

News from the Alzheimer Society of Canada

People in Early Stages Shaping the Future of their Care

This year, the Alzheimer Society of Canada (ASC) is celebrating its 25th anniversary. As we commemorate one quarter of a century of helping people affected by Alzheimer Disease (AD)—whether through support and education programs or by funding Canadian researchers—we recognize a significant change that has taken place recently in our history: a change that has greatly influenced how we provide programs and services for people with AD and their families.

In the past, people with AD were often too far along in the disease process to play a part in making decisions with respect to their futures. For most of our history, therefore, the Society has provided support programs and educational information for family members and caregivers of people with AD. And when feedback on new programs was needed, we consulted with family members and caregivers. But in the last few years, there has been a significant shift in how the Society serves “people affected by AD.” Now, we also provide support programs and educational material for people with AD, because more and more they are being diagnosed in the early stages of the disease, and are able to participate in the management and care of their disease. Today, people with AD are increasingly playing a role in their own care and collaborating with the Society to provide input into the programs and educational materials that are created.

“The opportunity for early diagnosis of AD,” said Stephen Rudin, executive director of the ASC, “is a significant advance in the history of the disease and one that the Alzheimer Society of Canada fully encourages people to seek. Early diagnosis empowers people with the disease and allows them to seek information and support from the Alzheimer

Society, while also giving them more choice in the area of pharmacological treatments. The Alzheimer Society of Canada has benefited from having the insight of people living with the disease and we continue to partner with them to maintain and create new programs to serve them.”

One such effort took place in the summer of 2001. The ASC coordinated focus groups, across Canada, of people in the early stages of AD or a related dementia. The objective was to gather information from these individuals to assist the ASC in producing materials designed specifically for them and others living with AD or a related dementia.

A list of questions was distributed to provincial and local Alzheimer Societies that offer support groups for people in the early stages of AD. Ten early-stage support groups participated in the survey, representing seven provinces. Fifty-four men and women took part, ranging in age from 52 years to 83 years.

A variety of questions were posed to the participants eliciting helpful, insightful and sometimes surprising responses. The questions were as follows:

- What information do you need at this time?
- What concerns do you have with respect to losing abilities/family/staying in your home/dying?
- What kind of things do you need help with?
- What would you say to another person with AD/dementia to help them?
- What is your life like having AD/dementia?
- What is important to you?
- What is your hope for the future?
- Any other comments?

Across the country, some common themes emerged. They were as follows:

- Better doctor education about AD
- Reducing stigma
- Support for people who live alone and/or services for remote communities

(All three themes are important to the ASC and reducing stigma was chosen as the theme for the 2003 Alzheimer Awareness Campaign.)

Perhaps of most interest to readers of the *Canadian Alzheimer Disease Review* were the responses concerning doctors of people with AD or dementia. Comments from the focus-group participants identified the need for family physicians (FPs) to communicate the diagnosis of AD in a sensitive and caring manner, and to listen to the person's questions and concerns. Below is a brief summary of some of the replies pertaining to FPs that were communicated during the focus groups:

- Some participants were very happy with the kind care they received from their doctors. Others felt their diagnosis was communicated too coldly, without any consideration for how devastating the news would be to them.
- Some participants were disappointed that their FPs didn't have more knowledge of the disease to offer to patients upon sharing a diagnosis. For example: "I would like information from my FP about the new medicines and maybe vitamins. I had to go to the pharmacist to find out what might help me. The doctor can't provide the answers. When I went back to him after he diagnosed me, I asked him why he didn't give me any information; he told me he didn't think about it."
- While people in the focus groups recognize how busy their FPs are, they regret that their FPs aren't more available to them.

As a result of the information learned through the focus groups, the ASC created a booklet and companion audiotape (a more effective medium of processing information for some people with AD) incorporating the insights and experiences gathered from the focus-group participants.

This resource, entitled *Shared Experiences: Suggestions for those with Alzheimer Disease*, was created to assist people living with AD. It provides detailed information on the following topics: dealing with emotions; telling people you have the disease; learning more about the disease itself; what you can do; exploring treatment options; and planning for the future. Practical tips and suggestions, offered by the focus-group participants, are included as a way of helping others who are living with AD or a related dementia.

As more people with AD, or a related dementia, are diagnosed earlier in the disease process, they will participate increasingly in their own care. Groups working with people with AD or a related dementia should recognize that it is important to listen to and partner with them. During the last few years, since the Society has taken this approach, we have appreciated how much people in the early stages can contribute to advancing our knowledge of dementia by helping us understand things from their perspectives. We are confident that we are better serving this group of people.

Shared Experiences, as well as other educational material produced by the ASC, is available by contacting your local Alzheimer Society or visiting www.alzheimer.ca.

The Alzheimer Society of Canada is a not-for-profit health organization dedicated to helping those 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.

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 or call 1-800-616-8816.