

News from the Alzheimer Society of Canada

Tough Issues in Alzheimer Care

On a regular basis, perhaps even a daily basis, family physicians (FPs) are required to make difficult and sometimes controversial choices when caring for their patients. Generally, FPs make these decisions based on prior experience, with consideration for the values and beliefs of the patient, and with reference to the principles outlined in the Hippocratic Oath and the Code of Ethics of the Canadian Medical Association.

Treating people with Alzheimer Disease (AD) also poses many ethical challenges. The recent publication of *Tough Issues: Ethical Guidelines* is designed to assist FPs in making tough decisions by raising issues and providing guidance pertinent to various situations that may arise during the treatment and care of people with AD.

Tough Issues was launched in April 2003 at the Alzheimer Society of Canada's (ASC) 25th national conference in Ottawa. The publication provides information and guidance for people living with AD, as well as families, healthcare professionals and researchers involved with AD. This publication is actually the second by the same name. The first set of guidelines was published by the ASC in 1997, and was not created specifically for people living with AD but for AD caregivers and health professionals.

The new ethical guidelines represent the culmination of nearly two years of consultations nationwide, with over 150 people connected to AD representing different interest groups. An advisory committee was formed with people representing various viewpoints and areas of expertise, including people with AD.

There are three significant differences between the 2003 and 1997 ethical guidelines:

- 1) People with AD are now directly addressed in the guidelines, as they are capable of participating more in their own care (thanks to better awareness and earlier diagnosis of AD);

- 2) Two new guidelines have been added: "Living Alone" and "Intimacy and Sexuality"; and

- 3) Existing guidelines have been revised to reflect the progress that has been made in caring for people with AD.

Tough Issues examines nine topics that affect people touched by AD. Each section provides background information, explores an issue, offers recommendations (when possible) and lists additional resources. The topics are: communicating the diagnosis; driving; living alone; decision-making; respecting individual choice; quality of life; participation in research; genetic testing; restraints; and intimacy and sexuality.

"The first set of ethical guidelines," said Ilona Horgen, Director of Support Services and Education for the ASC and Chair of the Advisory Committee for the Alzheimer Society's ethical guidelines, "was received with a great deal of interest and enthusiasm when it was published in 1997 and we hope the 2003 document will prove to be just as helpful to healthcare professionals and members of the public. It's a valuable reference guide for every doctor's office."

Although all of the topics are relevant to FPs, the issues discussed below may pose particular challenges in the care of patients with AD.

Communicating the Diagnosis

Communicating the diagnosis of AD to a patient is often a very difficult task. FPs may wrestle with the fear that delivering the news will jeopardize their relationship with the patient or that the patient will not be able to cope with the information. Other common situations for FPs include learning that family members disagree about the need to communicate the diagnosis, or that the patient does not want to be told the cause of his/her symptoms. The Alzheimer Society believes that people with AD and their families need to be sensitively informed

about the diagnosis. If, however, a patient has expressed the wish not to know the cause of his/her symptoms, the request should be honoured. Knowledge of the diagnosis helps people to be directed to appropriate treatment, care and support, and provides the opportunity to develop plans for the future.

Use of Restraints

When is it appropriate to use chemical, physical or environmental restraints on a person with AD? Almost never, according to the new guidelines as well as “best-practices” research that exists on this subject. Although some aggressive behaviour may put others at risk of injury, there are preferred care strategies to assist in finding alternative solutions to restraints. The problem-solving approach advocated by the Alzheimer Society is described by the following steps:

1. Identify the problem prompting the behaviour.
2. Analyze the problem.
3. List possible strategies (solutions).
4. Choose a strategy (solution).
5. Take action.
6. Assess the results.

If it is deemed necessary to use restraints (*e.g.*, a lap belt at meal time) because restraint-free strategies are not possible, it is crucial that the least restrictive restraints are chosen and used appropriately, over the short-term, with regular monitoring and assessment. When minimal restraints are being considered, the positive and negative consequences for the person with AD and others must be carefully measured and monitored. The physical and mental well-being of a person in a restrained condition should not be compromised.

Living Alone

An increasing number of older people live alone. If family members do not live close by, it becomes morally incumbent upon FPs to help determine whether a patient with AD is still capable of living in his/her own home. In some communities, additional support can be provided in the home. FPs should consider the following factors before making their recommendation:

- Overall well-being
- Health
- Nutrition
- Safety
- Finances

For more information on the above, as well as day-to-day strategies to enhance independent living, see the “Living Alone” section in *Tough Issues*.

A diagnosis of AD does not automatically mean that a person is incapable of living alone. Some of the barriers to making informed decisions about a person’s ability to live at home include: privacy and confidentiality regulations; the limited availability of services to support independent living; and competency legislation. With growing numbers of people with AD living alone, there is a need for more public discussion of these issues.

Today, an estimated one in 13 Canadians older than 65 years of age (or 364,000 people) has AD or a related dementia. This ratio increases to one in three in those older than 85 years of age. Because of aging baby boomers, these numbers will escalate. An estimated 750,000 Canadians will have AD or a related dementia by the year 2031 if a cure is not found. Each year, approximately \$5.5 billion is spent on caring for Canadians with AD. There is an urgent need to provide appropriate care for Canadians who have AD. Awareness of the ethical issues can be an important first step in providing quality care.

Some topics covered in the new guidelines are among those that appear consistently and frequently in the literature on ethical issues in AD. Other topics are breaking new ground. As more people are diagnosed with AD, and understanding of the disease increases, discussions surrounding ethical issues will continue to evolve.

Copies of *Tough Issues* are available from local Alzheimer Societies across Canada. The information is also posted on the ASC’s website in the Alzheimer Care section at www.alzheimer.ca/english/care/ethics-intro.htm.

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.

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.