

# Caregivers for people with dementia

## *What is the family physician's role?*

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### abstract

**OBJECTIVE** To examine the role of family physicians in providing support and care to caregivers for people with dementia.

**QUALITY OF EVIDENCE** Data were obtained from Alzheimer Society guidelines, published consensus statements, and guidelines for family physicians caring for people with dementia and their caregivers. Most of the reported findings and recommendations are based on information from expert consensus statements and opinion.

**MAIN MESSAGE** Caring for people with dementia causes substantial psychological and physical morbidity. Services developed for caregivers (in-home respite and individual psychological interventions) and comprehensive support programs are helpful in relieving caregiver distress. There is a role for family physicians in following caregivers longitudinally to assess their physical and emotional health and coping skills, to provide information and assistance in dealing with problems as they arise, to assist caregivers in mobilizing family and friends, and to facilitate referrals to appropriate services and resources.

**CONCLUSIONS** Family physicians have an important role in identifying caregiver problems and providing direct and ongoing support to caregivers in their day-to-day role.

### résumé

**OBJECTIF** Examiner le rôle des médecins de famille dans la prestation de soutien et de soins aux soignants des personnes souffrant de démence.

**QUALITÉ DES DONNÉES** Les données ont été obtenues des lignes directrices de la Société Alzheimer, des déclarations consensuelles publiées et des guides de pratique à l'intention des médecins de famille qui traitent des personnes souffrant de démence et celles qui leur dispensent des soins. La majorité des conclusions et des recommandations rapportées se fondent sur des renseignements tirés des déclarations consensuelles et des opinions d'experts.

**PRINCIPAL MESSAGE** Prendre soin de personnes souffrant de démence cause une morbidité psychologique et physique substantielle. Les services conçus pour les soignants (un répit à domicile et des interventions psychologiques individuelles) ainsi que les programmes de soutien intégrés se révèlent utiles pour soulager la détresse des soignants. Il y a un rôle à jouer par les médecins de famille dans le suivi longitudinal des soignants pour évaluer leur santé physique et émotionnelle et leur capacité de réagir au stress, pour offrir des renseignements et de l'aide dans la prise en charge des problèmes à mesure qu'ils surviennent, pour assister les soignants à mobiliser la famille et les amis et pour faciliter l'aiguillage vers les services et les ressources appropriés.

**CONCLUSIONS** Les médecins de famille ont un rôle important à jouer dans l'identification des problèmes des dispensateurs de soins et dans la prestation d'un appui direct et permanent dans leurs fonctions quotidiennes.

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*Cet article a fait l'objet d'une évaluation externe.*

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**T**he Canadian Study of Health and Aging has estimated that 8% of Canadians older than 65 and 35% of those 85 and older have a dementing illness.<sup>1</sup> As Canada's population ages, more and more physicians will be providing care to people with dementia and their families.

Providing care to elderly patients is often a challenge for family physicians because of the complex nature of these patients' problems. When a patient has dementia, care is increasingly complex because of the many cognitive, behavioural, psychiatric, and physical changes that occur over the course of the illness. Given the progressive nature of dementing disorders, challenges often change with the stage of the disease, necessitating ongoing assessment and changing treatment plans.

Families and friends (caregivers) are integral to the care and treatment of people with dementia. Caregivers themselves are affected by their caregiving role and also have changing needs as their role evolves. This paper will highlight how family caregivers support people with dementia and the effect of these responsibilities on the caregivers. It will outline recommendations for family physicians who work with caregivers.

#### Data sources

MEDLINE was searched from 1985 to 1998 using the key words dementia, family physician, and caregiver. This was not designed as a study to examine the effectiveness of caregiver interventions per se but to examine what has been written about the role of family physicians with respect to these caregivers. Guidelines from the Alzheimer Society of Canada and other relevant guidelines about dementia care written during this time were also reviewed. Most of the available information is from expert consensus statements and opinion. There is less information derived from randomized controlled studies.

#### Role of caregivers

The Canadian Study of Health and Aging documented that approximately half of people with dementia in Canada live in the community.<sup>2</sup> For 94% of this community-dwelling group of people with dementia, care is provided by family or friends. Most caregivers are women: wives and daughters of the affected people. Spouses represent the largest group of caregivers (37%).

Caregivers are intricately involved in many aspects of day-to-day life for people with dementia. This involvement usually increases of necessity as the disease progresses. Caregivers provide assistance with .....

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activities of daily living (bathing, grooming, dressing, toileting, meal preparation, shopping, etc) and help with decision making. Clinicians often turn to caregivers for input in assessing changes in patients' cognitive and functional status, assessing acute or chronic health problems, and assessing response to treatment.

Caregivers' sense of well-being is an important predictor of how long people with dementia will reside in the community before they are moved to long-term care institutions. The higher the perceived burden of care by the primary caregiver, the more likely care in the community will be terminated.<sup>3</sup> Even when people with dementia move into long-term care institutions, caregivers continue to visit regularly and stay involved with day-to-day care and decision making. People with dementia do not always have insight into their deficits or need for help. Consequently, the efforts of caregivers are not always appreciated or acknowledged by those for whom they care.

#### Consequences of caregiving

Care provided by family and friends has been closely studied in recent years. Caregiving has many consequences, some more readily apparent than others. Caregivers need to provide a great deal of day-to-day support for people with dementia. They sometimes also need to assume new roles in the household (banking, cooking, etc), with which they are unfamiliar. They can become more socially isolated as they see their friends drift away and as it becomes more difficult to socialize with or without the affected person present. Adult children caregivers must assume a parenting or guardianship role, for which they might not be prepared. Alternatively, caregivers could be intimately involved with people they do not know well from the past (eg, aunts, in-laws). Caregivers ultimately grieve as they face the inevitable changes dementia brings.

Caregiver burden and the negative consequences of caring have been described.<sup>3,4</sup> Caregivers must deal with many losses as dementia brings changes to affected peoples' cognition, personality, and relationships. The prevalence of clinical depression and anxiety disorders is high among caregivers.<sup>4</sup> Caregivers of those with dementia also perceive their general health to be worse than others'.<sup>4</sup> Psychotropic drug use is high among these caregivers. Predictors of psychiatric and physical morbidity in caregivers include low income, high perceived stress, low life satisfaction, and low self-esteem or self-mastery. These mirror the predictors of morbidity in other categories of caregivers.

Additional variables are important when considering those caring for people with dementia. Problem

behaviours of dementia patients and increasing cognitive impairment predict increased psychiatric and physical morbidity, respectively, in this caregiving group.<sup>4</sup> This increase is further complicated by variables, such as the nature of the prior relationship between caregiver and affected person, the ethnic and cultural background of the family, and whether they currently reside together or apart.<sup>3</sup> Other factors that influence caregiver burden and could mediate the negative affects of caregiving include perceived adequacy of help from family and friends, quality of prior relationships, the family's organization and functioning, and the caregiver's ability to cope with the challenges of the caregiving role.<sup>3</sup>

Caregivers also identify several positive aspects of their caregiving role. These are now being studied more carefully and include a sense of mastery and pride in keeping a relative at home.<sup>5</sup> These experiences can have a profound effect on a caregiver's decision making regarding use of services or placement in a long-term care institution. For example, caregivers might not want to relinquish their role to others if they find it satisfying and rewarding. Understanding the consequences of caregiving (both negative and positive) and common caregiver coping strategies is an important first step in assisting caregivers with their task.

### Services for caregivers

A variety of services have been developed to alleviate the negative consequences of caregiving. These include respite (dementia day programs, in-home respite, and out-of-home respite) and psychosocial interventions (individual counseling or support groups). The respite and individualized interventions have been found moderately effective in reducing caregiver distress; the group interventions less so.<sup>6</sup>

These services are not always used by caregivers and are often reported to be underused.<sup>2</sup> More research is needed to understand why. Factors identified to date include availability, accessibility (eg, cost and location), and acceptability of services. The latter relates to caregivers' perceived need for help, the desire to have someone else in the home, and the types of services offered.<sup>3</sup> For example, support groups (although highly rated by those who use them) could be seen as undesirable for many caregivers.

The most effective interventions reported to date are comprehensive support programs combining several of these interventions. Brodaty et al<sup>7</sup> in Australia and Mittelman et al<sup>8</sup> in New York have described examples of such programs.

Brodaty et al<sup>7</sup> provided caregivers with an intensive 10-day residential program. Caregivers had sessions

with a variety of professionals to learn how to deal with stress, social isolation, and guilt. They were taught how to use community services, how to use new coping skills in dealing with dementia daily, and how to begin planning for the future. Finally, they were given information about the medical aspects of dementia. Telephone conferences were arranged at regular intervals between the coordinator and cohorts of caregivers. Reunions were held for follow-up assessments at 3, 6, and 12 months after the program was completed.

Brodaty's group<sup>7</sup> was able to demonstrate a delay in institutionalization of dementia patients when caregivers were enrolled in their program. They suggest that these interventions are probably more effective in the early to middle stages of dementing illness. They were not able to determine which aspects of the program were most helpful for which groups of caregivers.

Mittelman et al<sup>8</sup> developed an intervention combining individual and family counseling sessions "tailored to each specific situation, with primary focus on increasing support for the spouse-caregiver from other family members." These sessions also provided education about behavioural problems and how to deal with them. Counselors emphasized the need for caregivers to care for themselves. Caregivers also attended weekly support groups. Most importantly, they could request ad hoc consultation by telephone at any time (including evenings and weekends in the event of a crisis). This program allowed continuous support for primary caregivers as long as was needed. Researchers noted that the effects of the intervention were not immediate but take some time to be helpful to the caregivers. They reported that their intervention delayed institutionalization of dementia patients and reduced the prevalence of depression among spouse caregivers.

These comprehensive support programs comprise three major components (as conceived by Brodaty et al<sup>7</sup>): psychological support, education about dementia, and help eliciting support for the caregiver from other family members and formal service providers. Although these comprehensive programs are not readily available across Canada, clinicians can organize a variety of interventions on a case-by-case basis to address these three basic areas of need for caregivers in their practices.

### Caregiver expectations

Surveys and studies of caregivers highlight their concerns in relation to health care providers in general and family physicians in particular.<sup>9</sup> Caregivers have expressed a desire for information about the diagnosis of dementia and about ongoing assistance after the diagnosis. They also stress the need for recognition of

the importance of their caregiving role and the desire to be treated as full and equal partners. Finally they have requested assistance with the behavioural problems of people with dementia and for referrals to social agencies. Caregivers do not always perceive the need for specific dementia services. This poses a challenge, given the available data supporting the modest benefits of these services.

### Role of primary care physicians

Little research exists on the role family physicians are currently playing in supporting caregivers. Use of physician care (adjusted for age, sex, number of chronic diseases, and depression) was no higher for family caregivers of elderly patients with dementia than for comparable caregivers of people without dementia. Caregivers of dementia patients used services billed by psychiatrists and internal medicine specialists significantly more frequently, however.<sup>10</sup>

An emerging consensus recognizes a role for family physicians in assisting caregivers of people with dementia. This is consistent with the role of family physicians in working with all their patients in the context of their families.<sup>11</sup> The role of family physicians is complicated when patients with dementia have different physicians from their primary caregivers. Particular care might have to be taken in these situations for collaboration between physicians and caregivers in the care of an identified patient. In more straightforward situations where physicians know the family well, they can still play roles specific to dementia care.

Given the research to date, it is important that physicians recognize the consequences (negative and positive) of caring for someone with dementia. It seems prudent for family physicians to work to provide the three basic components of care encompassed by successful comprehensive support programs for caregivers: psychological support, education about the disease, and assistance in mobilizing caregivers' support systems. Physicians will probably not be able to provide all these services themselves, but will need to know where to turn for help to ensure that caregivers can get help as they need it (Alzheimer societies, local Alzheimer day programs, seniors' services, etc). To this end, caregivers will need to be seen regularly not only to acknowledge their important role but also to assess their needs.

Family physicians should see caregivers regularly to assess whether they are depressed and how they are coping. Caregivers might need individualized psychological interventions or assessment and treatment of psychiatric disorders (particularly anxiety and depression).

### Key points

- Eight percent of Canadians older than 65 and 35% older than 85 have a dementing illness.
- For those with dementia still in the community, most care is provided by women: their wives and daughters.
- Consequences of caregiving can be negative, such as increased prevalence of depression, greater anxiety, and poorer perceived health, but they can also be positive, such as pride in preventing a loved one from being institutionalized.
- Comprehensive caregiver support programs have been effective, using individual psychological support, education about dementia, and practical home services and social supports.

### Points de repère

- Une démente se présente chez 8% des Canadiens de plus de 65 ans et chez 35% de ceux de plus de 85 ans.
- Les personnes souffrant de démente qui habitent toujours dans la collectivité sont soignées pour la plupart par des femmes, soit leur conjointe ou leur fille.
- Les conséquences de prodiguer de tels soins peuvent se révéler négatives, notamment une prévalence accrue de dépression, une plus forte anxiété et une perception d'être en moins bonne santé, mais elles peuvent aussi être de nature positive, comme la fierté d'empêcher une personne chère d'être institutionnalisée.
- Les programmes de soutien aux dispensateurs de soins intégrés se sont prouvés efficaces, offrant du soutien psychologique individuel, de l'éducation concernant la démente ainsi que des services pratiques à domicile et du soutien social.

They might need counseling to help them cope with the caregiving role and modify their coping skills.

Caregivers will need education and assistance with a variety of issues. Those that have been highlighted repeatedly in guidelines for family physicians<sup>9,12-18</sup> include issues related to diagnosis of dementia, advance planning (medicolegal issues and long-term care placement), and treatment of behavioural problems. Helping with these issues would be in addition to providing the basic information caregivers require about the nature of dementing illnesses and the needs of people with dementia as their illness progresses. Physicians can provide this information or refer caregivers to local

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Alzheimer societies; books and pamphlets; or community agencies providing counseling, support groups, and courses for caregivers.

Caregivers also need help to mobilize their social support system. This would include family and friends as well as formal supports in the community. This can be a challenge, as caregivers often find it difficult to ask for help or accept the type of help available. They can require individual counseling to help them understand the need for help and develop the skills to ask for it. They can require family counseling to help elicit assistance from those close to them. Referrals for additional support from community services, such as respite care, are also important, as this support has been found to decrease caregiver burden. Once again, caregivers could need counseling and encouragement before they feel comfortable using such services. Family physicians are in a unique position to encourage and facilitate referrals to other appropriate agencies.

### Conclusion

Information is now available regarding the negative and positive consequences of caring for people with dementia. Interventions, such as respite care and individualized psychosocial counseling, are reported to relieve caregiver distress. Consensus guidelines concur that family physicians' role is to support these caregivers. Such support includes ongoing assessment of caregivers, acknowledgment of their important role, attention to their individual psychosocial needs, education and assistance with specific problems, and referrals to appropriate services and resources. Little information is available on the effectiveness of these interventions by family physicians. ❀

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