



# THE DEMENTIA EPIDEMIC ARE WE READY?

BY KAREN HENDERSON

**ALZHEIMER'S DISEASE, THE MOST COMMON FORM OF DEMENTIA AMONG OLDER ADULTS, IS A PROGRESSIVE, FATAL BRAIN DISEASE.**

**A**LZHEIMER'S DISEASE WAS FIRST DIAGNOSED by Dr. Alois Alzheimer in 1906 in Frankfurt, Germany. The symptoms of Alzheimer's—memory loss, cognitive and language deficits, auditory hallucinations, delusions, paranoia and aggressive behavior—were usually referred to as “senile dementia” and generally considered a normal part of aging.

We now know better—unfortunately. As scientists began to realize that Alzheimer's was a disease characterized by plaques and tangles in the brain, the Alzheimer Society of Canada—the first organization of its kind in the world—was founded by Madeleine Honeyman in 1978. Madeleine cared for her husband who suffered from dementia and when she asked for help or guidance, she was abandoned by the medical industry who told her that her husband would be dead in three years and to think only about herself. She is now 98 and has not stopped advocating for those who suffer from this terrible affliction.

Alzheimer's Disease has no known cause and no cure; the medications available may slow the progression of the disease in some but will not stop it.

In January 2010, the Alzheimer Society of Canada released an alarming report titled, “Rising Tide: The Impact of Dementia on Canadian Society.” In the report the Society

## Additional Stats

If dementia care were a country, it would be the world's 18th largest economy. If it were a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion). *The World Alzheimer Report 2010*

	CANADA	US	THE WORLD
<b>NUMBER OF PEOPLE SUFFERING FROM DEMENTIA NOW</b>	500,000	5.3 million	35.6 million
<b>IN APPROXIMATELY 20 YEARS</b>	1,125,200	7.7 million	65.7 million

Stats sources: Canada: Alzheimer Society of Canada; United States: Alzheimer Association; World: Alzheimer Disease International.

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# What About The Caregivers?

BY KAREN HENDERSON



**A**S OUR POPULATION rapidly ages, more of us are being called upon to become caregivers. In our society this is a thankless job; caregivers receive no formal training, too little community support and of course no financial compensation for taking time off work or indeed, quitting entirely, which too often happens when the care receiver has dementia and needs 24/7 care and supervision.

Caregivers are primarily spouses, which is not ideal because they, too, are usually coping with age-related issues. Typically the second most common caregivers are the daughters of the patient, who must often juggle the demands of caregiving with the demands of a career, children and otherwise busy lives.

Unfortunately caregivers take on the burden with little complaint. This accepting attitude has allowed governments to ignore their plight and happily accept the \$25 billion<sup>1</sup> a year in unpaid labor, often allowing the caregivers to destroy themselves physically, emotionally, socially, and financially while doing the right thing by their loved ones.

The burden is huge. In 2008, 231 million hours of care were spent in Canada by the families of people suffering from Alzheimer's. The Rising Tide study anticipates that this will be 750 million hours in 2038.

The Canadian Institute for Health Information (CIHI) issued a report in late August called, "Supporting Informal Caregivers:

The Heart of Home Care." It showed that one in six people caring for ailing seniors at home is in distress. The number shoots up to one in three if the senior has cognitive problems such as Alzheimer's Disease; one in two if the senior is aggressive or abusive.

Nearly 40 percent of family members caring for a loved one with dementia suffer from such signs of distress as depression, rage and an inability to cope.

And what if a person suffering from dementia can no longer stay at home because the caregiver is burned out or the dementia sufferer has become violent or dangerous? The Rising Tide report stated that although the number of long-term care beds in nursing homes is forecasted to grow from approximately 280,000 beds in 2008 to 690,000 in 2038—10 times the current demand—there will be a projected shortfall of more than 157,000 beds. Families are waiting months, even years now for a long-term care bed; how will they survive in the future?

Once again, there is no national strategy to support caregivers, although this has been "discussed" for years.

Caregiving until the end of life leaves few untouched. In most cases the death of a loved one allows caregivers to heal and move forward, wiser in the knowledge that the circle of life continues as it always has. Dementia, however, imposes its own set of unique sorrows upon caregivers because when the dementia journey is supposed to be over, it's not over. After this unspeakable injustice has robbed us, daughters and sons, of those we love, after we are finally able to shake off the shock, the fatigue and the disbelief over what we have managed to live through, what remains is the dark terror that we will follow in our parents' genetic footsteps. **A**

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#### FOOTNOTE:

<sup>1</sup> M. J. Hollander, et al., "Who Cares and How Much?" *Health Care Quarterly* 12, 2 (2009): pp. 42-49.

warned that the number of Canadians living with Alzheimer's Disease or dementia is expected to swell to epidemic proportions within a generation. About half a million Canadians are now affected; the Society predicts that within 25 years, the number of cases of Alzheimer's or a related dementia will more than double, ranging between one million and 1.3 million people. It is seen in all cultures, but affects more women. Women account for 72 percent of Canadians with Alzheimer's Disease.

### ECONOMIC BURDEN

The current cost to Canadians for dementia care is \$15 billion; over the next 30 years dementia is expected to cost society over \$872 billion in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with the provision of unpaid care.

"These new data only reinforce the fact that Alzheimer's Disease and related dementias are a rising concern in this country, an epidemic that has the potential to overwhelm the Canadian health care system," Ray Congdon of the Alzheimer Society said in a statement.

### DEMENTIA IS STRIKING A GROWING NUMBER OF BOOMERS

The report also stated that of the half-million Canadians affected by various forms of dementia, about 71,000, or almost 15 percent, are under 65. Of those, 50,000 are 59 or younger.

"We know that we're finding far more individuals in their 50s and 60s who have dementia," said Society CEO Scott Dudgeon. "We're talking about dementia generally, including Alzheimer's Disease."

### WHAT SHOULD WE BE DOING TO PREPARE?

At this time Canada does not have a national strategy to cope with the oncoming crisis. Only a handful of governments have national dementia or Alzheimer's policy strategies—France, England and Australia do, but the United States and many developing nations do not.

The Canadian report recommends the following:

1. Accelerate investment in all areas of dementia research
2. Recognize the critical role that fam-

ily caregivers play; provide them with information, education and financial support

3. Recognize the importance of prevention and early intervention
4. Place greater emphasis on care integration
5. Strengthen Canada's dementia workforce

### WHO IS SOUNDING THE CALL?

We read the papers. We watch the news. We know there is a problem. But who is taking action? The dementia crisis is not a priority for the Canadian government. Individuals and families are reluctant to take the time to plan for aging and long-term care planning. The majority of professionals who advise aging citizens—financial, legal, accounting—are uneducated about aging and dementia and resist stepping up and discussing the issues.

So it is up to individuals to respond and react. Become aware and become educated. Recognize the need for long-term care planning now! **A**

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## LET'S START A CONVERSATION!

The information presented here focuses on the Canadian perspective of Alzheimer's Disease, the most common form of dementia among older adults.

There has been much written about this brain disease. We know it's progressive and fatal. We know that today there is no cure. We also know it's not just a disease that affects the elderly. It can strike people in their 40s and 50s.

Armed with that knowledge, it's important to know what's being done, not just in our own backyards, but throughout the world as well. In short, what are we doing to prepare for this oncoming crisis?

As actuaries, what is your perspective about this growing epidemic? How will it affect the work you do? How will it affect the health care industry? What will be the impact on long-term care? On life insurance?

Please share your views with us. Your feedback is important and may be included in an upcoming issue of *The Actuary*. Send an e-mail to [theactuary@soa.org](mailto:theactuary@soa.org).

We welcome your comments. Let's start a conversation!