

# **Statistics, Strategies and.... Snoopy!**

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Alzheimer Society of Canada**

Dear Alzheimer's Society,

I see nowhere on your website information about how caregivers can cope with this disease. My husband has it. He refuses to admit it. How can I cope with his asking the same question three times in an hour, forgetting names of close friends, being totally apathetic about everything?

I take him for long walks twice a day, feed him nutritious meals, encourage him to do the puzzles in the paper every day, which he does quite well, amazingly enough, but he is lost in his own world, and can no longer help me with mine.

He used to be such a clever carpenter and to know everything about carpentry, etc. He was in fact a brilliant mathematics professor. Now I have to do all that - well not the mathematics, but all the other "technical" stuff around the house. He almost killed himself with a power saw until I intervened. He can't even remember any more how to program a VCR, and I used to think that was the equivalent to rocket science. Now it's all my responsibility.

We have no children, and any relatives we do have don't want to admit I have any problems. They more or less tell me I'm lucky I don't have their problems. I'm so totally terrified, not to mention bored out of my skull having to deal with a person who is operating at kindergarden level. There's no one I can talk to. All our friends refuse to admit my husband has Alzheimer's. Has anyone else ever experienced this? Do I just have to tough it out?

Has anyone else ever had to face these dilemmas walking down that horrific road to the end with an Alzheimer's patient? If so, could they please tell me how to do it with grace and courage? My friends in similar situations, and I have at least three of them, have behaved very badly in my opinion, shoving their spouses into institutions at the first possible opportunity. I do not want to do that. I think there must be some way of ensuring that my husband can enjoy a better life during his last years. Please refer me to information that shows me how to give this to him, and help me retain some sanity too.

Hoping you can help,

# Dementia in Canada at a glance

- Approximately **500,000** Canadians are living with Alzheimer's disease or a related dementia.
- More than 70,000 Canadians living with Alzheimer's disease or a related dementia are **under the age of 65**.
- Women make up **72 per cent** of Canadians with Alzheimer's disease.



Within a generation (25 years), the number of people living with Alzheimer's disease or a related dementia could reach between **1 million** and **1.3 million**.

# What *Rising Tide* says

- The growth of the dementia problem in Canada will accelerate as the population ages. The first of the Baby Boomers will enter their senior years (65+) in 2011.
- By 2038, the rate of dementia incidence for 65+ is expected to increase to 250,000 new cases per year (2.5 times the current level).
- By 2038, 1.1 million Canadians are expected to have dementia, approximately 2.8% of all Canadians.
- In the next 30 years, the excess demand for long-term care required by dementia patients will increase over 10-times the current demand.
- Over the next 30 years, dementia is expected to cost society over \$872 billion dollars in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with the provision of unpaid care.

# What *Rising Tide* says: incidence

**Incidence: Number of new cases of dementia per year**

The number of new cases of dementia in 2038, among Canadians (65+), is expected to be 2.5 times that for 2008.

Within a generation, we will jump from one new case of dementia every FIVE minutes to one every TWO minutes.

# The Ripple Effect of Dementia\*

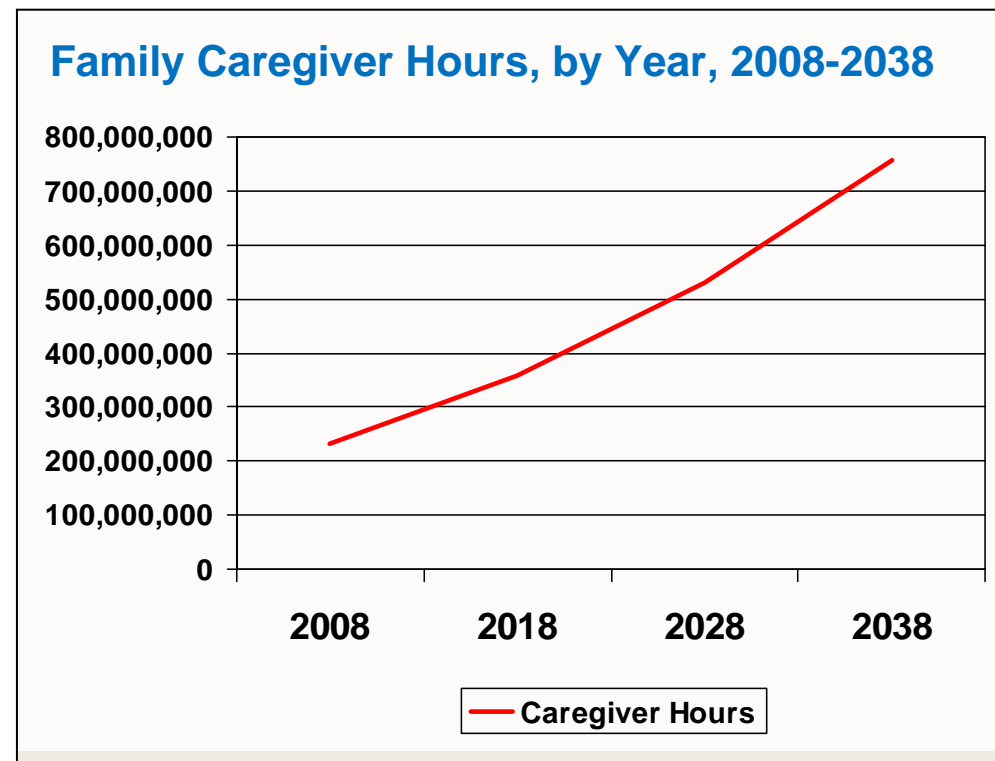
- Family remains the cornerstone of care, but their need for support is often overlooked.
- Need for care varies by level of dementia:
  - ❖ 30% for mild/early dementia
  - ❖ 69% for moderate/middle stage dementia
  - ❖ 88% for severe/late stage dementia
- Very high levels of psychological problems in caregivers: 40% to 75%
- Prevalence of clinical depression among caregivers: 15 to 32%



\* World Alzheimer Day Report, Sept, 2010

# What *Rising Tide* says: caregiving

- As care shifts away from care facilities there will be an increase in the need for family-based care.
- The number of hours spent on family-based care is expected to more than triple by 2038.



Now

**231 million hours**

Within a Generation

**756 million hours**

**The time Canadians will be providing in informal care**

# What if?

**1. *What if we focused on primary prevention?***

Brain Health Cognitive Training; delay onset through a comprehensive risk reduction strategy.

**2. *What if we focused on secondary prevention?***

Early diagnosis in order to treat and mitigate the course of the disease. Delay disease progression through focused exercise and other prevention programs for individuals diagnosed with MCI or early stage dementia.

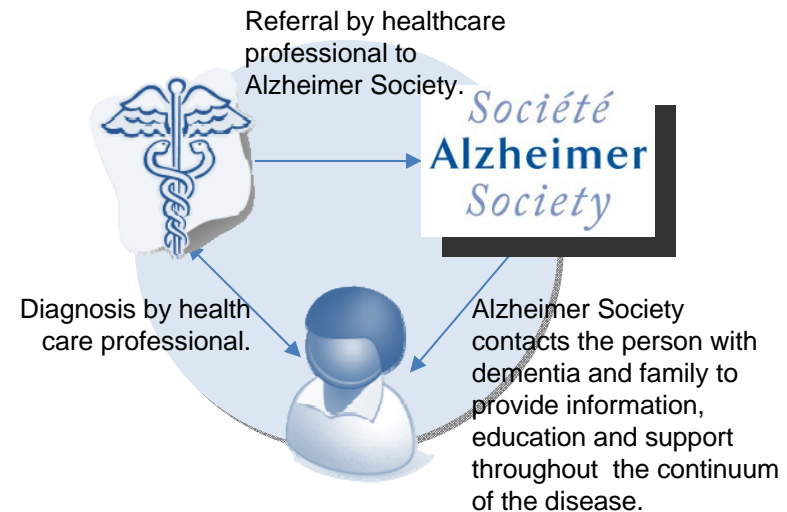
**3. *What if we focused on assigning a System Navigator to all people when they are diagnosed with dementia?***

**4. *What if we focused on providing caregiver education and support through the Alzheimer Society's First Link® Program?***

*Stemming the rising tide....*

## First Link<sup>®</sup>

**First Link<sup>®</sup>** focuses on referral sources (like Family Physicians) getting to know the Alzheimer Society and referring the person and family and their local Alzheimer Society as soon as possible after diagnosis.



*Soci t  Alzheimer Society*



## What *Rising Tide* says: long term care

- The *Rising Tide* report assumes that the number of long term care beds in Canada will grow from approximately 280,000 in 2008 to 690,000 in 2038. This leaves a projected shortfall of more than 157,000 beds in 2038.
- This increase in need signals that all the current issues regarding the quality of dementia care in care home settings will only be multiplied with approximately 260,000 more individuals living in long term care in 2038 than in 2008.

*Stemming the rising tide....*

## **Person-Centred Care in Long Term Care Homes**

- The Alzheimer Society believes that people with dementia have the right to enjoy the highest possible quality of life and quality of care.
- The Society believes that each person with dementia is an individual, regardless of stage of the disease and that care should be individually tailored to their unique needs, interests, habits and desires.



*“I as a person have not changed ... only my mind”*

- Person-centred care is a philosophy that recognizes that individuals are *unique with personal values, unique history and personality*.
- Person-centred care recognizes that *each person has an equal right to dignity, respect, and to participate fully in their environment*.
- Person-centred care focuses on individuals as *whole persons* rather than tasks.



- Person-centred care takes into account the specific needs and preferences of each person; it is grounded in *mutually beneficial partnerships established between people living with dementia and their caregivers.*
- The ultimate goal of person centred care is to create partnerships between people with dementia and their caregivers that will lead to the best outcomes and *enhance the quality of life and the quality of care of people living with the disease.*

hi my name is Jennifer and im taking care of my grandmother that has alzheimers and i was wondering if there was something we could do to make her so that she wont worry as much as she does. we got her a dog and that helped alot but now i dont know wat else to do to help her to keep her from obsessing over things. i was wondering if u had any tips on how to help ease her mind.

Hello Jennifer: I am glad that you contacted us at the Alzheimer Society of Canada and that you are asking for our help. It sounds like your grandmother is really lucky to have someone like you to help her out. It also sounds like it can be very hard at times to try to make her happy.

Getting a dog probably makes your grandmother feel less alone and it also means she needs to get out and walk the dog sometimes. Exercise and companionship are two really important things that we all need and your grandmother is the same! The fact that she worries a lot may be because of a lot of different reasons. She may have always been the kind of person who worried about things and she may also be worrying more now because she knows she doesn't remember things like she used to and she is nervous about forgetting something really important. Alzheimer's disease is a sickness that makes people forget things and that includes the things that we take for granted everyday - like knowing how to get dressed or finding our way home from the local store. Your grandmother may be obsessing about things because she sees these changes in herself and it is scary.

There are a lot of things you can do with your grandmother to help ease her mind. Spending time together in new or familiar activities (whichever she seems to enjoy more) is one great way to help her to feel good about herself and to enjoy your company. Doing things that will help her to keep the abilities she still has is important and we have lots of suggestions on our website.

But I also suggest that you give the knowledgeable staff at your local Alzheimer Society a call. They know a lot about the disease and what it does to people. They also know how hard it can be to watch someone you love change. They can give you suggestions about how to help your grandmother and also talk to you about how it feels for you because it is not always easy. The staff there are happy to be of help. I hope you will give them a call! Thanks for writing in, Jennifer. I hope you get some of the help you are looking for. All the best, Mary

thank you so much for ur help. thats pretty much wat we are trying to do. i got her a litle terrier named snoopy and she adores him. whenever she is realy obsessing over something i find that dressing him up in funny litle outfits distracts her and makes her very happy and amused and so far that is working great he is worth his weight in gold and more. thank you so much for ur reply. -Jennifer

You sound like a natural at this! What a great idea!  
Your grandmother is so lucky to have you in her life. Don't ever forget what a difference your love, laughter and support make to her. Thanks for sharing your story with us! Take good care, Mary

For Jennifer and her grandmother, person-centred care = a little terrier named Snoopy dressed up in funny little outfits.



What does person-centred  
care mean to you?

To each of your clients?

*It's our job to find out.*

*Société Alzheimer Society*



# Alzheimer Society of Canada

[www.alzheimer.ca](http://www.alzheimer.ca)

Progression Series:

<http://www.alzheimer.ca/english/disease/progression-intro.htm>

Guidelines for Care:

<http://www.alzheimer.ca/english/care/guidelines-care-intro.htm>

Communication:

<http://www.alzheimer.ca/english/care/dailyliving-communication.htm>

Related dementias:

<http://www.alzheimer.ca/english/disease/dementias-intro.htm>

Local and provincial offices:

<http://www.alzheimer.ca/english/offices/intro.htm>

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