Alzheimer's - an inspirational journey

Alzheimer's disease is a degenerative, progressive type of dementia that causes problems with memory, thinking and behaviour. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.



Discovering a loved one has Alzheimer's disease can be devastating. We explore what it's like caring for someone with Alzheimer's by walking a mile in Trish T.'s shoes. Trish's mom was diagnosed five years ago and has learned a lot since—about the system, the challenges of being a "sandwicher" and how to celebrate the little things.

Tell me about your mom. How old was she when she was diagnosed?

My mom was social. She kept a meticulous home and there was always something cooking in the oven in case of visitors — she was social and had an open door policy. She was diagnosed with Alzheimer's-related dementia five years ago at the age of 70.

Looking back, what were the signs and symptoms of Alzheimer's your mom experienced?

Before her Alzheimer's diagnosis, my mom experienced dramatic hearing loss so in hindsight, there were many signs but they went unnoticed because we thought they were due to this. She became less vocal and didn't contribute to conversations much.

Also, her kitchen cupboards suddenly became incredibly packed and unorganized. Normally, her cupboards are highly organized and anything less than that would cause her anxiety, but she seemed unaffected.

And then there was the incident that made us realize something was terribly wrong; she went to go to a doctor's appointment and ended up 40 kilometres away after boarding the wrong train. We got a call from the police who told us that staff at the train station found my mother wandering, disoriented and confused. At this point, we knew it had nothing to do with her hearing loss.

What are the challenges of caring for someone with Alzheimer's?

At first we thought, "How are we going to deal with this? What should we expect?" Ultimately, we made the decision that it was best to keep her at home and do anything we could to accommodate her there.

Some of the biggest challenges were removed when we made my parents' home accessible. Before this it was hard, for example, to guide her into the tub because she couldn't hear or follow instructions. She is no longer as mobile as she was and so there is no risk of her wandering.

Personally, my biggest challenge is juggling two homes ("sandwich generation"). I'm constantly coordinating care for my parents and taking care of my own family – especially my 13-year old son who demands a great deal of my time.

Tell me about some of the tasks you do to help on a regular basis?

My 84-year old father cares for my mom at home and has committed to doing so as long as he can. I'm currently the main contact and family "co-ordinator" for all her care including her visits to her day program, visits by her home care providers (for personal care, help with feeding and caregiver relief). I am constantly trying to find ways to make life easier for my father to care for her in their home.

What are some tips you can provide to someone who has just learned a parent has Alzheimer's?

The best advice I was given, is to contact the local Regional Geriatric Program as soon as a loved one is diagnosed. Nothing compares to dealing with geriatric professionals who really "get" this disease. Prior to this, we felt lost in the system. Also, contact your local community care network–they are a wealth of information and the best navigators through the system.

What's your biggest concern about caring for your mom?
I worry that the time will come when we can't care for her at home. And, of course, ultimately, my concern is for my dad. He is 84 years old and, thankfully, is in great shape. However, I do worry about caregiver burnout. I fear my dad will get exhausted caring for her so it's important to me that he gets enough time to rest and get away from the stresses of caring for someone with Alzheimer's. This is why I advocate for him to get caregiver relief – this gives him the chance to get out and meet with friends, go for walks and also volunteer his time at church.

How do you stay positive?
It can be difficult — there isn't really a bright side to Alzheimer's. But with the modifications to my mom's home and home care in place, I'm relieved knowing that my mom will be able to stay at home for awhile to come and there's some comfort in that.

Top Signs of Alzheimer's

Forgetting entire events, not just details.
It's not uncommon to forget or confuse smaller details of an event, but if the person doesn't remember ever meeting a friend for coffee or making the doctor's appointment in the first place, a flag should go up.

Putting objects in odd spots.
If you're mystified as to why the keys are in the toaster oven or why the remote is in the fridge, you're right to be concerned.

Trouble with simple directions or problems.
Being unable to follow a recipe is a classic sign of Alzheimer's as is trouble balancing a chequebook.

Forgetting common names of people and objects as well as everyday routines.
A father forgetting his daughter's name or replacing the word "friend" with an unrelated word like "shoe" are common signs of trouble. Getting lost going to a familiar place like the grocery store or the doctor's office is also an indicator.

Personality, behaviour and mood changes.
Someone with Alzheimer's may experience emotional mood swings—laughing one minute and weeping the next. Withdrawing socially—cancelling appointments or remaining silent during family conversations— is another important warning sign to look out for.

Hearing loss.
Recent studies show a link between moderate to serious hearing loss and Alzheimer's. In fact, for every 10 decibels of hearing ability lost, the risk for Alzheimer's increased by 20 per cent. There are a number of theories about why this is, but it's definitely something to watch for and a challenge that can delay diagnosis.

Remember, every person is unique and so is each individual's experience with Alzheimer's. But there are some common threads in most cases. If any of these signs seem familiar, seek help from a doctor immediately for a diagnosis.

Alzheimer's Alert

- One in 11 Canadians over 65 has Alzheimer's or a related dementia.
- Women account for 72% of all Alzheimer's cases.
- Alzheimer's cases are expected to more than double by 2036.

An Ounce of Prevention:

Age isn't the only risk factor for Alzheimer's (though it is a big one). Enhance your brain power and reduce your risk with these bright ideas to keep your brain sharp.

Get active. Many studies suggest a link between regular weekly physical activity and improved brain function.

Stay connected. A large social circle might not just be a key to a longer life, it may also protect you from showing the signs of neurological decline.

"Work out" your mind. Reading, crossword puzzles and discovering new routes to take to work can all help keep your mental "muscles" strong and flexible. Even better preventative medicine: learning a second language. A recent St. Michael's Hospital study found Alzheimer's symptoms can be delayed by up to five years if you know more than one language.

Keep blood pressure, cholesterol levels and diabetes at bay. A healthy body can help maintain a healthy mind, but ensuring your blood pressure, cholesterol and diabetes are all under control are especially important in reducing your chances of Alzheimer's disease.

Sleep. A lack of sleep may cause plaque buildup in the brain. This buildup is thought to be linked to Alzheimer's, so turn off that computer, mobile device or TV and turn in early!

Go Mediterranean. Eat more fish, leafy green vegetables, fruit, olive oil and nuts and cut back on your consumption of saturated fats like those found in red meats, organs and high fat dairy products including butter.