me yet. The sands of life will continue to shift. And I will continue to change and grow. ◀

Celebrate our accomplishments, recognize our dedicated volunteers and honour those who have lost their lives to dementia at the Alzheimer Society's

Annual General Meeting, Volunteer Recognition & Tree of Memories Ceremony

Tuesday, June 20, 5:30 pm, 10-120 Donald Street, Mezzanine, Winnipeg, MB

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 leaf on the Tree of Memories. For information, please email lwilliams@alzheimer.mb.ca or call 204-943-6622.

SAVE THE DATE!



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

Saturday, October 28
Canadian Mennonite University,
500 Shaftesbury Blvd., Winnipeg, MB

Get Your MOTORS RUNNING!



22nd Annual MOTORCYCLE POKER DERBY

Brandon, MB
Saturday, August 26, 9 am to 7 pm

Online registration to open soon at alzheimer.mb.ca
For more information, contact: alzwm@alzheimer.mb.ca

Volunteer Takes Care of the Invisible but Essential Tasks

When Marlene Reimer's mother was diagnosed with Alzheimer's disease a decade ago, there was little in the way of supports or services for families in the Steinbach area.

"We had to do all of our own research," Marlene says. "There was just whatever you got through home care – maybe some pamphlets or a bit of information, but no programs or workshops that we were aware of."

When the Alzheimer Society announced it was opening an office in Steinbach in 2014, Marlene took notice. By then her mother had progressed past the point where most of the services could benefit her family, but she found herself drawn to the new organization all the same.

"There was a small article in the local newspaper about the office opening and

about its volunteers, so I cut it out," Marlene recalls. "I didn't do anything about it right then, but I kept it for a long time."

Then about a year ago, Marlene signed up to do some canvassing with the Society and got to talking with the office's coordinator, Leona Doerksen, who mentioned she was short an office volunteer. As the only staff member in an office offering five support groups and serving over 100 families, Leona relies on the dedication of volunteers for the vast majority of the behind-the-scenes administrative work.

Marlene, who worked as a receptionist in an optometrist's office for 17 years before retiring in 2007, thought she had the skill set needed and was eager to help.

Today she spends a half-day every week taking care of the kinds of tasks that are invisible to most but essential to keeping the South Eastman office running. She assembles information packages, delivers posters and keeps the shelves stocked with resource material. She also tracks volunteer hours for the Touch Quilt Project.

"I appreciate Marlene's support and her insights as someone who understands

the caregiver journey," says Leona. "I could not offer the services I do without volunteers like Marlene."

Marlene sees her work as a chance to help the Society assist families who may be feeling alone and overwhelmed – a feeling she says she can very much relate to.

"The resources that are available now are really amazing," she says. "If we'd had them when my mom was first diagnosed, it would have made a world of difference. When you have a loved one with Alzheimer's disease, it's not an easy journey for them or for those close to them, and it's just very fortunate we have these resources here in Steinbach now." ◀



Marlene Reimer, Alzheimer Society volunteer

To make a difference in the lives of families affected by dementia through volunteer work, contact the Alzheimer Society of Manitoba. We'll match you up with the perfect job for your interests and skills!

Contact us at 204-943-6622 or email alzmb@alzheimer.mb.ca

Last year, 3,389 volunteers contributed 15,276 hours to the Alzheimer Society's programs and services. Thank you!

COMING UP!

Living with Dementia: First Steps Winnipeg – Three Part Workshop:

Part 1: Sat., Apr. 22, 9 am to 12 pm
Part 2: Sat., May 13, 9 am to 12 pm
Part 3: Sat., June 17, 9 am to 12 pm
Windsor Park United Church,
1062 Autumnwood Dr.

Brandon – One Day Workshop:

Sat., June 3, 9 am to 4 pm
Lecture Theatre, 2nd Fl, Nurses Residence,
Brandon Hospital Assiniboine Centre,
150 McTavish Ave. E.

Family Education: Next Steps Dementia Care at the End of Life

Wed., May 17, 7 to 8:30 pm
Park Manor Care Home,
301 Redonda St., Wpg.

Understanding Changing Behaviours in People with Dementia

Wed., June 14, 7 to 8:30 pm
The Waverley and Rosewood,
857 Wilkes Ave., Wpg.

Telehealth Sessions (for regional communities only)

Join us on Tues., Apr. 25 from 6:30 to 8 pm for the following topic:

Food and Nutrition: Understanding a Person's Needs as Dementia Progresses:

Check our website for designated locations in Manitoba.

Minds in Motion®

Minds in Motion® sessions are currently running at six Winnipeg locations and in Gimli. For information on times and locations, check our website.



To register online, visit alzheimer.mb.ca or call 204-943-6622 or 1-800-378-6699 for more information.

CELEBRATE MOTHER'S DAY!



Did you know that women are:

- more at risk than men of developing dementia
- more likely than men to take on a caregiver role?

The Alzheimer Society challenges you to celebrate these strong and caring women on Sunday, May 14th.

THEY DESERVE IT!

QUESTION:

I have a family member with dementia who is approaching her final days. What can I expect and how can I help?

Ask an Expert

It's never easy when someone you care about is nearing their final days of life, especially if you've never experienced a death before. It's no different when a family member has dementia. Here are some things you may notice and some tips on how you can make the person more comfortable:

Decreased circulation: You may notice that your family member's hands and feet are pale to bluish in colour and feel cool to touch. **You can help** by giving a gentle massage with an alcohol-free lotion. Warm your hands first and let them know who you are and what you are going to do before touching.

Dry mouth: Not eating and drinking is a natural cycle of physical decline in the final days. **You can help** by moistening your family member's mouth and lips with a damp cloth. If the person is still aware, offer small amounts of ice chips or fluids.

Dry skin: With age, skin may naturally become drier and more fragile. **You can help** by applying an alcohol-free lotion to the skin and by wiping the person's head, eyes, wrists and hands with a warm cloth.

Increased sleepiness or drowsiness: This usually signals the final days or hours of a person's life. **You can help** by playing your family member's favourite music, holding their hand and sharing calmness, peace and quietness together. If the person finds comfort in spiritual care, you can arrange for their clergy member to visit.

Changes in breathing: The rhythm, depth and rate, and the sound of your family member's breathing may change. This is normal at end of life. **You can help** by discussing your concerns with the health care team. They may drain secretions from the mouth, elevate the head of the bed, or open a window/turn on a fan to attain a feeling of air movement.

At the bedside: Your family member may at times be unresponsive, but there is no way to know how much can be heard and processed by the brain when death is near. **You can help** by being sensitive to what is shared at the bedside and by leaving the room if the conversation might cause upset. If your family member seems confused or restless, **you can help** by reminding them that they are safe and cared for. Speak calmly and reassuringly, or share stories about good times.

Remember that, as your family member approaches end of life, your quiet presence can be the most profound gift. ◀



Rachael Mierke,
First Link Coordinator, Alzheimer Society of Manitoba



Jessica Phillips-Hunt believes in the work of the Alzheimer Society, and she's done her part to help. She has championed a team in the annual Walk for Alzheimer's for the last two years, and she's doing it again this year.

However, it was the Society's Touch Quilts that moved Jessica to give in a different way – a way that was meaningful to her – by making a personal \$2,000 gift directly to the Touch Quilt Program.

Putting a Meaningful Touch on Giving

As a community mental health worker specializing in seniors care, Jessica has seen first-hand how the lap-sized quilts help reduce agitation and provide comfort for residents in care.

Dementia has touched Jessica's life personally, as well. Her two grandfathers had vascular dementia, and she wishes her family had known about the Society at the time. It would have helped them understand and navigate the changes they saw in their family members.

Raising awareness and providing comfort, through the quilts, to people living in the later stages of dementia was important to Jessica. Giving this particular gift was a way she could help make the dementia journey a little easier for other families.

"I love how these quilts provide a way to meet people with dementia where they are at," explains Jessica. "It's a little thing, but it makes such a huge difference."

A Direct Impact

Jessica also appreciates seeing the direct impact her money has had. While various communities donate fabric for the Touch Quilt Program, additional supplies are also needed. Jessica's donation was used to purchase batting and labels for up to a year's worth of quilts that were distributed to long term care facilities throughout Manitoba.

CEO Wendy Schettler emphasizes that all donations have an impact on the programs and services the Society provides; however, giving to a particular program or area of interest may bring that impact closer to home for some people.

"We do our best to accommodate donors like Jessica who have very specific interests," explains Wendy. "We always find a way to make it work."

Jessica is grateful for the chance to direct her personal gift in a way that touched the hearts of those living with dementia, as well as her own. ◀

CEO Message

Dementia Friendly Communities: A Personal Matter

In last September's newsletter, I let you know about a new program launched by the Alzheimer Society: the Dementia Friendly Communities initiative. It gives me great pleasure to report that this program hit a chord and has grown by leaps and bounds in a few short months.

The program is all about reducing the stigma of dementia by including people with the disease in community activities. The goal is to ensure that these individuals feel welcome to participate in society, whether buying groceries, using public transportation, taking a course at a recreation centre or attending their church.

To make this happen, we knew we had to get people in the community on board through education about the disease. We had to teach people what they could do to make their organizations inclusive. The Alzheimer Society got busy; last fall, we started approaching a multitude of organizations, including businesses, government agencies, schools, churches and community groups.

At first, we made a lot of cold calls to explain the initiative. Now, through word of mouth, organizations are calling us. From September 2016 to now, over 60 Dementia Friendly Community presentations, workshops and meetings have taken place around the city – and the calls keep coming.

I truly believe that the interest we have received means that organizations and businesses are taking the program seriously. They want to understand how their staff can make it easier for people with dementia to participate. They are open to physically altering their premises – improving lighting and signage, for example – so that these individuals can more easily navigate while visiting.

With this success, I'd like to take Dementia Friendly Communities to the next level. Our communities are made up of individuals, and I challenge you, as an individual, to join this initiative. Don't wait for others to lead; lead yourself. Help a neighbour with dementia to safely make their way to the coffee shop.

Assist someone at your local leisure club to find the materials they need to participate. Provide harmonies for a fellow vocalist in your choir. Smile. Listen. Understand.

These are just some of the ways we can all help people with dementia to be accepted as part of the fabric of our society. If you want to learn more about helping to build dementia friendly communities, give us a call at 204-943-6622 (Winnipeg) or 1-800-378-6699 (Manitoba). ◀



Wendy Schettler, CEO

The Alzheimer Society thanks the Winnipeg Foundation for supporting the Dementia Friendly Community project.

"Outside Guy" continued from page 1...

challenges of a diagnosis before age 65.

Deric comments that someone in their eighties is a lot different than someone in their sixties with young onset. "In my case, we're talking about a healthy 62-year-old person. I could be in the shower and by time I get out, she's out of the neighbourhood."

Norma Kirkby, Program Director at the Society and group co-facilitator, understands this. "Care partners of younger people with dementia experience the caregiver journey differently – they may have busy lives with many responsibilities, such as working or caring for children or parents," she says. "To accommodate, people can attend the group in person or participate by teleconference from anywhere in Manitoba."

Deric says that group members provide each other with encouragement and affirmation around difficult decisions, such

as whether to move their family member to a care setting.

"People wrestle with the guilt. They feel like they're giving up on the person," Deric says. "But it gets to the point where it's too much to keep someone at home."

Now that Anni is in supportive housing, Deric says he comes away from Support Group meetings with practical advice for how to make the most of his visits with her. He looks forward each month to the opportunity to learn from others and share his own insights.

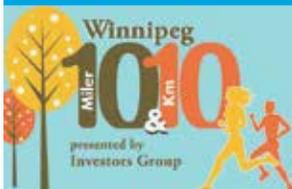
"You'd think that, considering what is being discussed, it would be a stressful place, but it's not," he says. "I always feel a calming effect."

To learn more about this group and others offered at the Society, call 204-943-6622 (Winnipeg) or 1-800-378-6699 (Manitoba), or visit alzheimer.mb.ca and click on "Programs and Services." ◀



Support the Alzheimer Society's programs and services by hosting a fundraising event of your choice. Click on the "Anything for Alzheimer's" link at: alzheimer.mb.ca

UPCOMING EVENTS!



Winnipeg 10/10 & 5km
presented by Investors Group

Register: events.runningroom.com and help to support the Alzheimer Society of Manitoba. Information: Chris Walton at cwalton@runningroom.com

Upcoming Event:
Winnipeg 10 & 10

It's a run like no other! Run or walk 30km, 10mile, 10km or 5km events that start and finish in downtown Wpg during Manyfest on Sunday, September 10, 7:30 am. The Running Room is partnering with the Alzheimer Society for this event.

Saturday, August 12th
at the site of
Dauphin Countryfest



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FOR DEMENTIA

To register, visit alzheimer.mb.ca



For information, contact Wanda Sime:
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alzprk@alzheimer.mb.ca

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