

# Caring for a Family Member with Dementia

The role of caregivers in maintaining persons with a dementia in the community is a challenging job. Caregiving can have negative physical, psychological, social and financial consequences and therefore management has to focus on supporting the person with dementia and their caregiver. The recommendations intended to assist family caregivers of persons with Alzheimer's disease (AD) arising from the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD3) provide a first-step towards supporting caregivers in their vital and challenging work.

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The important role of caregivers in maintaining persons with a dementia in the community is widely recognized, but it is a tough job. Caregiving can have negative physical, psychological, social and financial consequences.<sup>1</sup> Management has to

focus on supporting the person with dementia and their caregiver.

This paper deals with the recommendations intended to assist family caregivers of persons with Alzheimer's disease (AD) arising from the Third Canadian Consensus Conference on the

some of the 28 recommendations for the management of mild to moderate AD and dementia<sup>3</sup> that pertain to family caregivers. The numbers in brackets throughout the current paper refer to the recommendation numbers from the Hogan et al<sup>3</sup> paper. The article by

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Diagnosis and Treatment of Dementia (CCCDTD3).<sup>2</sup> A full set of the recommendations made can be found in the series of articles published in the October 2007 issue of *Alzheimer's and Dementia*. This article focuses on

Gibson et al in this issue of *The Canadian Review of Alzheimer's Disease and Other Dementias* focuses on severe dementia in long-term care settings but is also relevant to family caregivers of persons with dementia.

### Case Presentation

Mrs. Brown is 76 years old and lives with her husband in a middle-class residential area of a small town in Saskatchewan. She completed high school and then was a stay-at-home mother. Their two married daughters live in the same area and have four adult children of their own. The daughters have a good relationship with each other and with their parents.

Mrs. Brown was recently diagnosed with early-stage AD by the interdisciplinary Rural and Remote Memory Clinic. Her husband has noted a progressive deterioration of her memory (*i.e.*, frequent lapses of short-term memory, mild word-finding problems, and difficulties in following complex directions). The problems came on gradually beginning about three years ago and have slowly progressed since then. Over the last six months Mrs. Brown has required help with some activities of daily living such as using the washing machine and preparing meals. With some reminding and coaching, she is able to dress and bathe herself. She occasionally has difficulty sleeping and Mr. Brown has found her wandering about their home during the night. She no longer drives, as her husband fears that she will get lost. Mrs. Brown's involvement with her church groups has lessened over the last two years as she has found it difficult to participate in

the group meetings. On their most recent vacation, Mrs. Brown would not leave her husband's side and became very anxious if she lost sight of him. She claims her memory problems are related to aging and does not believe that she has AD.

Mrs. Brown scored 23/30 on the Mini-Mental State Examination. She denied being depressed and scored 2/15 on the Geriatric Depression Scale. Physical examination was unremarkable with no focal neurological findings. Mrs. Brown accepted a prescrip-

tion for galantamine, which like the other two cholinesterase inhibitors available in Canada, has shown modest benefits in the treatment of mild AD. There is no known family history of dementia. Mrs. Brown has a history of hypertension which is controlled by medication. She is otherwise physically well. Mr. and Mrs. Brown are non-smokers and non-drinkers.

Mr. Brown has a university degree in food science and worked with the Saskatchewan Food Processors Association. He has a five-year history of diabetes mellitus that is managed by an

oral agent and diet, and has a history of hypertension which is currently under control with medication. Mr. Brown experienced a mild heart attack one year ago. Following his hospitalization, he participated in a six-month cardiac rehabilitation program. He is monitored closely by his family physician.

### Case Discussion: First Steps

Following Mrs. Brown's diagnosis of AD, an appointment should be made with her primary-care physician (recommendation 1) to

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discuss the certainty of the diagnosis, its prognosis, safety issues such as driving, treatment options, availability of support groups and other services, and the importance of advanced planning, which includes updating her will and enacting an advance directive and an enduring power of attorney (recommendation 6). Ideally, not only Mrs. Brown, but also her husband and their daughters if interested, should participate in these discussions so that all are hearing the information first hand. This would give them the opportunity to have their questions answered and their own needs dis-

cussed and addressed. It may be necessary to schedule some of these appointments separately from Mrs. Brown (recommendation 26).

Understandably, Mrs. Brown was upset when told of her diagnosis (recommendation 6) and became agitated when her family

stop source of information and a 24/7 toll-free information hotline for caregivers. Mr. Brown should also contact the local home-care program, as they may be able to provide information on available community resources, provide anticipatory guidance, assist with personal care when the need arises, and inform him

in assessing the effectiveness of galantamine in improving or stabilizing her symptoms. This information will be vital in determining if there is no clinical benefit and whether to discontinue the medication (recommendation 16). Monitoring for possible side effects of galantamine, such as anorexia, nausea, vomiting, diarrhea, short-term weight loss, and dizziness is also important and something with which Mr. Brown and his daughters can assist. If Mrs. Brown did not have a live-in caregiver who could assume medication management, other potential strategies to improve adherence would include the use of compliance aids and computer telephony systems.<sup>4</sup>

***Those with mild AD frequently experience anxiety (60%), lack of energy (55%), anhedonia (lack of pleasure in activities that are normally pleasurable; 51%), agitation (49%), irritability (39%), and delusions or hallucinations (26%).<sup>5</sup>***

members used the term AD. Talking about trying to manage her memory loss may be more acceptable to her. Nonpharmacologic approaches would be more appropriate for treating her mild anxiety than the prescription of a psychotropic. Aside from other potential problems, psychotropic medications with anticholinergic effects may blunt the effects of galantamine.

Family members need support, education, and training (recommendation 26). They should be referred to their local Alzheimer Society (e.g., [http://www.alzheimer.sk.ca/english/support/#support\\_for\\_caregivers](http://www.alzheimer.sk.ca/english/support/#support_for_caregivers) in the case of Mrs. Brown). The First Link™ program is a way to connect persons newly diagnosed with AD and their caregivers to a community of learning, services, and supports ([www.alzheimerott.org/first\\_link](http://www.alzheimerott.org/first_link)). VON Canada is developing a one-

about available respite services such as day programs and in-home respite services.

### **Treatments for AD and Comorbidities**

In the management of a person with a dementia, who likely has one or more comorbidities such as hypertension, there is usually less reliance on the person self-managing these conditions and more dependence on their caregivers (recommendation 4). Mr. Brown will need to become involved in administering his wife's medications for her hypertension and AD either now or in the future. He may wish to keep a written record of his impressions of her progress and response to therapy (recommendation 11). His involvement in tracking his wife's cognition, behavior, social and daily functioning will assist their physician

### **Treatments for Mood and Behavioral Disturbances**

Those with mild AD frequently experience anxiety (60%), lack of energy (55%), anhedonia (lack of pleasure in activities that are normally pleasurable; 51%), agitation (49%), irritability (39%), and delusions or hallucinations (26%).<sup>5</sup> Major depression occurs most often when cognition is mildly to moderately impaired, whereas most other psychiatric symptoms are more common with severe dementia. Mrs. Brown does not appear to be depressed. However, should depressive symptoms occur, nonpharmacologic measures should be considered first. When indicated, an antidepressant with minimal anticholinergic activ-

ity, such as a selective serotonin reuptake inhibitor, would be another treatment option (recommendation 21).

Behavioral disturbances, such as wandering, general restlessness, agitation and uncooperativeness<sup>6</sup> have been reported to occur in 63% of community-dwelling persons with dementia.<sup>7</sup> These disturbances increase distress for those with dementia and the strain felt by caregivers. Those with behavioral disturbances enter long-term care facilities nearly two years earlier than those without.<sup>8</sup>

The management of behavioral disturbances should include a careful documentation of the problem behaviors coupled with a search for potential triggers. The evaluation would be geared to rule out treatable or contributory causes. With certain types of dysfunctional behavior (*e.g.*, wandering, aggression) consideration must be given to assessing the safety of the person with dementia, their caregiver, and others in the environment (recommendation 20). Again, Mr. Brown and his daughters can play an important role in understanding the meaning behind Mrs. Brown's behaviors and mood.

Many research studies, systematic reviews, and Cochrane Reviews have examined the effectiveness of a variety of interventions in managing the behavioral and psychological symptoms of dementia. Psycho-education pro-

grams that are group-based<sup>9</sup> or offered in the home<sup>4,10-12</sup> for caregivers on the management of behavioral and psychological symptoms demonstrated a decrease in the frequency and/or severity of disturbing behaviors. However, access to these pro-

grams may be limited for those who live outside large cities, like Mr. and Mrs. Brown. Other interventions such as reminiscence therapy,<sup>13</sup> validation therapy,<sup>14</sup> bright light,<sup>15</sup> music therapy,<sup>16</sup> aroma therapy,<sup>17</sup> and multi-sensory stimulation<sup>18</sup> have shown some promise but have not clearly demonstrated long-term, signifi-

cant benefits.<sup>19</sup> Although there is insufficient evidence to strongly advocate for the routine use of these interventions in the management of behavioral disturbances, some persons may benefit from their use (recommendation 23).

Mrs. Brown occasionally experiences sleep disturbances (up to

44% of community-dwelling persons with dementia can be affected with problems of this nature).<sup>20</sup> Her insomnia and wandering at night can be difficult for Mr. Brown to deal with, especially if his sleep is interrupted. Mrs. Brown should be carefully assessed for factors

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that might be contributing to this problem such as pain, depression, ambient noise and light, and daytime naps (recommendation 22). Nonpharmacologic approaches (*i.e.*, sleep hygiene, daily walking and light exposure) can be effective<sup>21,22</sup> and should be considered first. If medications are used, the lowest effective dose of the select-

***The Compassionate Care Leave provides claimants with six weeks leave with 55% income replacement. In June 2006 the eligibility criteria were expanded to include a wider range of family members and close friends.***<sup>23</sup>

ed agent should be used for the shortest time possible (recommendation 22).

### **Driving and AD**

Mrs. Brown has voluntarily stopped driving. This is not always the case. Males with dementia may be more reluctant,

especially those living in rural areas where there may be no other means of transportation. However, giving up driving is an inevitable consequence of a progressive dementia like AD and strategies for this transition should begin early. Driving is contraindicated in persons who, for cognitive reasons, have an inability to independently perform multiple

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instrumental activities of daily living or any basic activity of daily living (recommendation 25). To determine driving ability, the Mini-Mental State Examination, the Clock Completion Test or any other brief cognitive measure are inadequate in themselves. Where there is uncertainty about driving safety, a comprehensive off- and on-road driving evaluation every six to 12 months as a minimum, and sooner if indicated, is felt to be the fairest approach (recommendation 25). Compensatory strategies (*i.e.*, retraining, education programs, use of co-pilots, use of on-board navigation and crash warning systems, restricted licensing) are not appropriate for persons with dementia deemed unsafe to drive (recommendation 25).

### Support for Caregivers

The important role played by caregivers in dementia care should be acknowledged (recommendation 26). Mr. Brown should be seen regularly by his physician to ensure that his own health issues are monitored and appropriately treated. The impact of his care work on his health must be considered. His

education and support needs should be determined and dealt with as required by a referral to the local home-care agency and/or Alzheimer's Society. These programs can provide information on available community resources, provide anticipatory guidance, assist with personal care when the need arises, and provide respite services.

Mr. Brown may find it necessary to purchase supportive services such as homemaking, yard work and snow shoveling. He may also find it necessary to purchase additional respite services to supplement the amount that the provincially-funded home-care program is able to provide. Other expenses such as incontinence supplies,

medications and bath aids may also be incurred. Mr. Brown should be reminded that government policies may provide some financial relief. For example, most persons with a dementia would be eligible for a disability tax credit, Form T2201, available at [www.cra.gc.ca/forms](http://www.cra.gc.ca/forms). Mr. Brown's daughters may wish to take advantage of the Compassionate Care Leave that provides claimants with six weeks leave with 55% income replacement. In June 2006 the eligibility criteria were expanded to include a wider range of family members and close friends.<sup>23</sup>

### Conclusion

Baby-boomers are now just starting to enter the age of greatest risk for the development of a dementia. There will be increasing numbers of persons with a dementia living in our communities.<sup>24</sup> The societal costs of caring for persons with dementia will rise substantially, especially if we do not adequately support family caregivers,<sup>25</sup> and premature institutionalization is required.<sup>26</sup> These recommendations for family caregivers are a first step in our efforts to support them in their vital and challenging work. However, further research is required to better demonstrate which interventions are most effective in meeting the needs of persons with dementia and their family caregivers.

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