Dealing with Dementia in Family Practice

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Revised (2014) by Amy Freedman, MD, CCFP

The Working With Families Institute, Department of Family & Community Medicine, University of Toronto
In today’s world, families are under increasing stress, from financial and time constraints, to family breakdown, substance abuse, and threats of violence. Family physicians are seeing an increase in psychosocial issues such as anxiety and stress-related disorders, often co-existing with and complicating medical problems such as diabetes or pneumonia. The psychosocial issues are often more difficult to diagnose and manage than are the medical problems—and all take place in the family context. Very often, the family is the key to dealing effectively with the whole spectrum of complaints, requiring a psychosocial assessment. In the crowded family medicine curriculum, this vital area of knowledge and skill is often ignored in favour of more clear-cut procedural skills.

To educate family physicians about dealing with families, a group of family medicine educators, practitioners and mental health professionals affiliated with the Department of Family and Community Medicine at the University Of Toronto founded the Working with Families Institute (WWFI) in 1985. The WWFI has developed various training experiences for trainees and practising physicians.

Goals
The goal of these modules is to provide a learning resource for physicians dealing with common medical and psychosocial issues that have an impact on families. The modules seek to bridge the gap between current and best practice, and provide opportunities for physicians to enhance or change their approach to a particular clinical problem.

The modules have been written by a multidisciplinary team from the Faculty of Medicine, University of Toronto. Each module has been peer-reviewed by external reviewers from academic family medicine centres across Canada. The approach is systemic, emphasizing the interconnectedness of family and personal issues and how these factors may help or hinder the medical problems. The topics range from postpartum adjustment to the dying patient, using a problem-based style and real case scenarios that pose questions to the reader. The cases are followed by an information section based on the latest evidence, case commentaries, references and resources.

How to Use the Modules
The modules are designed for either individual learning or small group discussion. We recommend that readers attempt to answer the questions in the case scenarios before reviewing the case commentaries or reading the information section.

The editors welcome feedback on these modules and suggestions for other modules. Feedback can be directed to Dr. Watson at dfcm.wwfi@utoronto.ca.

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SUMMARY

With the aging of the Canadian population, family physicians (FPs) will be seeing increasing numbers of elderly patients with dementia. The number of Canadians with dementia is expected to reach more than 1.1 million by 2038. It is the most significant cause of disability among Canadians over age 65. Within 20 years, worldwide prevalence is predicted to increase twofold.\textsuperscript{1,2} The average FP has 30-40 patients with dementia in his or her practice, and this number is expected to rise.\textsuperscript{3} Often, FPs are the only physicians caring for these patients and in many cases for their families too. The care of patients with dementia involves complex medical, psychiatric, social, ethical, and family issues. Many challenges arise for patients and families during the initial diagnosis of dementia and in the later stages. FPs care best for patients with dementia when they work in partnership with families and use community resources. This module includes many references and resources of interest to physicians and families.

OBJECTIVES

After completing this module, you will be able to
1. evaluate a patient with dementia.
2. include the patient’s family in care planning.
3. mobilize the necessary community resources.

Key Features
1. Family physicians will require effective knowledge and skills in dealing with an increasing number of patients with various forms of dementia.
2. Using an interdisciplinary approach that incorporates families and community resources will improve the overall care of patients with dementia.

Core Competencies
1. Understand the role of generalist physician in the health care system.
2. Display effective, professional and non-judgmental communication skills with the patient and family.
3. Utilize an approach that incorporates the cultural, social and family context.
CASE STUDY

Case: Mrs. Cadar, aged 85

First Visit: Mrs. Cadar has been a patient in your practice for approximately seven years. She worked in sales before her children were born. She has lived alone since her husband died 12 years ago, and has always been in fairly good health. She attends the office infrequently for care of her osteoarthritis and hypothyroidism. Today she is accompanied by her daughter, Lidia. Mrs. Cadar’s son, George, lives out of town. Lidia, aged 55, is a teacher, married with two children and one new grandchild. She is also your patient; she attends your office for her annual physical examination and for care of sporadic incidental illnesses.

Today Lidia looks anxious and Mrs. Cadar appears irritated. Lidia begins the visit by expressing concern about her mother’s memory.

- What are the issues in this case?
- How would you approach this visit?

Mrs. Cadar denies any memory problems. She reports that she is managing “just fine.” While she acknowledges that Lidia helps her out, she believes this help is unnecessary. She doesn’t cook as much as she used to, but still fixes most of her own meals. She has given up doing crosswords but still reads the paper. She has a car but uses it only very occasionally, to go to the grocery store a few blocks away in between the times that Lidia takes her shopping. She denies any driving problems and her daughter is unaware of any as she doesn’t accompany her mother when she drives. Mrs. Cadar wishes Lidia would stop worrying about her so much.

Lidia reports that her mother now needs assistance with paying her bills and remembering to take her medications. Most frustrating for Lidia are the facts that her mother calls several times a day with the same questions and tells the same stories over and over.

Your interviews with Mrs. Cadar and Lidia lead you to suspect that Mrs. Cadar may be suffering from dementia.

- Where do you go from here? What do you tell them today?

Second Visit: During Mrs. Cadar’s second visit with her daughter, you note that her skirt has a stain on it. Despite your request that she bring in all her medications, she has forgotten them. She scores 21 out of 30 on the Montreal Cognitive Assessment (MoCA). A score of 26 or more is considered normal. You ask her to draw a clock; the resulting drawing is poorly organized. She is unable to recall the name of your receptionist, whom she has known for years. Because she reads the newspaper daily, you ask her about current events. She is unable to tell you even basic information about current events. She is able to name the prime minister, but not the premier or the mayor. You ask Lidia more
about her mother’s driving, but she says that for many years she hasn’t been a passenger in her mother’s car.

On physical examination, you note that Mrs. Cadar has hearing loss and osteoarthritis. She has no focal neurologic deficits.

You are now very concerned that Mrs. Cadar has dementia, and you suspect Alzheimer’s disease (AD) may be the cause.

- **What do you tell Mrs. Cadar and Lidia?**

*Third visit:* Mrs. Cadar returns to your office with her daughter. Results of all her laboratory tests are normal. You find yourself dreading this encounter.

- **What are you going to tell them? How will you go about telling them?**
- **Do you reveal the diagnosis only to Mrs. Cadar, only to her daughter, or to both?**
- **Why do you think you are uncomfortable? What might help you feel less uncomfortable?**
- **What are some issues you will want to address with Mrs. Cadar and Lidia?**
- **What issues might arise for Lidia as a caregiver, and how can you help her manage them?**
- **How can you meet Lidia’s needs for information and education?**
- **What other resources may provide support for Lidia?**
- **What community resources would you consider for Mrs. Cadar?**

**Case variation 1:** Mrs. Cadar’s son, George, lives in Winnipeg. He has called you several times to voice his strong opinion that his mother should be referred to a specialist immediately and sent for magnetic resonance imaging to determine the problem. He believes that Lidia is neglecting their mother. He also thinks that, if Mrs. Cadar is “demented,” she should be placed in a nursing home right away.

- **How could you address George’s concerns from a distance?**
- **How can you best involve George in his mother’s care without breaching Mrs. Cadar’s privacy?**

**Case variation 2:** Mrs. Cadar has no living relatives. A neighbour has noted the smell of rotting garbage coming from Mrs. Cadar’s apartment, and brings her to your office.

- **How would the issues be different with no relatives involved?**
- **What if the neighbour reports that, in the past few months, the fire department has been called to Mrs. Cadar’s apartment several times because of small kitchen fires?**
INFORMATION POINTS

Prevalence

1. The Canadian Study on Health and Aging has documented that the prevalence of dementia is 8% among people over age 65 and 34.5% among those over age 85.2

Diagnosis

2. The criteria for dementia are included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).4 Memory impairment alone is insufficient for diagnosis. In order for a diagnosis of dementia to be made, the patient must have memory impairment as well as other cognitive deficits and this impairment must be sufficient to affect daily functioning. These other cognitive deficits may include aphasia (language disturbance), apraxia (impaired ability to carry out motor activities despite intact motor function), agnosia (failure to recognize or identify objects), or disturbances in executive functioning (planning, organizing, abstracting, judgment).

Assessment

3. In nearly 90% of dementia cases, the diagnosis can be made on the basis of a general medical and psychiatric evaluation.5 Caregivers’ complaints about their relatives’ memory problems are correlated with dementia, but patients’ subjective complaints about their own memory impairment are not a good indicator of dementia.6 A collateral history is therefore very important. As dementia progresses, the awareness of memory problems diminishes, making the patient’s history less reliable. For this reason, the physician must collect collateral information from family and/or friends when possible.

4. A complete assessment is important, not only to clarify the diagnosis, but also to reassure the patient and family that potentially reversible causes have been ruled out or addressed. In addition, this process serves to build a relationship between the physician, the family, and the patient, and increases the family’s and patient’s level of comfort with the diagnosis and proposed treatment. A complete assessment should include a history from the patient and family, a physical examination, brief cognitive testing with an instrument such as the MoCA, and selected laboratory and radiologic investigations. In addition, an occupational therapist’s functional assessment in the home can be very helpful.7,8 Families and patients should be made aware that patients with dementia may experience improvement when concomitant medical and psychiatric illnesses (e.g., depression) are treated, or when they stop taking certain medications.9,10,11
Communicating a Diagnosis

5. Disclosure of the diagnosis of dementia is difficult for patients, families, and physicians. Although the potential for an adverse psychological reaction is often used as justification not to disclose the diagnosis, a recent study found that this was not the case for most patients and caregivers.12

6. In a community survey, 80% of healthy seniors expressed a desire to be informed if they were diagnosed with AD.13 Communicating a diagnosis of dementia is the first step in forging an alliance with your patient and his or her caregiver. Ethical principles of autonomy also play a role in disclosing a diagnosis.14 Patients have a right to be informed of their medical problems, and knowing one’s diagnosis is an important element for consent to treatments and receiving support services. Without a diagnosis, future planning, including developing an advance directive and assigning an attorney for personal care, may not be done, and appropriate medications cannot be given.15, 16 The Alzheimer Society of Canada states that all patients with dementia should be sensitively informed of the diagnosis and directed to community services. Families need to be educated about their loved one’s capabilities so that autonomy can be preserved as long as possible. Disclosure has been identified by primary care physicians as a particularly difficult aspect of dementia care.14 A conversation guide is included in Appendix 1.

Patients with dementia and their families benefit from accurate and clear information about the diagnosis as early as possible. Although the FP (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.3

Although referral to the Alzheimer Society is an important part of dementia management, this often does not happen.3 The Alzheimer Society developed the First Link program to assist physicians in the referral process and to decrease the need to rely on patients to act on their physicians’ recommendations.3 With this program, the FP obtains permission from the patient and/or the 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.

Primary care physicians should be aware of resources that can assist with the care of those with dementia within their communities (e.g., support groups, adult day programs) and should make appropriate referrals to them.14

Insufficient evidence exists either for or against recommending cognitive interventions to maintain cognition in AD.14, 17
Good evidence indicates that individualized exercise programs have a positive effect on functional performance in those with mild to moderate dementia.\(^{17}\)

Some patients with dementia in the later stages may wander and become lost, which can result in physical and/or emotional harm or death. Restlessness and memory loss with spatial impairment can cause a wandering patient to become lost. Becoming lost is a highly unpredictable event. All patients with dementia are at risk for being lost, even when they live with a caregiver or are preforming activities they have done in the past without problems. Patients registered with the Alzheimer Society’s Medic Alert Safely Home Program receive an identification bracelet so they can be identified if they ever become lost. They also are registered in a national police database. The one-time fee is $60 (see Resources). GPS devices are also an option to help locate patients with dementia. The Alzheimer Society has developed a checklist for families to use when they are considering such a device.

Falls are a major concern, even early in the course of dementia. In one study, the risk of a hip fracture was twice as high in patients with an MMSE score between 18 and 23 as it was in those with no impairment.\(^{18}\)

A diagnosis of dementia does not automatically mean a patient cannot drive safely. However, drivers with dementia are at a significantly increased risk of being in a motor vehicle accident. Several resources and guidelines on driving are available for physicians. These resources include checklists that should be used when obtaining a driving history from patients and their families (see Resources, Dementia Toolkit)\(^ {14,15}\) Current guidelines state that patients who have moderate to severe dementia should not drive.\(^ {14}\) Moderate dementia is defined as impairment of two or more instrumental activities of daily living (IADLs) or one activity of daily living (ADL). Those who cannot drive safely should be advised to stop and informed that a physician has a legal obligation to report potentially unsafe drivers to the ministry of transportation. The family should also be informed if the patient is incapable of understanding and appreciating this information, or if the patient consents to disclosure. A physician who is unsure whether a patient can drive safely should refer the patient for an on-road driving assessment (see Resources). Even if the FP is sure the patient can drive safely currently, the patient and family/caregivers should be advised that giving up driving is an inevitable consequence of dementia and they should plan for this accordingly.\(^ {14}\)

**Pharmacologic Therapy**

7. Acetylcholinesterase inhibitors are used for treatment of mild to moderate AD. They exert their therapeutic effect by enhancing cholinergic function, which is deficient in AD. Cholinesterase inhibitors have been found to have modest benefits for global clinical impression, cognition, function and behaviour.\(^ {17}\) Three agents are available in Canada. They are thought to have equal efficacy but different side-effect profiles. Patients and families should be advised about potential side effects associated with these medications.
They should also be informed that these agents are not a “cure” for AD. Some patients may benefit from these medications and for many, the medication may keep them at the same point in the disease process for longer. However, AD is a chronic progressive illness, even when it is treated.17

Caregivers

8. In Canada, approximately 50% of patients with dementia live in the community. Over 98% of them have a caregiver. The Canadian Study on Health and Aging showed that a spouse (usually a wife) is the caregiver in 37% of cases and a daughter in 29%.20 The negative effects of caring for relatives suffering from dementia are well recognized. The incidence of depression, social isolation, chronic fatigue, and physical complaints is increased, especially as cognitive function declines or behavioural symptoms worsen. Caregiving has also been associated with exacerbation of pre-existing illnesses, more visits to physicians, increased use of psychotropic drugs and alcohol, and poorer subjective ratings of health. 21 Depression becomes more likely as the patient’s condition deteriorates, especially if behaviour problems are evident and/or when care needs increase. Because of feelings of shame or inadequacy in the caregiving role, many caregivers will not address or mention their challenges and burden to a physician. They may say something only when a crisis occurs. Most families prefer to avoid nursing-home placement, and spouse/caregivers are more reluctant than other relatives to place their relatives in care. The major reasons for admission to a nursing home for patients with dementia are behaviour problems and caregivers’ feelings of being overwhelmed.2

Caregiver Interventions

9. Protective factors that can mitigate caregiver distress include personality factors (mature coping strategies), a good relationship with the person with dementia, a supportive social network, education, availability of professional support, and a coping style that includes problem-solving and acceptance.21 Economic factors can have a negative impact on access to support services, formal and informal caregivers, and equipment.

Studies of individual caregiver support showed improved quality of life and contentment with the caregiving role in caregivers receiving formal support.22-26 One study of comprehensive caregiver support showed delayed long-term care (LTC) placement for patients with dementia and a lowered risk of depression in caregivers. 22

Caregiver support can take the form of respite, counselling, emotional support, and skill teaching. In several studies, respite care has been shown to decrease caregiver distress.26 Respite programs can be in the home (i.e., a personal support worker stays with a patient for a few hours to give the caregiver time out of the house) or in an institution, which involves admitting the patient for a limited time (from one week to three months). Costs may be associated with these forms of support.
The Alzheimer Society offers education, support groups, and individual support to help caregivers of people with any type of dementia understand the disease processes and what to expect. Support groups allow caregivers to receive and provide mutual support. The Alzheimer Society can also provide the family with strategies for behavioural problems and assist with planning for the future.

There may also be local specialized centres such as the CARERS program at Toronto’s Mount Sinai Hospital. These programs are specifically designed to support caregivers through skill-based tools and emotional support. Caregivers practice the scenarios they encounter with standardized patients and are coached about strategies and techniques.  

10. Adult day programs for people with dementia usually include physical activity and a social program. These programs may reduce the influence of exhaustion and stress on the caregiver.

**Care Planning**

11. Engaging patients in discussions about the natural history of their illness is important, as are discussions about the expected decision points likely to occur in their future. Capable patients can make meaningful choices about their future care and can express their values and beliefs to the physician, their family, and potential substitute decision-makers (SDMs). Patients should be encouraged to assign power of attorney for personal care and finances early in the course of the illness. If a patient has not designated an SDM through a power of attorney for personal care, a health care provider must turn to the hierarchy of substitutes named in the law to make health decisions. The highest-ranking person on this list, who is also available, capable, and willing to make these decisions, will become the SDM for treatment (see [http://www.seniors.gov.on.ca/en/advancedcare/docs/AdvancedCare.Guide.pdf](http://www.seniors.gov.on.ca/en/advancedcare/docs/AdvancedCare.Guide.pdf) and resources in Dementia Toolkit).

Values and beliefs are an important element in treatment decision-making by capable patients and SDMs of incapable patients. While patient wishes, values and beliefs may change over time, this information can be a useful reference point when making future decisions. These actions respect patients with dementia as persons, and support their moral agency.

Those close to patients, for example, their family members and close friends, may wish to be involved in the diagnostic process and care. Patients’ consent is necessary when they are capable of making decisions about the release of their health information and the inclusion of others in care planning.

12. When patients are capable, they and the physician should identify potential SDMs. Contact information should be obtained and information provided to SDMs about their role and responsibilities.
13. When patients are not capable, the physician must work with a patient’s relatives to identify an SDM. Substitute decision-makers should be engaged in care planning. This prevents the need to make treatment decisions in emergency situations when little or no thought has been given to an overall plan. Care planning may increase the likelihood that treatment and care decisions will be made in accordance with the patient’s capable, applicable wishes, or that decisions are in the patient’s best interests.

14. Advance care planning is an ongoing process of planning for future care and treatment decisions. It is often undertaken with a view to a future time when the client may no longer be able to make his or her wishes known. Advance directives should be made when the person with dementia still has legal capacity—the level of judgment and decision-making ability needed to sign official documents or make medical and financial decisions. These documents should be completed as soon as possible following a diagnosis of dementia.

If the patient creates an advance directive, a copy should be given to all those involved in decisions (family members, physicians, and other health care providers).

End-of-life decision-making should include a discussion of aggressive medical therapy, including intubation, cardiopulmonary resuscitation, use of feeding tubes, intravenous (IV) hydration, and use of antibiotics. Problems with eating and swallowing are common in the late stages of AD. Eating and drinking hold great meaning for many people and may have cultural components that influence decision-making. Patients and families should be made aware that feeding tubes do not extend life or prevent aspiration, and that IV hydration may extend the dying process.

Outlining the general goals of care is often helpful. For example, does the patient want only comfort care (treatment aimed at relieving pain and suffering, such as oral medication, wound care, being turned in bed, oxygen for comfort), limited medical interventions (such as medication by mouth, intravenously, or subcutaneously), or no limitations on medical interventions?
CASE COMMENTARIES

Case: Mrs. Cadar, aged 85

First visit—history: You want to explore Lidia’s concerns while respecting Mrs. Cadar’s autonomy. You may wish to interview them together and individually. During this initial interview, you will explore a history of cognitive change, as well as any impairment in functioning or performance of activities of daily living. In order to rule out the possibility of delirium or an acute physical cause of the symptoms, you need to obtain a history of the time course and nature of cognitive and physical changes, and of any medication changes. Undetected delirium has a very high mortality rate. The use of over-the-counter medications, prescription medications, and alcohol must be reviewed. Ask Mrs. Cadar and Lidia to bring in all the medications she takes, including those she purchases over the counter.

In addition, you should review any symptoms of depression, delusions, or hallucinations. Before Mrs. Cadar and Lidia leave, you should directly address issues of safety and security, such as any history of kitchen fires, floods from leaving taps on, driving difficulties, or wandering.

A complete evaluation of a patient with suspected dementia usually requires several visits. You should ask Mrs. Cadar and Lidia to return for a longer visit.

Today, you might speak in general terms about trying to sort out the reason for the forgetfulness. The family and the patient can be told several possible reasons may account for memory problems, and that finding the cause will take time.

Second visit—physical examination: A complete physical examination is imperative. You must look for neurologic signs and evidence of other systemic diseases that may exacerbate or mimic dementia.

Although you strongly suspect AD, you must rule out any coexisting medical conditions that may contribute to a change in cognition. Laboratory tests should be ordered (a complete blood count, electrolyte measurements, blood urea nitrogen testing, creatinine testing, glucose testing, calcium testing, vitamin B₁₂ testing), and a computed tomography scan or magnetic resonance imaging are helpful in some cases.³

Mrs. Cadar’s hearing should be formally tested, as her cognition may improve with a hearing aid. You may wish to prepare the patient and the family for a diagnosis by reiterating your concerns about Mrs. Cadar’s cognition. In addition, you should explore the patient’s concerns. Some patients are oblivious to their symptoms, whereas others have some insight. The process of making a diagnosis over several visits allows the patient and the family some time to prepare themselves.

Third visit—cognitive testing: A separate visit should be scheduled for cognitive testing, to provide objective information that is critical for ruling out
or verifying dementia. In addition, these tests serve as a baseline for future testing. Both the MMSE and the MoCA are commonly used in clinical practice. However, the MoCA is a more sensitive test for patients with mild cognitive impairment or mild dementia.

As a physician, you have an obligation to report unsafe drivers. You may wish to use questionnaires available online to gather more information on Mrs. Cadar’s driving, and to consult the Canadian Medical Association driver’s guide for guidelines on driving and dementia. The “grandchild question” is often useful for patients’ families: “Would you feel safe with your mother/father driving your child?”

Mrs. Cadar demonstrates impairment of two or more of her IADLs. According to the CMA driver’s guide and the CCCD guidelines, this impairment means she cannot drive safely. You should tell her this in a supportive way, and you will need to explore alternatives to driving with her and her family. You should inform her that you are obligated to inform the Ministry of Transportation about your concerns. You may wish to give her your findings in a letter, as well. (For a sample letter, see Resources, Dementia Toolkit, driving.)

**Fourth visit—review and diagnosis:** Now that you have completed the work-up, you can review the patient’s symptoms, the reason for the tests, and the importance of reaching a diagnosis. Whenever possible and with the patient’s consent, the diagnosis should be disclosed with a family member present. The diagnosis should be discussed openly. Choosing not to disclose the diagnosis reinforces any fears the patient or caregivers may have about their abilities to cope with the illness. You can reassure Mrs. Cadar that the changes are mild and fairly early. Patients and families are often unaware that most individuals with dementia live with a reasonable degree of independence and quality of life.

The disclosure of a diagnosis of a dementia can be the first step in forging or strengthening an alliance with a patient and his or her family. Use this visit to reiterate your commitment to working with them. Many families and patients have preconceived ideas about dementia, which are based on the experience of friends or family members who have suffered the terminal stages. Most elderly people die of other medical problems before reaching the severe stages of the disease. The family and the patient should be informed that medications may help delay cognitive changes, and that community supports can help the patient remain at home.

Many physicians feel uncomfortable delivering bad news. With the diagnosis of dementia, you may have a sense of being unable to “do something” or offer hope. You may also have images of patients with severe dementia who are in nursing homes. In a 1961 study of physicians’ willingness to tell patients about a diagnosis of cancer, 90% of doctors preferred not to tell their patients. When the same question was asked in 1977, the opinion had been reversed: 97% of physicians favoured telling patients. Maguire et al. speculate that because of changes in the treatment and management of AD, negative feelings about disclosing the diagnosis will decrease.
You may also feel overwhelmed by the prospect of caring for Mrs. Cadar in the future. You may see a future fraught with behaviour problems, paperwork, and family conflict. However, studies have shown that two of the most important aspects of managing dementia are treating comorbid physical and psychiatric illnesses and managing medications and side effects. Much of your care for the patient with dementia, therefore, will involve treating conditions that you already manage, such as constipation, hypertension, and depression. Other health professionals, such as community case managers, social workers, physiotherapists, occupational therapists, geriatricians, and geriatric psychiatrists, can provide assistance. Seeing the patient for surveillance and health maintenance at least once every three months will allow you to monitor her status and her family’s needs. These visits will allow you to know your patient and those close to her, identify potential SDMs, and plan ahead to decrease the possibility of a crisis.

An advance directive should be established early in the course of the disease, and you should seek to understand the patient’s values and beliefs about likely future conditions and care needs. The patient may have a window of opportunity to make her own decisions on issues such as resuscitation, long-term care placement, and the use of feeding tubes. Mrs. Cadar can be encouraged to give powers of attorney for personal care and for finances to those she trusts, and to discuss wishes, values, and beliefs with her health care providers, family members, and SDMs. Family members may want to be involved in these discussions. Most patients and caregivers benefit from a referral to the Alzheimer Society (the First Link program, if it is available). Mrs. Cadar may also be interested in pharmacologic therapy. Cognitive-enhancing medications such as donepezil and rivastigmine can be used to treat mild to moderate AD. You must ensure that Mrs. Cadar and Lidia have realistic expectations for these drugs. While some patients show modest improvements in cognition, these drugs do not cure AD and when they are discontinued, the effect on cognition is lost.

As Lidia’s FP, you will need to be alert for signs and symptoms of depression and poor physical health. Lidia will need some time to adjust to a caregiving role. Lidia’s own personality and coping style will play a role in how she deals with her mother’s illness. You should explore with Lidia her previous caregiving roles, her social support network, and her current physical and emotional health. Lidia’s current and past relationship with her mother should be explored. Different families and cultures have different values and beliefs attached to caregiving; you need to be aware of the values and beliefs in this family.

Lidia’s need for support from you and from community resources will vary with time. Lidia will likely need education on AD and related issues, as well as psychological support. Caregiver general mental health is positively affected by programs that address both the person with dementia and their caregiver. You can also discuss caregiver support groups with Lidia. Participants in such groups perceive them to be beneficial and helpful. These groups provide companionship, support, and information. Respite services offer caregiver relief, and may delay institutionalization of the care recipient.
You should refer to your local home care service agency. In most jurisdictions in Ontario, staff at a Community Care Access Centre (CCAC) can do an initial assessment of a client’s need for homemaking, nursing, and physiotherapy. An occupational therapist’s services provided through CCAC can do a home safety assessment to ensure Mrs. Cadar is safe in her home. This therapist will observe Mrs. Cadar in the kitchen and the bathroom, in particular, and make recommendations to improve safety. She will be assigned a case manager, who can provide education, assistance with transitions, emotional support, and guidance in locating and coordinating community resources such as day programs. In Ontario, the CCAC case manager is responsible for the initiation and coordination of LTC applications and admissions. Partnering with the CCAC case manager can enhance integration of care in the patient’s home and may avoid trips to the emergency department and admissions to the hospital.

Psychogeriatric resource consultants, where available, are knowledgeable about community resources for patients and families with dementia (see Appendix 1).

Palliative care and pain and symptom management programs can provide guidance and treatment for symptom management and care during the dying process.

Physiotherapists can educate families about an exercise program, which will help the patient with dementia maintain physical strength, coordination, and function. In addition, exercise programs may help prevent falls, a major cause of morbidity and mortality in the elderly.

Legal assistance and government resources can help the patient establish a power of attorney for health care and for finances, and engage in advance care planning.

**Case Variation 1**

It is important to acknowledge George’s concern for his mother. Being out of town creates stress and worry for George, albeit different from the concerns of his sister. He may feel guilty that he is not there or powerless to help his mother. You can reassure George that you take his concerns seriously. You can ask Mrs. Cadar if you have her consent to review her health information with her son. If she gives consent you can review your assessment and plans with George. If Mrs. Cadar does not give consent, you can listen to George’s concerns while being careful not to share any details of Mrs. Cadar’s health with him. You can suggest to George that he contact his local Alzheimer Society chapter and/or visit their website, as this can be an important source of information and potential support to him.

**Case Variation 2**

You will need to assess if Mrs. Cadar understands the concept of power of attorney (POA) and appreciation of the consequences of assigning a POA for property (finances) and personal care. If she does understand the concept, ask her if there are any friends or other relations that she would trust to be her POA, i.e. to make decisions about her personal care and/or finances if she is unable to
make them. If Mrs. Cadar has capacity, then she can ask a lawyer to help her in assigning power of attorney. There are legal resources for low income seniors. It is important to differentiate between capacity for treatment decisions and capacity for property (finances). In the case of finances, a capacity assessor can help with this determination, although this has a cost and the patient must consent to the assessment. For treatment decisions, a family physician can do this (see Resources, Dementia toolkit, capacity). Decisions related to personal care may address, but are not limited to, healthcare, nutrition, clothing, hygiene, shelter, and safety. An individual whose capacity is under review may have capacity to make personal care decisions in some instances and lack the ability to make decisions in other instances (see Resources, Dementia Toolkit, capacity).

If the fire department has been called to Mrs. Cadar’s apartment several times, she may be of more imminent danger to herself and to others in her building. An OT should be called in urgently to address this important safety issue. The stove may have to be removed or disabled. She will likely need personal support services for meal preparation. Mrs. Cadar’s suitability for long-term care will need to be assessed. In Ontario, capacity to make decisions about long-term care is assessed by Community Care Access Centres. In other areas, this responsibility may lie with others. If the risk of fire issue cannot be addressed quickly, then an urgent (crisis) placement in long-term care may be required.
Diagnosis of Dementia – Diagnosis Disclosure Aid for the Family Physician: A Conversation Guide

(Adapted from Dementia Toolkit for Primary Care http://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/prc-dementia-resources-for-primary-care/dementia-toolkit-for-primary-care/dementia-toolkit-for-primary-care)

Disclosing a diagnosis of dementia is never an easy task for physicians. The diagnosis can be life-altering for patients and their families and a variety of reactions can result, including disbelief, denial, shock or anger. Some patients are aware of the implications associated with a diagnosis of dementia, while others rely on their physician to educate them about the course of the illness, the inevitable decline and the lack of any definitive treatment. For most patients, having a conversation about dementia at the earliest possible opportunity can help them to better understand and manage the disease. Here are a few suggestions to help you better support your patients who have been diagnosed with dementia:

In preparation, ensure that you:

- Encourage patients to have a family member or friend with them.
- Have the results of the testing in front of you.
- Have a list of community resources with you, in particular a referral to First Link through the Alzheimer’s society.

General guidelines for the conversation:

- Remind the patient why testing was undertaken. Remind the patient about things they have said are causing them difficulty or concern (e.g., “You told me your memory is not good. These tests have confirmed that, and I think I have an explanation for why”).

- Test results: “The test results have come back and I would like to share them with you. They confirm our concerns about your memory.” Go through the results in detail if you think the patient would like to hear them (take into account what information would be most critical for the patient to hear).

- Provide the diagnosis: “According to the test results you have dementia” (state the type of dementia if possible). Ask if the patient would like to talk about this today or at your next meeting. This helps patients have a greater sense of control.

- When the discussion happens, consider using the following language: “Dementia is a disease of the brain that slowly progresses and worsens. Many people however, live in their own homes with some support for many years. Over time, you and your family will see changes in the way you feel and what you are able to do on your own. You may occasionally feel upset with yourself and with the people around you. Some medications may help to slow the progression of your symptoms and there are many community...
resources to help you and your family over the next few years. I would also like to see you regularly so I can help you manage this effectively”.

- Provide tools: Give the patient and caregiver/family member information sheets and resources. Patients and families often don’t take the next step of calling these organizations for help. It is important to follow up to see if they have done so. Let them know that valuable information, support groups and counseling services are available through the Alzheimer society.

- Referral: Make a referral to the Alzheimer Society and the First Link Program, where available.

Key messages:

- Acknowledge the patient’s feelings e.g. “I understand that this is difficult to digest” or “I can see you are confused/upset/shaken”

- Suggest that the patient and their family take time to absorb the diagnosis and come back at a later date for more information. Many people will be shocked at the stage of initial diagnosis and will not be able to ask questions or absorb information properly.

- Consider both the caregiver and the patient when addressing feelings.

- Let the patient and his/her family members know that they are not alone. Emphasis should be placed on the progressive nature of the disease, the importance of connecting with the appropriate resources, and planning ahead.
REFERENCES


RESOURCES

**Alzheimer Society of Canada**: [www.alzheimer.ca](http://www.alzheimer.ca)
- Information and resources on dementia for patient, caregivers and health care professionals. Resources for support for patient and caregivers.
- Information on MedicAlert Safely Home Program
- Excellent patient education handouts on a wealth of dementia related topics.
- Useful links for health care professionals including valuable resources on screening and assessment, driving assessment, First Link program and links for professional development

**Dementia Toolkit for Primary Care**:

This is a website for primary care practitioners to support their work in providing care for older adults with dementia and responsive behaviours and their caregivers. In this website you will find very useful tools, resources and information specifically designed for primary care settings. Each topic is linked to a folder with documents available for download. Topics include:
- Assessment and Screening Tools
- Diagnosis of Dementia
- Delirium
- Dementia and Medication Management
- Responsive Behaviours in Dementia
- Driving Safety and Dementia
- Capacity and Dementia
- Caregiver Support
- Palliative Care and Dementia
- Billing Codes and Dementia

**Psychogeriatric Quick Resource Guide**:

A two-page table with resources for a wide variety of problems from making a diagnosis, to transportation, to capacity assessment. Many of the resources are Toronto- or Ontario-specific.

**Capacity Assessment**: [ACE capacity tool](http://www.jointcentreforbioethics.ca/tools/ace_download.shtml)