

# Alzheimer Society

CANADA

## News from the Alzheimer Society of Canada

### Online Support for People Living with Alzheimer Disease

#### Canadian Trends for Online Health Information

The Internet is now the second most common source of health information for Canadians, ranking ahead of radio, television and newspapers. It is surpassed only by face-to-face contact with a health professional.

Findings of a 2001 Canadian Medical Association survey revealed that almost half of Canadian physicians “at least occasionally” referred patients to a medical website. Of these physicians, seven out of 10 recommended disease-specific websites.

The Alzheimer Society of Canada’s website ([www.alzheimer.ca](http://www.alzheimer.ca)) first came online in 1997. This site provides bilingual information on care, services, research and treatment of Alzheimer Disease (AD) in Canada. On average, visitors view 7,000 pages each day.

#### Who Visits the Website?

A recent survey of visitors to the Alzheimer Society website revealed that 84% of people searching for information knew someone with AD—a spouse, parent, relative or friend. It also revealed that 3% of visitors were people with AD.

Although most people prefer to use the website for research and information-gathering purposes, many use the Alzheimer Society’s Care Exchange and Caregiver Forum, and Ask the Expert services.

#### Online Support

**The Forum.** The Care Exchange and Caregiver Forum is a discussion board for people to share expe-

riences and exchange information with others who understand. For some it has become a virtual support group connecting people dealing with similar issues.

*“Unless you are faced with this disease, you can’t begin to understand how it feels to be dealing with a person with AD... It helps me to read this message board and see that others are facing the same problems. It helps me to carry on...”*

—Louise, 11:33 AM

It is also a place where those in the early stage of AD can share their experiences of living with the disease.

*“I’m now 54 and the changes are not so ‘little’ anymore... Yup, my brain is dying. Literally. And I get to watch it happen, day by day, week by week... To all you wonderful, so often unrecognized caregivers—I truly can’t imagine the sheer hell it must so often be for you...and while those with this disease who carry on ‘right to the bitter end’ [and lose] awareness of ‘dying,’ the caretaker’s hell continues right on. You are truly the silent victims.”*

—Marilyne, 2:16 PM

And because the Internet is available 24 hours a day, seven days a week, people in crisis can reach out when they need to.

*“It seems that when I am in crisis, this is the place I turn to, automatically. It’s almost 4 in the morning and I’ve not [been] to bed yet... It’s going*

*to be 4 years since I stopped working to care for my mother. There's nobody else to do it. No family living in Canada. I am it. 7 days/24 [hours]... Thanks for your ears and shoulders. I just needed to get it out of my chest for a little while."*

*—Elisabeth, 4:12 AM*

Forum visitors are not required to actively participate. Many benefit simply from reading the messages, knowing they are not alone. The Care Exchange and Caregiver Forum is the most visited part of the website.

**Ask the Expert ([expert@alzheimer.ca](mailto:expert@alzheimer.ca)).** The Ask the Expert service is intended to help people with questions who have not found the answers on the website. On average, 75 questions per month are submitted from across Canada and around the world. Users of Ask the Expert benefit from:

- a 24-hour response time
- answers tailored to their situation
- direction to a specific area of our website for more information
- referrals to their healthcare professional or local Alzheimer Society for information and resources
- the opportunity for future dialogue

"People who use Ask the Expert differ from people who may attend a support group," explains Ilona Horgen, Director of Support Services and Education at the Alzheimer Society of Canada. "These people want information quickly and they want to pose their question privately, anonymously and at a time that is convenient to them. They are also looking for a personal response."

Ask the Expert is a confidential service of the Support Services and Education department of the Alzheimer Society of Canada. Staff are knowledgeable about programs and services provided by the Society across Canada, and have access to healthcare professionals who provide information on a variety of topics related to AD.

The most frequently asked questions are from caregivers seeking support services close to where they live and disease-management information. Visitors to the website are reminded that the information presented is not a substitute for medical advice and are advised to see their doctor or other qualified healthcare provider for personal assessment.

***Health on the Net Code of Conduct (HONcode®).***

The Health on the Net Foundation, located in Geneva Switzerland, was formed in 1995 to establish a code of conduct for medical and health websites.

The HONcode consists of eight principles which aim to standardize the reliability of medical and health information available on the Internet. They address the authority of the information provided, data confidentiality and privacy, proper attribution of sources, transparency of financial sponsorship and importance of clearly separating advertising from editorial content.

Adopted by over 3000 websites worldwide, the HONcode seal of approval on subscribing sites helps users identify sources of reliable information. The Alzheimer Society of Canada website has been a HONcode member since 1998.

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***The Alzheimer Society of Canada is a not-for-profit health organization dedicated to helping people affected by Alzheimer Disease. The Society provides support and educational programs for people with Alzheimer Disease and their caregivers. The Society also funds research into finding the causes and cure of the disease, and into improved methods of caregiving. The Society consists of a national office, 10 provincial organizations and more than 140 local groups across the country.***

***For more information on Alzheimer Disease and related dementias, Alzheimer Society programs and services, and how you can help, contact your local Alzheimer Society or visit the Society's website at [www.alzheimer.ca](http://www.alzheimer.ca) or call 1-800-616-8816.***