

Communicating with families of dementia patients

Practical guide to relieving caregiver stress

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The increasing prevalence of dementia in Canada's aging population and the complexity of managing the psychosocial aspects of dementia are leading to an increase in the amount of time family physicians spend with dementia patients and their caregivers.¹ Patients with dementia frequently rely on family members to act as caregivers, and these family members (who might or might not be patients of the family physicians) will often accompany the patients to clinical appointments. When a visit to the doctor is mediated by a caregiver, the resulting dynamic can be complicated and unfamiliar, especially if it represents a change in a long-standing relationship between the physician and the patient. Nonetheless, addressing the needs of caregivers is not only important for their well-being, but also important for the health of the patients they care for, enabling the patients to remain in the greater community for as long as possible.

It is essential that family physicians work with families of dementia patients on an ongoing basis. Beginning at the time of diagnosis, it can be helpful to schedule regular appointments with patients and caregivers in order to help relieve stress and plan for upcoming challenges. Physicians, families, and patients can obtain valuable information from the Alzheimer Society of Canada, either through local offices or from the website.² There are also guidelines on working with caregivers published by the American Medical Association, although studies show that physicians do not always follow guidelines; in particular, clinicians are less likely to follow recommendations about referring caregivers to support services and providing guidance about behaviour management techniques.³

Things to keep in mind

Diagnosis. The diagnosis of dementia is a key moment in the relationships among physicians, patients, and caregivers. Uncertainty surrounding the diagnosis and prognosis of dementia, however, can lead to difficulties with communication. This can be counterbalanced by a progressive disclosure process that begins when cognitive impairment is first suspected and evolves as more information is obtained over time.⁴ Whenever possible and appropriate, this process should involve not only the affected individuals, but also their families and other current or future care providers.⁴ The Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia recommendations⁵ identify diagnosis as a

time to begin addressing issues such as power of attorney and advanced directives. It is important to pay special attention to the ability of patients to participate in the decision-making process and to include them for as long as possible.⁵

Susceptibility of the caregiver to stress-related health issues. Physicians should conduct an initial screen for depression or depressive effect, life satisfaction, perceived physical health, general distress, and subjective burden for family members who are entering into caregiving roles for relatives with chronic conditions such as dementia.⁶ A useful tool for assessing caregiver wellness is the Caregiver Self-Assessment Questionnaire, developed by the American Medical Association and available online.⁷ This questionnaire, which caregivers can complete before an appointment, assesses the effects of caregiving and the overall level of stress experienced by the caregiver. The questionnaire can be a useful means of opening up discussion about how the caregiver is coping with what can be a challenging task.⁷ Keep in mind that caregiving can offer many positive experiences.


Face-to-face support. Faced with anxiety and depression because of their role, caregivers are frequent users of the health care system. Caregivers are likely to seek more assistance from their physicians because the stress they are under can lead to greater risk of illness.³ These health risks include increased psychiatric morbidity and an increase in physical ailments due to decreased preventive action, such as exercise.³ In light of the risks to, and the importance of, the caregiver, it is recommended that physicians meet one-on-one with caregivers in order to encourage caregivers to implement strategies for maintaining their own mental and physical health.⁸ Further assistance can be provided to the caregiver by helping in the recruitment of other family members to share the burden of care, inquiring about caregiver health, and inquiring about the patient's behavioural problems and their effect on the caregiver. It should also be kept in mind that pharmacotherapy for the patient with dementia might be useful in reducing the caregiver's stress,⁶ especially if cognitive enhancers are able to effectively reduce caregiver burden. At other times, medications for behavioural and psychological symptoms of dementia might be indicated when non-pharmacologic interventions have failed. Respite care can also be explored.

Successful medical encounters. Caregivers often feel inadequate and overwhelmed; a small yet effective intervention is to acknowledge the caregiver's competence and help the caregiver feel valued. A simple comment such as "You are doing a great job" can be very meaningful. It is important to inquire about the specific needs of the caregiver, such as whether any support or information is required. Sensitive and effective communication strategies include not interrupting, not being impatient with slowness, giving enough time to the medical encounter, not ignoring the patient while speaking with the caregiver, and involving the patient in the decision-making process whenever possible.⁹ Conversely, unsuccessful medical encounters, which fail to reduce caregiver stress, are ones in which the physician speaks too fast, dominates the conversation, and uses medical jargon.¹⁰

Transition to institutional care. Clinical experience shows that families often have feelings of guilt about placing their relatives in long-term care, and might look to family physicians to provide guidance and even permission. This is a sensitive area, and it is best if the family physician can provide advice and support without assuming the responsibility of making the decision

for the family. Physicians can also make families aware of the option of temporary respite placements, which provide a break for caregivers as well as an introduction to the realities of institutional care. The point of transition to long-term care is also a good time to ensure that the substitute decision maker is clearly identified and that family members have been apprised of the types of decisions they will be asked to make around palliation (emergency transfer to hospital, feeding, use of medications, etc).

Support in difficult times

As more and more Canadians develop dementia, physicians will see more caregivers in their day-to-day interactions. Acknowledgment by the physician that the health of the caregiver is necessary to the health of the patient is important. Keeping the facts outlined above in mind will help the physician support family members in what can be a very difficult situation. 

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Competing interests

None declared

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