

**YOUR GUIDE TO
CARING FOR
A PERSON
WITH DEMENTIA**



WWW.PUTONTARIOPATIENTSFIRST.COM



CARING FOR A PERSON WITH DEMENTIA

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:

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.

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. Possible triggers may include:

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?

The following pages 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. 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.



FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA

COMMON BEHAVIOURS THAT RESULT FROM DEMENTIA AND POSSIBLE RESPONSES

BEHAVIOURS	RESPONSES
<p>Agitation</p> <ul style="list-style-type: none"> • Irritability, fidgeting, anxiety. 	<ul style="list-style-type: none"> • Reassure and support the person keeping a calm tone. • Use short, simple sentences. • Avoid asking too many questions. • Use a non-verbal method of calming, such as touch. • Provide another activity, or something to hold, to distract the patient. • Try gentle, soothing music, reading, or walks.
<p>Aggression</p> <ul style="list-style-type: none"> • Verbal or physical outbursts (e.g., screaming, hitting). 	<ul style="list-style-type: none"> • Watch for sudden increases in movement. • Respond in a calm, supportive manner. • Avoid arguing or getting angry. • Acknowledge the patient’s anger. • Speak slowly and use repetition. • Use touch carefully, as it may provoke further aggression. • Try to distract the patient with another activity. • Get away from the situation if you feel angry or threatened.
<p>Disruptive Sleep Patterns</p> <ul style="list-style-type: none"> • Getting up frequently through the night; inability to fall asleep. 	<ul style="list-style-type: none"> • Increase daytime activities, particularly physical exercise. • Discourage inactivity and napping during the day. • Expose the patient to sunlight to help reset the day-night body cycle. • Provide a light meal before bedtime, avoiding too many liquids. • Use a nightlight to reduce the agitation of waking up in unfamiliar surroundings. • Consider talking to a physician about medication.
<p>Hallucinations</p> <ul style="list-style-type: none"> • Experiencing things that others do not see, hear or feel. 	<ul style="list-style-type: none"> • Validate the patient’s fear by saying, “That must be very frightening for you.” • Use physical touch as reassurance. • Don’t judge or scold — this is real to the patient. • Increase lighting to reduce shadows. • Distract with music, exercise, playing cards or photos. • Meet with physician to review medications, schedule hearing and vision tests, check for illness, infection, etc.

FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA

COMMON BEHAVIOURS THAT RESULT FROM DEMENTIA AND POSSIBLE RESPONSES (CONTINUED)

BEHAVIOURS	RESPONSES
<p>Incontinence</p> <ul style="list-style-type: none"> • Loss of bladder control that often occurs as dementia progresses. 	<ul style="list-style-type: none"> • Establish a routine for using the toilet every two hours. • Avoid diuretics like coffee, tea, cola, or alcohol. • Use incontinence pads or similar products. • Use easy-to-remove clothing with elastic waistbands or Velcro. • Watch for body language that may indicate a full bladder. • Be understanding and reassuring to minimize embarrassment. • Use word signs or pictures on the bathroom door.
<p>Repetition</p> <ul style="list-style-type: none"> • Repeats words or actions over and over again. 	<ul style="list-style-type: none"> • If the behaviour does not bother you, do nothing. • Try to change the subject, go for a walk, etc. • For repetitive actions, such as tapping or hand-wringing, distract the patient with simple activities, e.g., folding laundry, dusting. • Offer something to occupy the patient’s hands (e.g., a doll, string, a soft ball). • Speak calmly and answer the question like the first time.
<p>Sexual Behaviours</p> <ul style="list-style-type: none"> • Removing clothes/ exposing oneself. • Masturbation. • Physical and verbal advances toward others. 	<ul style="list-style-type: none"> • Stay calm and don’t judge or scold. • Provide privacy. • 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. • Distract with activities that suggest comfort (e.g., cuddling a pet or stuffed animal, looking at family photos). • Offer something to cuddle at night (e.g., a body pillow, a stuffed animal, a hot-water bottle wrapped in a towel). • Avoid actions that might be misunderstood (e.g., stroking the patient’s knee).
<p>Sundowning</p> <ul style="list-style-type: none"> • Becoming restless, confused, anxious or agitated later in the day (usually late afternoon or early evening). 	<ul style="list-style-type: none"> • Allow for rest and naps between activities. • Avoid appointments or other stressful activities during this time. • Prevent over-stimulation from the television or radio. • Provide adequate lighting to lessen shadows as it gets dark. • Distract with simple, low-stress activities. • Allow quiet time if this helps decrease agitation. • Provide items of comfort (e.g., a favourite pillow or blanket).

FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA

COMMON BEHAVIOURS THAT RESULT FROM DEMENTIA AND POSSIBLE RESPONSES (CONTINUED)

BEHAVIOURS	RESPONSES
<p>Suspicion/ Paranoia</p> <ul style="list-style-type: none"> • Thinks others are trying to hurt him or her. • Accuses others of stealing possessions. 	<ul style="list-style-type: none"> • Don't argue or try to reason with the patient. • Don't take accusations personally. • Don't scold for losing or hiding things. • Try non-verbal reassurances like a gentle touch or hug. • Distract with another activity. • Learn the patient's favourite hiding places for storing objects. • If possible, keep a spare set of frequently lost items.
<p>Wandering/ Exit-Seeking</p> <ul style="list-style-type: none"> • Walks away from home unattended, with the risk of becoming lost. 	<ul style="list-style-type: none"> • Install locks that require a key, or alarms for doors and windows. • Disguise doors with paint, wallpaper, or coloured paper. • Put a "stop" or "do not enter" sign on the door. • Add "child-safe" plastic covers to doorknobs. • Put reminders like coats, shoes and hats out of sight. • Ensure regular walks and exercise. • Inform neighbours about wandering and provide contact information. • Affix an ID shoe tag or bracelet with phone number and address. • Use other technologies, such as global positioning systems (GPS) that can be worn as a watch or clipped on a belt. • Register with Safely Home, an Alzheimer Society of Canada wandering registry. • Have a current photo available should the patient go missing.

FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA

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.

Safety devices and steps may include:

- Automatic stove turn-off devices that stop 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.
- Doorknob 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.

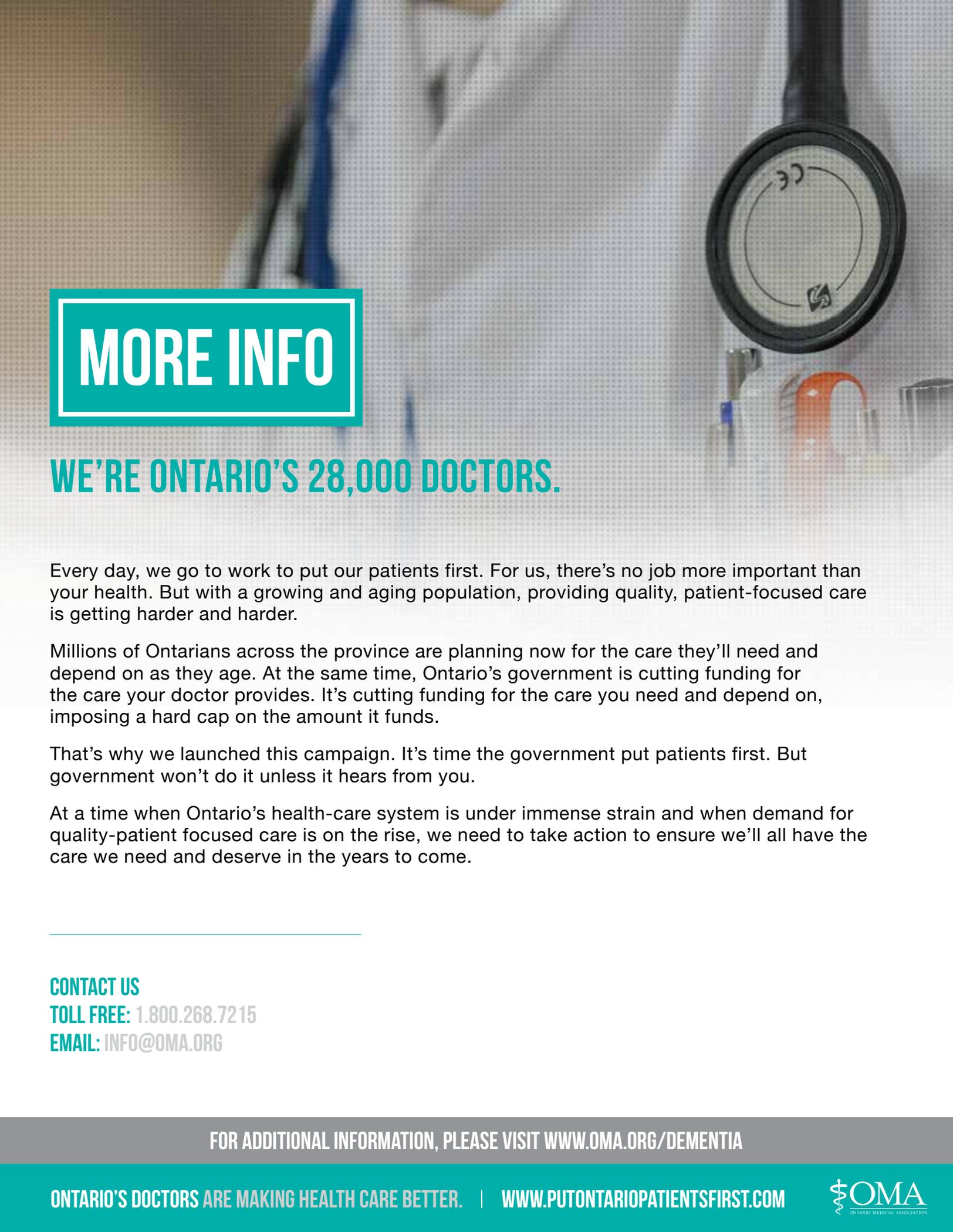
- Removal of objects on display that could break and hurt the patient (e.g., crystal vases, china, glasses, etc.).
- Removal of furniture with sharp edges.

There are many other ways in which to improve the home care environment so that it assists the patient and the care provider with everyday living. Many literature sources recommend the following:

- Adhere to a consistent routine to reduce uncertainty for the patient.
- Eliminate clutter so as not to confuse the patient.
- Affix large calendars and clocks on a wall most visible to the patient.
- Lower noise levels and play soft, calming music to reduce stress and anxiety.
- 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.



FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA



MORE INFO

WE'RE ONTARIO'S 28,000 DOCTORS.

Every day, we go to work to put our patients first. For us, there's no job more important than your health. But with a growing and aging population, providing quality, patient-focused care is getting harder and harder.

Millions of Ontarians across the province are planning now for the care they'll need and depend on as they age. At the same time, Ontario's government is cutting funding for the care your doctor provides. It's cutting funding for the care you need and depend on, imposing a hard cap on the amount it funds.

That's why we launched this campaign. It's time the government put patients first. But government won't do it unless it hears from you.

At a time when Ontario's health-care system is under immense strain and when demand for quality-patient focused care is on the rise, we need to take action to ensure we'll all have the care we need and deserve in the years to come.

CONTACT US

TOLL FREE: 1.800.268.7215

EMAIL: INFO@OMA.ORG

FOR ADDITIONAL INFORMATION, PLEASE VISIT WWW.OMA.ORG/DEMENTIA

ONTARIO'S DOCTORS ARE MAKING HEALTH CARE BETTER. | WWW.PUTONTARIOPATIENTSFIRST.COM

