

Resources for people with dementia

The Alzheimer Society and beyond

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Abstract

Objective To summarize services provided by the Alzheimer Society and discuss other supports and resources available for the management of people with dementia.

Sources of information Ovid MEDLINE was searched using the terms *dementia, Alzheimer disease, community health services utilization, and caregiver stress.*

Main message Early diagnosis of dementia has been shown to be of benefit to patients and caregivers. Referral to the Alzheimer Society can help with nonpharmacologic management of dementia at the time of diagnosis and at any time during the course of the illness. Services include education about dementia, caregiver support, coordination of community services, and a variety of written resources for patients and caregivers. When available, the First Link program can assist with referral by minimizing the need for patients or caregivers to contact their local society branches. Other resources, including respite care and technological approaches to managing wandering, are discussed.

Conclusion The Alzheimer Society is an important part of dementia management, and family physicians should always consider referral at the time of diagnosis, regardless of the severity of the condition. First Link, when it is available, can facilitate referral. Resources such as respite care and day programs should be considered when available.

Case

Mr W. is an 84-year-old retired veteran brought to your office by his wife and daughter. They report a 2-year history of declining memory, increasing word-finding difficulties, and withdrawal from his hobbies of woodcarving and fishing. He has a history of hypertension and stable angina. Clinical evaluation during several visits leads to a diagnosis of dementia, likely Alzheimer disease. After sharing the diagnosis and providing basic education about dementia, including prognosis and expectations, safety issues such as driving, and follow-up plans, you discuss pharmacologic treatment options. Mr W. and his wife decline a trial of a cholinesterase inhibitor, given his brother's experience with nausea and decreased appetite. His wife asks what else they can do. You refer them to the Alzheimer Society First Link program and discuss activities that might be of help in optimizing health and function.

In 2010, the Alzheimer Society of Canada published *Rising Tide: The Impact of Dementia on Canadian Society*, which outlined the realities of increased rates of dementia and the effects on Canadian health care and our society.¹ The average family physician has 30 to 40 dementia patients in his or her practice, and this number is expected to rise as the prevalence of dementia increases to more than 1.1 million Canadians by 2038. Although neurologists, psychiatrists, and geriatricians provide specialty management of these conditions, family physicians play a crucial role, both in the community and

KEY POINTS The family physician is often the primary coordinator of care for the management of dementia, but there are resources that can augment care and improve outcomes. This article highlights the role of the Alzheimer Society in dementia management and summarizes the resources available to family physicians from the Alzheimer Society and other organizations to optimize care for patients and their caregivers. In addition to educational resources and support groups, locating technology and registration programs are available to help return patients home safely when they wander, and in-home respite care, day programs, and institutional respite care can be considered to help manage caregiver stress. The Alzheimer Society can provide information and help coordinate such services.

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in long-term care facilities. Caring for dementia can be time-consuming and challenging,^{2,3} given the profound effects the disease can have on patients, their families, and their caregivers. Although pharmacologic management should always be considered, the cornerstone of treatment remains nonpharmacologic (**Box 1**).^{4,5} The family physician is often the primary coordinator of care for the management of dementia, but there are resources that can augment care and improve outcomes.^{6,7} This paper highlights the role of the Alzheimer Society in dementia management and summarizes the resources available to family physicians from the Alzheimer Society and other organizations to optimize care for patients and their caregivers.

Sources of information

In order to identify English-language research and review articles related to the effects of community resources on caregiver stress and patient outcomes, Ovid MEDLINE was searched from 2000 to 2010 using the terms *dementia*, *Alzheimer disease*, *community health services utilization*, and *caregiver stress*. Articles cited in reviewed papers were also used when appropriate, as were the Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia guidelines.⁴

Main message

Initial role of the Alzheimer Society. Patients with dementia and their families benefit from accurate and clear information about the diagnosis as early as possible. Although the family physician (or other specialist) initiates discussions about what a dementia diagnosis means and provides practical information

about management, the time limitations on most clinic visits mean that additional strategies to support and educate patients and their families are needed. There are many misconceptions about Alzheimer disease and other dementias that can have profound effects on patients' experiences, particularly soon after diagnosis.^{8,9} Although pharmaceutical companies have produced useful patient information packages, the Alzheimer Society should play the main role in this patient education task.

Although some patients are overwhelmed with a new diagnosis, you should consider referral to the Alzheimer Society, or at least mention the role of formal support services, such as those provided by the Alzheimer Society, at the time of diagnosis. Physicians can suggest to patients that they contact the closest society chapter office and, if the service is available, refer them directly via the First Link program.¹⁰ Although there are no studies looking at early involvement with the Alzheimer Society specifically, evidence suggests that early diagnosis and use of formal services can help caregivers adjust to their new role and help establish relationships with service providers.⁸ It is important to stress that the Alzheimer Society can aid patients and families throughout the continuum of the disease, regardless of the type of dementia, and that the services are generally free. The local society chapter can also assist the family physician in identifying and accessing local resources that might be helpful to patients or families.

First Link program. Although referral to the Alzheimer Society is an important part of dementia management, it has been shown that it often does not

Box 1. Summary of Canadian guidelines related to nonpharmacologic management of dementia

Most patients with dementia can be assessed and managed adequately by their primary care physicians. However, in order to assist family physicians in meeting the needs of patients and their caregivers, the following are recommended:

- All patients with dementia and their families who consent should be referred to the local chapter of the Alzheimer Society (eg, First Link program where available).
- Primary care physicians should be aware of the resources available for the care of those with dementia in their communities (eg, support groups, adult day programs) and should make appropriate referrals to them.

Recommendations for nonpharmacologic interventions for the management of the cognitive and functional limitations arising from mild to moderate Alzheimer disease include the following:

- Further research is required to be able to conclude that cognitive training or cognitive rehabilitation are effective in improving or maintaining cognitive and functional performance in patients with mild to moderate dementia.
- Although there is some indication of a beneficial effect on IADL and ADL, there is insufficient evidence to make firm conclusions about the effectiveness of environmental interventions in promoting functional performance in persons with mild to moderate dementia.
- There is good evidence to indicate that individualized exercise programs have an effect on functional performance in those with mild to moderate dementia.
- For other nonpharmacologic therapeutic interventions, there is insufficient evidence to allow any conclusions about their efficacy in improving or maintaining functional performance in persons with mild to moderate dementia.

ADL—activities of daily living, IADL—instrumental activities of daily living.

Data from the Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia.⁴

happen.³ The First Link program was developed by the Alzheimer Society to assist physicians in the referral process and to decrease the need to rely on patients to act on their physicians' recommendations. The First Link referral process begins when the family physician seeks permission from the patient and family to provide the Alzheimer Society with contact information and sends a simple referral sheet to the local chapter office. The Alzheimer Society proactively contacts the patient or caregiver to introduce the services available and to arrange follow-up contact.

Unfortunately, First Link is not yet available across the country, and there is no central listing of programs as a result of funding variability. However, the Alzheimer Society exists in 150 communities across Canada, and physicians can inquire with their local chapters to clarify the availability of First Link in their areas. To find the office closest to your community, visit the Alzheimer Society of Canada website at www.alzheimer.ca or call 800 616-8816. If First Link is not available, family physicians can still suggest to patients and caregivers that they contact the local chapter to access services.

The local Alzheimer Society office contacts Mr W. and his wife. A staff member, Anne, talks with them about their experiences, exploring their reactions to the diagnosis and the questions the diagnosis has raised for them. Anne describes the services that might be helpful at this stage, such as participating in learning sessions about the disease or some informal groups of other newly diagnosed individuals and their family members. Mr and Mrs W. agree that they will need some help, but admit to feeling quite overwhelmed and report the initial visit to your office to have been quite stressful. Anne provides them with some brochures about things to think about in the early stages of the disease, including legal issues such as power of attorney and estate planning, and suggests that they clarify power of attorney for personal care and finances and that they discuss advance care planning for health issues.

The family remains connected to the staff at the Alzheimer Society. Mrs W. finds the peer support groups to be helpful, even though leaving home to attend them can be distressing. Nine months later, Mrs W., who is also one of your patients, presents to the office reporting distress and sleeplessness because she has to supervise her husband and because she is concerned about leaving him at home alone. After ruling out any important health issues that could be contributing to her symptoms, you reassure her that many caregivers of patients with dementia experience caregiver stress and you make some suggestions to help.

Caregiver stress and patient quality of life. Physicians and the staff at the Alzheimer Society can identify

triggers and provide suggestions about responses to minimize stress. The Alzheimer Society offers learning opportunities, peer support, and individual or family support in which the caregiver can learn from others' experiences and develop strategies to respond to challenging behaviour. The general benefits of meeting with others who face similar challenges can be helpful in diminishing caregiver stress. Understanding the disease and what to expect as it progresses can help family caregivers anticipate the person's needs and behaviour. Providing strategies for responding to behavioural changes can help family members proactively avoid crises associated with advancing disease (eg, wandering), and this can delay a move to long-term care by as much as 18 months.^{11,12} These roles are usually shared between the family physician and the Alzheimer Society, but greater direct collaboration would be helpful in many clinical situations.

Several other practical strategies can be helpful for caregiver stress and to assist patients. Respite options can be important to explore, especially as the severity of the illness progresses. In-home respite care to allow caregivers to attend social activities or do errands can be crucial. These services vary across the country, but usually a personal support worker is available to visit the home for several hours at a subsidized rate to give the caregiver a break.

Many regions also have community-based adult day programs located in community centres, hospitals, nursing homes, or retirement homes. These programs provide physical and social activities for patients, as well as caregiver relief. "Friendly visitor" programs from health care organizations or community groups might also provide in-home respite.

Developing a plan for a period of institutional respite care in a nursing or retirement home, where the patient leaves the home for 1 to 3 weeks, can allow the caregiver to travel for a short period of time. Downsides to this form of respite care are that people with moderate to severe dementia sometimes decompensate in new environments, contributing to caregiver distress. Some caregivers are stressed by the perception or concern that they need to supervise care in the new facility, thus negating the benefit of time away. The Alzheimer Society can support family members in preparing for the transition to a day or respite program, helping them to learn how to move from being sole care providers to being members of a larger care team.

Eventually, Mr W. develops more severe dementia. His wife has continued to attend support groups, going while an in-home respite worker is visiting. One day Mr W. wanders away from home while Mrs W. is doing laundry, and she calls you distraught after a neighbour brings him home.

Safety issues. Although wandering is very difficult to manage, there are several resources that can be helpful. The Alzheimer Society offers a service called Safely Home, initially developed with the Royal Canadian Mounted Police. For a one-time fee of \$35, the patient can be registered in a national police database to facilitate identification and safe return home. The fee also covers an identification bracelet, a caregiver handbook for managing wandering, and identification cards.

Technology is evolving rapidly in this area, and global positioning-based strategies are becoming available to allow searchers to identify dementia patients' locations. Many of these have limitations, and to help patients determine what to look for when considering locating technology, the Alzheimer Society's information and checklist on locating devices might help patients make decisions (**Box 2**).

A listing of online resources available to physicians for the nonpharmacologic management of dementia is found in **Box 3**. Specialized geriatric psychiatry or medicine programs and Community Care Access Centre services can also be resources for collaboration in management.

Box 2. Alzheimer Society documents of relevance to family physicians

Guidelines for care

www.alzheimer.ca/english/care/guidelines-care-intro.htm

Tough choices and ethical guidelines

www.alzheimer.ca/english/care/ethics-intro.htm

Physician's corner

<http://alzheimer.ca/english/disease/physicianscorner.htm>

Brochure on the importance of early diagnosis

<http://alzheimer.ca/docs/PhysiciansCorner/EarlyDiagnosisEnglishFINAL.pdf>

Locating-devices checklist

www.alzheimer.ca/docs/Day%20to%20Day%20Locating%20Eng%20final.pdf

Mr W. is admitted to a nursing home 4 months later, after several other episodes of wandering and episodes of aggression to the personal support workers. Once there, he participates in the Alzheimer Society-supported arts program, which is noted to improve his mood for a period of time afterward. His wife continues to visit her husband and to collaborate with the staff on her husband's care. Eight months later he develops pneumonia and, based on his previously stated wishes, clarified while he was still capable, he is treated at the facility but deteriorates and dies with his wife at the bedside. The Alzheimer Society staff members invite Mrs W. to remain in contact with the Alzheimer Society whenever needed.

Box 3. Links to resources for nonpharmacologic management of dementia

Management of common behaviour

Alzheimer Society

www.alzheimer.ca/english/care/behaviours-common.htm

www.alzheimer.ca/english/disease/physicianscorner_resources.htm

PIECES Canada framework

www.sagelink.ca/uploads/BPSD_Project_200912/BPSD_Toolkit_2009/BPSD-toolkit-full.pdf

Dementia in long-term care

www.ccsmh.ca/en/projects/ltc.cfm

General dementia and geriatric resources

College of Family Physicians of Canada Health Care of the Elderly Program

www.cfpc.ca/HCOE_Resources

Regional Geriatric Programs of Ontario GiiC project

<http://rgps.on.ca/giic/Giic/dementia-screening-and-assessment.html>

Canadian Consensus Conference on Diagnosis and Treatment of Dementia

www.cccdt.ca/pdfs/Final_Recommendations_CCCDT_2007.pdf

Driving

Ottawa Regional Geriatric Assessment Program

www.rgpeo.com/en/health-care-practitioners/health-care-resources/driving.aspx

Alzheimer Knowledge Exchange

www.akeresourcecentre.org/DrivingModule

Canadian Geriatrics Society

<http://canadiangeriatrics.ca/default/index.cfm/resources/family-physician>

Conclusion

Collaboration among family physicians and community resources is important in the management of dementia, regardless of the severity of the disease. The Alzheimer Society is a cornerstone of dementia management, and physicians should refer patients at the time of diagnosis whenever possible. The First Link program specifically offers an easy way to improve follow-up care, where it is available. Other resources such as respite care and day programs should be used when appropriate and can be coordinated with assistance from the Alzheimer Society.

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Contributors

All authors contributed to the literature review and preparing the manuscript for submission.

Competing interests

Ms Schulz is employed by the Alzheimer Society but has no other financial interest in the paper.

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