



Taking Care of Caregivers: More After- Hours Support for Dementia Caregivers

*“Caring for someone with dementia is a 24-hour a day job”
say the Alzheimer Society of Ontario and the Ontario Dementia Network*

Questions and Answers

What is Telehealth Ontario and what services do they offer to support dementia caregivers?

Telehealth Ontario is a free, confidential telephone service Ontarians can call to get health advice or general health information from a Registered Nurse. This free service is available in both English and French, with translation services available to support several additional languages by dialling 1-866-797-0000.

Telehealth Ontario will connect family caregivers of people with dementia to support, advice, and referral, particularly when other services are closed. Telehealth Ontario resources have been reviewed and updated specifically to support family caregivers of persons with dementia.

What is dementia?

Dementia is an umbrella term for a variety of brain disorders. Alzheimer's disease is the most common form of dementia and accounts for 64 per cent of all dementias in Canada. Alzheimer's disease erases memory, steals the ability to think, and eventually can make simple daily tasks, such as eating or getting dressed, impossible. It robs independence and ultimately, takes life.

Why do we need an after-hours helpline for dementia caregivers?

Families and friends provide most of the care for the 200,000 Ontario seniors with dementia. They play a critical role as part of the caregiving team, yet they have no one to call for reassurance, information, symptom management, and anxiety relief after business hours.

Leveraging this service was determined after two years of study by the Ontario Dementia Network, which included consultation with more than 600 caregivers of persons with dementia. Results showed that 97% of focus group participants and 93% of online survey participants expressed strong support for an after-hours telephone support service.



Who are the family caregivers?

According to Ontario home care assessments, most people with dementia have at least one person providing unpaid care. Primary caregivers are most often spouses (31%) or adult children and in-laws (54%). In Ontario today, families and friends spend 100 million unpaid hours caring for people with dementia and by 2020 will be offering 144 million hours.

What are the issues relating to dementia that can arise outside of business hours?

People with dementia may have problems sleeping or will see increases in behavioural issues that begin at dusk and last into the night (known as sundowning). Research shows that as many as 66% of people with Alzheimer's disease or other dementias will experience confusion, anxiety, aggression, agitation or restlessness.

What training is being provided to Telehealth Ontario responders to provide dementia support?

The Telehealth Ontario responders are registered nurses who have access to an extensive database to complement their medical expertise, from which they can suggest appropriate community services and supports depending upon the caller's needs. With the help of the Alzheimer Society of Ontario and the Ontario Dementia Network, further training will be available to better comprehend key dementia concerns and be able to deliver emotional support to reduce caregiver stress. Training will specifically include the areas of:

- General information about dementia and its impact on the caregiver
- Assessment
- Caregiving strategies for specific situations.

How will Telehealth Ontario be able to help dementia caregivers?

When reaching out to a Telehealth nurse, the family caregiver will find compassionate understanding and advice to

- Assist with managing issues such as wandering, sleep disturbances, disinhibition, paranoia, delusions, memory loss; challenges and strategies, late day restlessness, hoarding, anger/agitation, and repetition
- Navigate the health care system including receiving information and referrals to organizations. Telehealth Ontario nurses will use the Alzheimer Society locator link www.alzheimer.ca/en/on/postal-code to identify and provide the correct local Alzheimer Society phone number to the caller.



Why provide support to the family caregiver?

The number of persons with dementia in Ontario is projected to rise to 255,000 by 2020. The impact on the health-care system can be lightened if caregivers continue taking care of family members with dementia at home as long as it is possible. The need to recognize dementia caregivers as active members of the health-care team and provide them with the necessary information and support is increasingly being acknowledged.

Caring for a person with dementia at home is a difficult task and can become overwhelming. Lack of home support can impact one's mental health and well-being, and ultimately the ability to continue providing home care. Caregivers' stress symptoms include anxiety, depression, sleep deprivation, and chronic health problems (backaches, high blood pressure).

Who is making it possible?

The Ministry of Health and Long Term Care is strengthening the Telehealth Ontario system to better support the Alzheimer Society and the Ontario Dementia Network and, most importantly, family caregivers of persons with dementia.

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For more information, or to book an interview with the Alzheimer Society of Ontario, the Ontario Dementia Network or Telehealth Ontario, please contact:

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