Ontario Physicians Supporting Patients With Dementia: A Call For An Ontario Dementia Strategy

Ontario Physicians Support The Establishment Of An Ontario Dementia Strategy

In September 2015, Statistics Canada confirmed that for the first time in history, Canada has a greater population of seniors aged 65 and older than it has children aged 14 and younger. By 2024, more than one in five Canadians will be a senior citizen. As a result, the prevalence of dementia in society is expected to increase significantly over the next several years as the risk for the condition doubles every five years after age 65. By 2020, it’s estimated that approximately 250,000 seniors in Ontario will be living with dementia, up from about 200,000 in 2015.

Dementia has a negative impact on society at several levels — on patients, on their informal caregivers, on the health care system, and ultimately on the economy as a whole:

- Dementia is a debilitating, progressive, and fatal condition that places significant physical, emotional and psychological stress on patients.
- Many individuals living with dementia will stay in their homes supported by informal caregivers, primarily family members. Family caregivers are often older and frail themselves. The strain of caring for someone with dementia can be overwhelming, causing physical or mental illness in the caregiver.
- The increased incidence of dementia will put considerable pressure on the Ontario health care system in the coming years. Studies show that patients with chronic conditions such as dementia typically have poorer quality of life and require considerable health care resources. Patients with dementia are at increased risk for complications due to pre-existing or co-existent health care issues, such as diabetes, coronary disease, chronic pulmonary disease, etc., and often require more frequent and intensive hospital visits.
- Dementia has a significant impact on the provincial economy. The Alzheimer Society of Ontario estimates that the total annual economic burden of dementia in the province will increase to approximately $15 billion by the year 2020.

This includes the direct costs of health care services and the associated costs of caregivers’ lost economic opportunities, productivity and wages. In 2014, informal caregivers provided 87.1 million unpaid hours caring for people with dementia. By 2020, it’s estimated they will be providing 144 million hours, an increase of 65%.

This paper highlights some of the significant challenges related to dementia that need to be addressed by decision-makers in the very near future to ensure that the increasing number of dementia patients and their informal caregivers receive the appropriate care and support they need. The paper provides preliminary recommendations from the OMA to address some of these challenges, including the establishment of a co-ordinated Ontario Dementia Strategy (ODS). The Strategy will provide a framework for the co-ordination of dementia care and services in the home and in the community. It will have a positive effect on patient and caregiver quality of life and will lessen the burden of the condition on the health care system and the overall provincial economy.

An effective Ontario Dementia Strategy must be built in partnership, including patients, physicians, other health care professionals, and government. We need to build upon local solutions that are already working well for patients and their caregivers.
The word dementia describes a set of symptoms that occur when the brain is affected by disease and/or other conditions. The symptoms are severe enough to negatively impact a person’s ability to perform their regular everyday activities, and may include:
- Memory loss.
- Impaired judgment or reasoning.
- Challenges processing information or problem-solving.
- Challenges in planning and execution (executive brain function).
- Difficulties with understanding or producing language.
- Changes in mood or behaviour.
- Deterioration of the various portions of the brain responsible for motor functions.

Alzheimer’s disease is the most common form of dementia, accounting for approximately 60%-70% of dementia cases. 

**Physicians Provide Support To Dementia Patients And Their Caregivers**

Physicians take an active role in providing support to their dementia patients and their caregivers in several ways.

1. **Diagnosis And Management Of Dementia**

Physicians play an important role in the diagnosis of dementia and the management of its symptoms. When dementia is suspected, physicians apply various cognitive, physical, and mental tests to confirm its presence. Tests can be conducted to rule out other possible causes for dementia symptoms, such as stroke or head trauma. Additional information about possible assessment tools physicians utilize to assist with diagnosis and/or treatment are contained in Appendix 1 (see p. 19). Appendix 2 (see p. 19) contains information about possible diseases, such as Parkinson’s, or conditions, such as sleep disorders, that physicians look for as they can also cause dementia or dementia-like symptoms. Appendix 3 (see pp. 19-20) provides a comparison of the common signs of dementia versus the common signs of aging.

Physicians have the clinical and medical expertise to diagnose and manage the symptoms of dementia, but they also rely on the patients’ families and/or informal caregivers as the individuals who know the patients best. Families and caregivers can provide helpful insights regarding memory or personality changes that may signal the onset of the condition. An early dementia diagnosis can help patients get the support they need sooner, before a potential health crisis occurs. It can also help the patient and their family members prepare for what is to come.

**Recommendation: An Ontario Dementia Strategy (ODS) should educate the public about dementia, its symptoms, and about the benefits of early diagnosis. The strategy should include information about the impact and the progression of dementia so that patients and their families are prepared and can proactively plan for what is to come.**

Physicians provide various treatments or drug therapies to help ease some of the symptoms of dementia, and address physical illnesses that are often present in dementia patients, such as heart failure, hypothyroidism, diabetes, etc. They also monitor patients for possible drug side effects, and to determine whether specific therapies are having the desired effect. Specialists also play a significant part in the diagnosis and management of dementia. Family physicians may refer their dementia patients to specialists, such as neurologists, geriatricians, geriatric psychiatrists, or family physicians that specialize in the care of patients with dementia. Physicians also refer patients to various other health professionals to help in the overall management of the condition, such as physiotherapists who can perform a needs-assessment related to loss of motor functioning.

The Alzheimer Society of Canada has introduced a program called First Link that supports individuals with dementia by linking them and their caregivers with support services sooner. This program accepts referrals to the Society directly from health professionals rather than putting the onus on patients to self-refer. Results from the First Link program indicate that the health professionals and caregivers involved have gained a greater understanding about the condition and about how to manage it. Participants reported an earlier awareness of the available community services and resources that helped support individuals with dementia to remain at home for as long as possible. Also reported was a reduced “failure-tocope” use of health system resources.

**Recommendation: An ODS should provide the public with information about dementia supports and resources, such as specialist treatments and community supports.**

Physicians play a significant role in monitoring and treating patients’ co-existing health concerns. Patients with dementia are at increased risk for complications due to pre-existing or co-existent health care issues such as diabetes, coro-
nary disease, chronic pulmonary disease, etc. In 2012, more than 90% of community-dwelling older adults with dementia were living with two or more co-morbid conditions. Dementia patients have a greater incidence of avoidable hospitalizations due to the poor self-management of co-existing chronic diseases. Referred to as the “dementia domino effect”... patients with dementia...“are prone to cycles of emergency department-use and hospitalization, stabilization, discharge to home, poor self-management, deterioration, and readmission to the hospital.”

Physicians take a proactive role in trying to prevent the dementia domino effect by ensuring they meet regularly with dementia patients to monitor their co-existing conditions and to educate patients and their caregivers about the signs and/or symptoms that may signal the need for additional care in areas unrelated to their dementia. Physicians offer advice about illness prevention, fitness and nutrition. Physicians educate patients and their caregivers about basic self-care activities they can perform at home to ensure that their co-existing health conditions remain as stable as possible, for example, taking the patient’s blood pressure at home, measuring blood glucose levels, observing weight loss/gain, fever, etc.

**Recommendation: An ODS should facilitate the creation of system approaches that support access to timely medical and supportive care for dementia patients.**

### 2. Ensuring The Patient’s Caregivers Are Supported

Many individuals living with dementia will stay in their homes supported by informal caregivers, most often spouses or other family members, along with neighbours and friends. In the later stages of dementia, when the care needs of patients increase significantly due to cognitive decline and functional impairments, it is estimated that the total care contributed by family and friends ranges from seven to 15 hours per day. In 2012, the Health Council of Canada estimated that informal caregivers who care for persons with dementia provided 75% more care hours than other caregivers.

Informal caregivers can become overwhelmed as their loved one’s condition deteriorates. A recent Canadian Institute for Health Information study determined “that rates of caregiver distress were five times greater among individuals caring for seniors with moderate to severe cognitive impairment — likely resulting from Alzheimer’s disease or other forms of dementia — compared to individuals caring for seniors without cognitive impairments.” A family member or friend who is the primary caregiver for a person with dementia often reports feeling distress, anger or depression, and often to a greater degree than other caregivers.

Physicians know that it is important for caregivers to stay healthy so that they may continue to provide good care to their family members. Standard health promotion strategies, including maintaining a healthy weight, not smoking, and managing alcohol intake, should be an active part of preventive maintenance for caregivers. Family caregivers often put their own needs behind those of the person they are caring for, and subsequently their health can decline as well. As a result, informal caregivers frequently suffer from physical, psychological and emotional strain. As many as 25% of caregivers have two or more chronic health conditions of their own to contend with — conditions that can be aggravated and exacerbated by the strain of sleep deprivation, worry, and the continuous care demands they are under.

Physicians watch for signs of excessive stress in caregivers, such as anger, withdrawal from friends, anxiety, depression, sleeplessness, emotional reactions, lack of concentration, and exhaustion. Caregivers may need to be reminded about basic health strategies, such as getting enough sleep, proper nutrition, and regular exercise. They may need prompting to attend their medical appointments, to keep up their treatments and medicine, and to not neglect their own health care issues. As well, caregivers may need to be prompted to stay in touch with friends and family to help with feelings of isolation and loneliness.

Unfortunately, many caregivers wait to seek help from support services until they face a crisis or their caregiving burden is too great. Physicians help caregivers to understand that it is alright to ask for help and that they should not have to bear the burden of care for a loved one all by themselves. Caregivers may need to be reminded to take regular breaks from caregiving, even short ones, to prevent exhaustion. Physicians inform the patient and caregiver about community services, including community nursing, Meals on Wheels, short home visits to provide respite for caregivers, adult daycares and recreation centres, personal care centres, counselling services, dementia clinics, transportation assistance, etc.

It may be that the caregiver needs someone to talk about the stresses he or she is experiencing. Physicians provide support and counselling, can recommend a support group, or simply encourage the caregiver to speak with a friend, a religious advisor, another family member, etc.

Patients and caregivers can also receive tax credits from the government, such as the disability tax credit, the eligible dependent credit, and the caregiver credit. Other claims can be made for medical expenses and attendant care. Physicians make patients and their caregivers aware of these credits, and possibly direct them toward additional sources of information.

**Recommendation: An ODS should:**

- **Address access to community, respite and home support services to provide relief for informal caregivers.**
- **Review the effectiveness of financial supports, tax credits, grants, etc. for informal caregivers.**

### 3. Educating Patients And Their Families About What Is To Come

After diagnosis, patients and their families look to their physicians for information, guidance and support. Providing information about how the patient’s behaviours may change over time, and advice about how to respond to those behaviours,
is important information provided by physicians that may help to facilitate better home care for the patient. As well, physicians provide helpful advice about how to create a home environment that will help to keep the patient safe as their condition deteriorates.

One of the more challenging aspects of dementia for family members and informal caregivers is addressing patients’ behaviour and personality changes that develop as the condition progresses. Physicians educate families and caregivers about how to respond to dementia behaviours as they occur. They encourage caregivers, as the persons who know the patient best, to view the situation from the patient’s perspective so they can identify the trigger for the behaviour, and then try to modify it in some way, if necessary. ¹³

Appendix 5 (see pp. 21-23) contains a list of the most common problem behaviours that arise in dementia and suggestions from several sources about how to handle them when it becomes necessary. Physicians, often in concert with other health professionals, provide advice to patients with dementia about how their homes may need to be modified as their condition worsens. Since dementia patients are affected physically, mentally, and psychologically, they are extremely vulnerable to injury. For example, burns may be caused by patients suffering from memory loss and distractibility when they forget to turn off the stove. Poor balance, depth perception, vision problems, and loss of physical strength can lead to falling down stairs, around bathtubs, into sharp table corners, etc. Losing the ability to recognize objects (anosognosia) may lead patients to use instruments inappropriately, e.g., knives, scissors, razors. ¹⁴ As well, suitable home adaptations help to create environments that empower patients and enable them to remain independent as long as possible.

To ensure safety in a home care situation, arrangements can be made for an occupational therapist to do a home safety assessment to assist with planning for the future when dementia symptoms will have progressed. Appendix 6 (see p. 23) contains suggestions for home alterations that may make the home safer for the dementia patient.

**Recommendation: An ODS should:**

- Provide education for patients, caregivers, and the public about potential dementia behaviours and possible solutions so that behaviours are more easily recognized and appropriately addressed with dignity for the patient.
- Examine the case for subsidies for patients to alter their homes for safety purposes.

Unfortunately, part of educating patients and their informal caregivers about dementia is tempering their expectations regarding the availability of dementia care. While many dementia patients live at home and receive care from a variety of highly trained paid professionals, there are simply not enough home care providers available to meet the growing needs of seniors. If caring for seniors at home is the direction the province wishes to take, then funding and social policies must be addressed to enable this to happen.

**Recommendation: An ODS should provide for:**

- More formal caregivers with specialized knowledge in caring for seniors with complex care issues, particularly dementia.

Ontario’s long-term care facilities are also under considerable pressure to meet the needs of the province’s existing elder population and they will not be able to absorb the increasing number of seniors entering the system. According to the Ontario Long Term Care Association, Ontario has 629 long-term care homes licensed and approved to operate in Ontario, providing care, accommodation and services to approximately 70,000 seniors annually. As of October 2014, over 23,000 seniors were on waiting lists to be admitted to long-term care facilities. The median wait time for long-term care is 108 days, although some of the more specialized facilities have lists of several years. Also concerning is the fact that 52% of long-term care homes do not meet most 2009 provincial design standards and require redevelopment.¹⁵

The Ontario government has stated “that Home Care is going to be a central feature in health care moving forward and that it is shifting care to individuals’ homes under certain circumstances.”¹⁶ However, there is still a need for long-term care facilities to provide care and support for seniors whose conditions have advanced beyond the capabilities of home care.

**Recommendation: An ODS should provide for:**

- Specialized long-term care services that are designed to care for patients with dementia.
- Shorter wait times to access care in long-term care facilities.

**Conclusion**

The Ontario health care system will be challenged in the near future to deliver care and support to more patients with dementia. Ontario physicians will continue to meet that challenge by diagnosing and managing care of dementia patients, co-ordinating care with specialists and/or other health care professionals, partnering with patients and their informal caregivers to maintain their health as long as possible, providing education and resources, and offering emotional support and understanding during a difficult time.

However, more supports are needed in the home, in the community, and in Ontario’s long-term care facilities if the province is to be truly successful in supporting dementia patients and their families. Without a co-ordinated Ontario Dementia Strategy that provides for better system supports, such as more home care workers with specialized knowledge about dementia, improved assistance for informal caregivers, and co-ordinated pathways to track dementia patients and to monitor their care, the province’s health care system may struggle to cope under the demands of our aging population.
Appendices: Supplementary Information About Dementia

Appendix 1

Possible Assessment Tools To Assist With Diagnosis And/Or Treat Dementia

If dementia is suspected and further investigation is warranted, cognitive assessment tools such as the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MOCA) could be applied. These tests can also be used to track the progression of the condition and its severity.17

After a dementia diagnosis, other tests can be done to rule out treatable systemic causes. Physicians can conduct a physical examination to identify signs of a systemic disease, such as anemia, heart failure and hypothyroidism. The Canadian Consensus Conference Guidelines recommend that individuals suspected of dementia have the following bloodwork: a complete blood count, serum electrolytes, renal function, calcium, B12, TSH and fasting glucose. Neuroimaging can be used selectively to rule out potential reversible causes of dementia, or when dementia has atypical features. For example, a CT scan may be done to exclude a treatable structural lesion, such as a brain tumor. Other diagnostics could include genetic testing if inherited disorders, such as Huntington’s, are suspected, or psychiatric assessments for depression.17

Treating heart failure, urinary infection, hypothyroidism or anemia, and recognizing drug side-effects, especially anticholinergics or sedatives/hypnotics, may improve mentation (mental activity) and ease caregiving. The management of mild to severe Alzheimer’s disease can include treatment with cholinesterase inhibitors and it is recommended that a trial of approximately six months be initiated for treatment benefit. Memantine can be considered for moderate to severe dementia. On average, the effects of these palliative medications are modest and expectations should be realistic. It is standard to control vascular risk factors such as hypertension, hyperlipidemia, and diabetes.

There is much controversy regarding the effectiveness and use of psychotropic drugs to treat the symptoms/behaviours of dementia.

Appendix 2

Possible Diseases/Conditions That Can Cause Dementia Or Dementia-Like Symptoms

Alzheimer’s disease is the most common form of dementia, accounting for approximately 60%-70% of dementia cases.6 Vascular dementia, resulting from brain cells being deprived of oxygen, usually during a stroke, is the second most common type of dementia, accounting for up to 20% of dementias.18 Alzheimer’s disease and vascular dementia commonly co-exist.

Other relatively common dementias include frontotemporal dementia, dementia with Lewy bodies or Parkinson’s dementia disease. Other distinct, but less common, dementias include:

- Dementia associated with head injury.
- Huntington’s chorea.
- Creutzfeldt-Jacob’s disease.
- Normal pressure hydrocephalus.
- Parkinson’s plus syndromes (e.g., progressive supranuclear palsy, corticobasal degeneration, multiple system atrophy).
- Wernicke-Korsakoff syndrome.
- Demyelinating disease.19

Some of these conditions with clearly identifiable etiology may be treatable. A neurological, geriatric medicine, or psychiatric consultation may be helpful in sorting out the less common varieties and to reach increased diagnostic certainty.

There are also several other conditions that can cause “dementia-like” symptoms. However, the symptoms can be controlled and in many cases reversed with the proper treatment. Treatable conditions can include:

- Vitamin deficiencies.
- Thyroid disease.
- Sleep disorders.
- Depression.
- Side-effects from medication or drug interactions.
- Alcohol and/or drug abuse.
- Head trauma (e.g., concussion).
- Dehydration.
- Brain tumor.
- Environmental toxins.19

Appendix 3

Common Signs Of Dementia Versus Signs Of The Normal Aging Process

Although the likelihood of having dementia increases with age, dementia is not a normal part of aging. While older adults often experience physiological changes that can slow the recall of information, these age-related memory changes are not the same as dementia.20 Many mental abilities are largely unaffected by normal aging, such as:

- The wisdom and knowledge one has acquired from life experience.
- One’s inherent common sense.
- The ability to form reasonable arguments and judgments.20

The table on page 20 outlines the common signs of dementia versus signs of the normal aging process as identified by the American Academy of Family Physicians (AAFP) and the Alzheimer Society of Canada.21,22 This information could be used by patients or family members as an informal self-assessment tool and discussed with the physician should the patient have concerns he or she is experiencing symptoms of dementia.

(continued on p. 20)
## Common Signs Of Dementia Versus Normal Aging
(Source: American Academy of Family Physicians and the Alzheimer Society of Canada)

<table>
<thead>
<tr>
<th>Sign</th>
<th>Examples of Normal Aging</th>
<th>Possible Signs of Dementia</th>
</tr>
</thead>
</table>
| Memory changes.             | • Temporary memory lapses, e.g., forgetting the name of a movie or a person’s name, but remembering it later.  
• Not being able to remember details of a conversation or event that took place a year ago.  
• Not remembering the name of an acquaintance. | • Forgetting and not remembering things later.  
• Repeating the same question multiple times, each time forgetting that the question had already been asked and answered.  
• Not being able to recall details of recent events or conversations.  
• Not recognizing or knowing the names of family members.  
• Struggling to learn and retain new information. |
| Difficulty performing familiar tasks. | • Able to function independently and pursue normal activities, despite occasional memory lapses. | • Difficulty performing simple tasks (e.g., paying bills, getting dressed, personal hygiene).  
• Forgetting how to do things done many times before (e.g., cook a meal, do laundry, drive). |
| Problems with language.     | • Occasional difficulty finding the right word, but no trouble holding a conversation. | • Forgetting words or substituting words that don’t fit the context, words are frequently forgotten, misused or garbled.  
• Phrases and stories are repeated in the same conversation. |
| Time and place disorientation. | • May pause to remember directions, but doesn’t get lost in familiar places. | • Not knowing what day of the week it is or getting lost in a familiar place. |
| Poor judgment.              | • May become distracted but still makes decisions appropriate for the situation. | • Making decisions out of character (e.g., not recognizing a medical problem that needs attention, or wearing light clothing on a cold day). |
| Problems with abstract thinking. | • Maintain ability to think in terms of concepts and general principles. | • Not recognizing items and what they are usually used for (e.g., not recognizing a chair as a piece of furniture, not understanding what numbers signify on a calculator). |
| Misplacing things.          | • Temporarily forgetting things, like where the car is parked or where the keys are. | • Putting things in the wrong place, having difficulty recalling where objects were placed. |
| Changes in mood.            | • Occasional moodiness. | • Exhibiting uncharacteristic mood swings, persistent depression or anxiety, feeling suspicious or threatened. |
| Personality changes.        | • May exhibit some characteristics to a greater degree (e.g., mildly more impatient, but generally maintains the same basic personality traits, such as sense of humour). | • Having drastic changes in personality, becoming erratic, agitated, irritable, suspicious or fearful. |
| Loss of initiative.        | • May occasionally be disinterested in activities previously enjoyed. | • May become passive, not wanting to go places or see other people.  
• Losing interest in friends, family and favourite activities. |
Appendix 4
The Stages Of Dementia

Dementia is characterized by a progressive deterioration of cognitive functioning and motor skills. Below is a brief description of what can be expected at the various stages of dementia:23, 24

Mild Dementia
Patients do not generally experience major impacts on their basic activities of daily living (e.g., getting up, going to the bathroom, or getting dressed).

Earliest signs of dementia may include difficulty with instrumental activities of living, such as:
• Impaired work performance.
• Some forgetfulness and memory loss.
• Social withdrawal.
• Personality changes.
• Anxiety and/or depression.
• Verbal repetition.
• Impaired organization and concentration.
• Trouble with complex tasks and problem-solving.
• Difficulties with driving, including poor judgment or becoming disoriented.
• Losing items without being able to retrace steps to find them.
• Trouble managing medications.
• Difficulties managing finances.

Moderate To Severe Dementia
At this stage, patients may have difficulty completing routine tasks, such as cooking, laundry, or using the phone. Patients may need some assistance with their day-to-day activities, such as dressing, bathing, etc. Other dementia symptoms during this stage may include:
• Definite recent memory loss.
• Difficulties with wandering or getting lost.
• Sleep disorder.
• Emotional instability.
• Agitation, aggression.
• Psychotic symptoms such as delusions or hallucinations.
• Apathy or lack of drive or motivation.
• Inability to use or find the right words and phrases.

Severe Dementia To End Of Life Care
Caregivers will need to help patients perform even basic daily activities, such as eating, using the toilet and other self-care. During the final stage of the condition, patients are unable to care for themselves. They suffer from both communication and motor impairment. They may lose the ability to speak, smile or to walk without help. Symptoms of dementia during this stage may include:
• Incontinence.
• Inability to recognize or use objects.
• Misidentification of spouse.
• Disabling anxiety, paranoia or delusions.
• Pronounced memory loss, even remote memory (memories from many years ago).
• Loss of language skills.
• Loss of awareness of surroundings.
• Loss of muscle control to swallow, walk or sit without support.
• Complications such as weight loss, recurrent infections.

Appendix 5
Common Behaviours That Arise In Dementia Patients And Suggested Responses

It is possible that a patient may react adversely to a situation and that it will not be immediately clear what has caused the reaction. Physicians encourage caregivers, as the persons who know the patient best, to view the situation from the patient’s perspective so they can identify the trigger for the behaviour and then try to modify it in some way, if necessary.13

Possible triggers may include:25
• Physical
Are the patient’s basic needs being met? Is she in discomfort or pain? Is he hungry or thirsty? Does she need to use the washroom? Is her clothing uncomfortable? Is she too warm or cold? Is he tired? Is there too much sugar or caffeine in her diet?
• Intellectual
Is the patient bored, insufficiently occupied or stimulated? Is he struggling with speech or other activities he used to be able to accomplish? Is he frustrated by his limitations? Are expectations that others have for the patient realistic for their level of functioning?
• Emotional
Has the patient displayed increased tearfulness or anxiety? Has he exhibited any new unusual behaviour (e.g., suspicious of others)? Is she experiencing stress due to her deteriorating capabilities? Is he frightened? Is he depressed?
• Environment
Is there too much noise or too large of a crowd around the patient? Are there barriers preventing him from getting around? Is the lighting poor and causing shadows? Is the patient getting too much, or enough, stimulation?
• Social
Does the patient have any past experiences from her childhood, early adulthood or employment that may provide a clue to her behaviour? Perhaps there are cultural or religious reasons for the patient’s behaviour?

Pages 22-23 feature a list of the most common problem behaviours that arise in dementia and suggestions from several sources about how to handle them when it becomes necessary.13,14, 25, 26, 27 The first step after noticing a behaviour is to try to identify a possible trigger, whether it be physical, intellectual, emotional, environmental, or social, as noted above, and then to eliminate that trigger if possible. Then try to respond to the patient using some of the suggestions in the table appearing on the following pages.
## Common Behaviours That Result From Dementia And Possible Responses

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Agitation</strong></td>
<td>• Irritability, fidgeting, anxiety.</td>
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<tr>
<td></td>
<td>• Reassure and support the person keeping a calm tone.</td>
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<td></td>
<td>• Use short simple sentences.</td>
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<td>• Avoid asking too many questions.</td>
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<td></td>
<td>• Use a non-verbal method of calming, such as touch.</td>
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<td></td>
<td>• Provide another activity, or something to hold, to distract the patient.</td>
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<td></td>
<td>• Try gentle, soothing music, reading, or walks.</td>
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<tr>
<td><strong>Aggression</strong></td>
<td>• Verbal or physical outbursts (e.g., screaming, hitting).</td>
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<td></td>
<td>• Watch for sudden increases in movement.</td>
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<td></td>
<td>• Respond in a calm, supportive manner.</td>
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<td></td>
<td>• Avoid arguing or getting angry.</td>
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<tr>
<td></td>
<td>• Acknowledge the patient’s anger.</td>
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<td></td>
<td>• Speak slowly and use repetition.</td>
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<td></td>
<td>• Use touch carefully, as it may provoke further aggression.</td>
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<tr>
<td></td>
<td>• Try to distract the patient with another activity.</td>
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<tr>
<td></td>
<td>• Get away from the situation if you feel angry or threatened.</td>
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<tr>
<td><strong>Disruptive Sleep Patterns</strong></td>
<td>• Getting up frequently through the night; inability to fall asleep.</td>
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<td></td>
<td>• Increase daytime activities, particularly physical exercise.</td>
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<td></td>
<td>• Discourage inactivity and napping during the day.</td>
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<td></td>
<td>• Expose the patient to sunlight to help reset the day-night body cycle.</td>
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<td>• Provide a light meal before bedtime, avoiding too many liquids.</td>
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<td></td>
<td>• Use a nightlight to reduce the agitation of waking up in unfamiliar surroundings.</td>
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<td></td>
<td>• Consider talking to a physician about medication.</td>
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<tr>
<td><strong>Hallucinations</strong></td>
<td>• Experiencing things that others do not see, hear or feel.</td>
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<tr>
<td></td>
<td>• Validate the patient’s fear by saying, “That must be very frightening for you.”</td>
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<td></td>
<td>• Use physical touch as reassurance.</td>
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<td></td>
<td>• Don’t judge or scold — this is real to the patient.</td>
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<tr>
<td></td>
<td>• Increase lighting to reduce shadows.</td>
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<tr>
<td></td>
<td>• Distract with music, exercise, playing cards or photos.</td>
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<tr>
<td></td>
<td>• Meet with physician to review medications, schedule hearing and vision tests, check for illness, infection, etc.</td>
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<tr>
<td><strong>Incontinence</strong></td>
<td>• Loss of bladder control that often occurs as dementia progresses.</td>
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<tr>
<td></td>
<td>• Establish a routine for using the toilet every two hours.</td>
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<td></td>
<td>• Avoid diuretics like coffee, tea, cola, or alcohol.</td>
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<td></td>
<td>• Use incontinence pads or similar products.</td>
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<td></td>
<td>• Use easy-to-remove clothing with elastic waistbands or Velcro.</td>
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<td></td>
<td>• Watch for body language that may indicate a full bladder.</td>
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<td></td>
<td>• Be understanding and reassuring to minimize embarrassment.</td>
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<tr>
<td></td>
<td>• Use word signs or pictures on the bathroom door.</td>
</tr>
<tr>
<td><strong>Repetition</strong></td>
<td>• Repeats words or actions over and over again.</td>
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<td></td>
<td>• If the behaviour does not bother you, do nothing.</td>
</tr>
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<td></td>
<td>• Try to change the subject, go for a walk, etc.</td>
</tr>
<tr>
<td></td>
<td>• For repetitive actions, such as tapping or hand-wringer, distract the patient with simple activities, e.g., folding laundry, dusting.</td>
</tr>
<tr>
<td></td>
<td>• Offer something to occupy the patient’s hands (e.g., a doll, string, a soft ball).</td>
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<tr>
<td></td>
<td>• Speak calmly and answer the question like the first time.</td>
</tr>
<tr>
<td><strong>Sexual Behaviours</strong></td>
<td>• Removing clothes/exposing oneself.</td>
</tr>
<tr>
<td></td>
<td>• Masturbation.</td>
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<tr>
<td></td>
<td>• Physical and verbal advances toward others.</td>
</tr>
<tr>
<td></td>
<td>• Stay calm and don’t judge or scold.</td>
</tr>
<tr>
<td></td>
<td>• Provide privacy.</td>
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<tr>
<td></td>
<td>• Put a pillow or a blanket on the patient’s lap as a barrier between the patient’s hands and genitals, or to allow more discreet behaviour.</td>
</tr>
<tr>
<td></td>
<td>• Distract with activities that suggest comfort (e.g., cuddling a pet or stuffed animal, looking at family photos).</td>
</tr>
<tr>
<td></td>
<td>• Offer something to cuddle at night (e.g., a body pillow, a stuffed animal, a hot-water bottle wrapped in a towel).</td>
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<tr>
<td></td>
<td>• Avoid actions that might be misunderstood (e.g., stroking the patient’s knee).</td>
</tr>
</tbody>
</table>
Appendix 6
Creating A Safer Living Environment For The Dementia Patient

Since dementia patients are affected physically, mentally, and psychologically, they are extremely vulnerable to injury. Home adaptations help to create safer environments that empower patients and enable them to remain independent as long as possible.13

Safety devices and steps may include:14, 28

- Automatic stove turn-off devices that stops electricity in the case of a fire.
- Grab bars along the walls, next to beds and toilets, along with bath chairs and non-slip mats in the bathroom.
- Safety locks on drawers where scissors/knives are kept.
- Door knob covers or an alarm system that rings when the doors or windows open.
- Plastic covers for electrical outlets so patients cannot put their fingers or other objects into the holes and get electrocuted.
- Signs (words or picture) on doors for various rooms (e.g., bathroom, bedroom, kitchen, etc.).
- Locks on doors, or door gates to basements or places where there may be steep stairs.
- Removal of objects on display that could break and hurt the patient (e.g., crystal vases, china, glasses, etc.).
- Removal of furniture with sharp edges.

- Keep household objects and furniture in the same places to reduce confusion.
- Keep special objects, mementoes and photographs to provide comfort and a sense of security.
- Remove carpets, mats, wires, etc., from the floor to help prevent falls and to facilitate the use of a walker or cane.

(References appear on pp. 24-25)
References


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