

# Dementia and Home Care

## Advice on Ontario's Dementia Strategy

March 2017

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## ADVICE ON ONTARIO'S PROPOSED DEMENTIA STRATEGY

**255,000** people in Ontario are projected to have dementia by 2020

That's a **70%** increase since 2011

Families are the mainstay of the home care system and they are working harder than ever. In 2014-2015...

**34.5%**

of family caregivers had symptoms of caregiver distress

**15.7%**

of caregivers were unable to continue in their caring activities

**27.9%**

of caregivers expressed distress, anger or depression

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It is time to improve home care in Ontario

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HOME CARE  
ONTARIO  
Bringing Health Care Home

*By 2020 there will be a 70% increase in the number of Ontarians living with dementia at home, making dementia planning for the home and community sector a priority.<sup>1</sup>*

**Home Care Ontario** is pleased to offer comment on *Developing Ontario’s Dementia Strategy: A Discussion Paper*. The Association’s members are witness to the toll that dementia places on individuals, families and friends. As partners in care responsible for the patient’s experience, Home Care Ontario members are advocates for increased support to enable care at home. A strategy that improves access to resources is crucial to achieving person-centred health care and Home Care Ontario members welcome a Dementia Strategy for the province.

While not a normal part of aging, dementia is more predominant in the elderly and, with an aging population, the prevalence of persons with dementia in society will increase. Individuals with dementia can live independently for some time; however, the condition ultimately has a profound effect on loss of function and independence.

A Dementia Strategy in Ontario will serve to focus policy, practice and resources on awareness, education, prevention and supports. The framework in the proposed strategy addresses these issues. Home Care Ontario’s submission speaks to each element.

*“I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity. I can think of no other disease that places such a heavy burden on families, communities, and societies. I can think of no other disease where innovation, including breakthrough discoveries to develop a cure, is so badly needed.”*

*Margaret Chan, Director General, World Health Organization  
(Opening remarks at the First WHO Ministerial Conference on Global Action  
against Dementia, 17 March 2015)*

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<sup>1</sup> MOHLTC (2017) Slide 2

## The members of Home Care Ontario recommend that:

- 1.** The Home Care program must be structured so that the services can be responsive to the specific needs of the person and those of the family and family caregiver. The maximum funding for frontline publicly funded home care service for people with moderate to severe dementia should be increased to enable a bundle of up to 35 hours per week of flexible care.
- 2.** Frontline Home Care Providers must be provided with funds for staff training to better understand and provide care for people with dementia; and to provide replacement personnel when staff and families are receiving dementia care education.
- 3.** Transitions between service providers must be strengthened through adequate funding to enable information exchange - electronically, orally and/or in person - to achieve continuity in approach and seamless care for patients and families.
- 4.** Implementation of effective Caregiver Education Programs must be a priority.
- 5.** Enhanced training and a home care PSW specialization in dementia care must be designed and funded; and criteria established for the deployment of staff with additional expertise when caring for persons with dementia.
- 6.** Communities must work collectively to implement dementia-friendly services that are responsive and respectful of the complex challenges facing patients and families.

## The Importance of Home Care

Home care is defined as an “array of services, provided in the home and community setting, that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the family caregiver”.<sup>2</sup>

Services within home care include nursing, personal support/homemaking, therapy (including physiotherapy, occupational therapy, speech language pathology, social work, nutrition/dietetics), medical supplies and equipment in the home. Home care services are intensely personal and provided at a time when individuals are most vulnerable.

The home care program works closely with community support services such as day programs, respite care facilities, volunteer services, meals and transportation services. Publicly funded home care is designed to complement and supplement, but not replace, the efforts of individuals to care for themselves with the assistance of family friends and community. In Ontario therefore the government only funds the services to supplement that care. Additional investments by government have helped to increase the number of Ontarians able to remain at home but the requisite policy changes to enable more flexible care for those with dementia have not yet been made.

## The Numbers

In 2015/16, over 729,000 individuals received publicly funded home care services.<sup>3</sup> While the capacity of home care to serve more people has increased, so has the complexity of need for those in receipt of home care services. Today 94% more patients have higher needs than in 2008/2009<sup>4</sup> and since that time, the number of patient referrals from hospital has increased 13%.<sup>5</sup> At present 77.4% of people receiving home care have a cognitive impairment and 18.9% have a diagnosis of dementia.<sup>6</sup>



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<sup>2</sup> Canadian Home Care Association

<sup>3</sup> OACCAC Fast Facts

<sup>4</sup> OACCAC (2016)

<sup>5</sup> Ibid.

<sup>6</sup> Canadian Institute for Health Information HCIRS Quick Stats, tab8 and 1

## ***The Home Care Team***

PSWs provide care that individuals could be expected to perform by themselves if physically and/or cognitively able. Their activities are supportive and non-medical in nature. PSWs have a skill and

Frontline Home Care Providers have a privileged view of everyday life in the homes of their patients and families, when they are most natural and authentic in their emotional and physical responses to stress.

knowledge level that equips them to provide high quality personal care, supportive care for ongoing conditions and/or cognitive impairments, assistance to the family/caregiver with activities or respite, assistance with medications and caring for palliative care patients and their families.

Rehabilitation services are important for patients with dementia to improve balance, muscle strength, and mobility. Safe physical activity will maintain strength, balance and prevent falls. The rehabilitation team is called upon to address environmental modifications and assist with activities of daily living when activities such as bathing, dressing and toileting become challenging.

Nursing contributes to the care of patients with dementia through clinical assessment of the physiological effects of the condition and impact of medication and treatment. The registered nurse serves as the care manager in the home establishing the plan of care to support the patient and the family.



## ***The Family Caregiver***

The system of publicly funded care is designed to complement and supplement, but not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community.

Families are the mainstay of the home care system – 96.7% of patients on home care have a family/friend (informal) caregiver present.<sup>7</sup> Family caregivers provide 80% of care at home and many choose to privately retain support to cope with the challenges of work, family and distance to a person in need of care.<sup>8</sup> Without family caregivers, the government funded home care system, as it is currently configured, would not be a feasible option and Ontarians would not be able to remain at home.

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<sup>7</sup> Canadian Institute for Health Information HCERS Quick Stats, tab6

<sup>8</sup> Home Care Ontario (2013)

Family caregiver is the term used to denote a family member and/or friend of choice who gives unpaid care to someone, either at home or in a facility, who has a physical or mental health condition, or is chronically ill, frail, or elderly.<sup>9</sup>

It is vital that society recognizes the rapid rise in the rate of dementia and the toll it takes on individuals, families, caregivers and healthcare systems. In Ontario in 2015-16, 34.5% of family caregivers of individuals receiving home care had symptoms of caregiver distress,<sup>10</sup> 15.7% of caregivers were unable to continue in their caring activities and 27.9% caregiver expressed distress, anger or depression.<sup>11</sup> Those caring for someone with dementia have increased symptoms.<sup>12</sup>

### **FRAMEWORK ELEMENT: *Supports for People Living with Dementia***

Dementia is one of the major risk factors for loss of community-dwelling status. Social isolation created by the stigma associated with dementia, and the escalating fears about safety risks and caregiver burnout can prompt the family to consider, and/or the health care team, to recommend, an institutional option. Research has shown that supporting individuals with early stages of dementia in the home is compassionate and potentially effective to maintaining independence and dignity.

However, when need exceeds services permitted by the publicly funded home care system – even when just a small amount of additional support is needed – there are few options but admission to facility based care. Investment in supportive care to enable optimum functioning for individuals at the ‘fringe’ of admission to a care facility can help to shift the balance of care to the community.<sup>13</sup> The impact is the avoidance of the often-rapid decline in independence that occurs in an institutional environment. Ontario’s provincial home care program is vital to supporting the publicly insured health system by enabling early discharge of patients from hospitals and providing an alternative to long-term care homes.

Supporting individuals with early stages of dementia is compassionate and potentially effective to maintaining independence and dignity for individuals.<sup>14</sup>

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<sup>9</sup> Caregivers Nova Scotia

<sup>10</sup> Canadian Institute for Health Information HCERS Quick Stats, tab6

<sup>11</sup> Ibid

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<sup>13</sup> Home Care Ontario (2007) p2

<sup>14</sup> Home Care Ontario (2007) p3

Home Care Ontario member experience shows that families will not typically ask for, or use, more home care service than they need. Invariably, families take on more care for their loved one than may be best for their personal wellbeing and ongoing ability to sustain care at home. Members report the tipping point for families that drives the decision to institutionalize their loved one occurs when the person is regularly incontinent, is no longer able to weight bear, and begins to have difficulties distinguishing nights from days. Additional service and overnight respite is critically important to sustaining family caregivers when these symptoms begin to appear.

There must be a more flexible and patient/family-centred approach to respond to the unique needs of the person living with dementia so they can remain at home longer. The publicly funded home care system must therefore become less rigid and rules based.

## Recommendation

1. The Home Care program must be structured so that the services can be responsive to the specific needs of the person and those of the family and family caregiver. The maximum funding for frontline publicly funded home care service for people with moderate to severe dementia should be increased to enable a bundle of up to 35 hours per week of flexible care.

The service must be tailored and adjustable to meet individual needs. For example, short or long service visits, accumulation of service hours to allow overnight coverage or a few days of respite. The needs of patients and family caregivers must be separately assessed to identify their respective needs and enable distinct plans of care for each. Family caregivers must receive the services they need to establish balance in their lives and to cope with care needs of their loved one.



## FRAMEWORK ELEMENT: *Accessing Dementia Services*

Society in general must acknowledge the growing prevalence of dementia. The numbers of people with dementia in Ontario is projected to be as many as 255,000 in 2020 and over 430,000 people by 2038<sup>15</sup>. Fear of a dementia diagnosis however, results in a lack of understanding about the condition. Dementia awareness is therefore key to early diagnosis and dementia-friendly communities make it easier for everyone to understand this condition and access services best suited to their needs.

Using rates drawn from the Canadian Study on Health and Aging, it was estimated that in 2016 there were 564,000 persons in Canada living with dementia. By 2031 it is estimated that the number will increase to 937,000. More than 65% of these will be women.<sup>16</sup>

Analyses by the Mental Health Commission of Canada suggest that when mild cognitive impairment is included, the dementia and mild cognitive impairment prevalence estimate would be about 50% higher than if only dementia is included in the estimate.<sup>17</sup>

Initiatives such as the Primary Care Memory Clinic established in 2006 in the Centre for Family Medicine Family Health Team (FHT) in Kitchener, Ontario, have effectively improved access to care and early diagnosis of memory loss.<sup>18</sup> Early diagnosis is essential to initiating treatment and establishing a sustainable plan of care. To ensure follow-through at home, frontline Home Care Providers must have strong linkages with the members of the primary care team, enabled by technology.<sup>19</sup>

Helplines and telephone ‘apps’ must be available 24/7 to assist people in the moment of distress when they are most in need of immediate information and support. Regular education programs targeted to all age groups and available virtually or in person must be established, promoted and referenced as part of the teaching provided by members of the health team.

People with dementia can remain at home longer when dementia-specific day programs are available. These programs help to maintain behavioural supports for the patient and provide much

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<sup>15</sup> Ontario (2018) Developing, p7

<sup>16</sup> Alzheimer Society of Canada, p27

<sup>17</sup> Ibid

<sup>18</sup> Accreditation Canada (2013) Primary

<sup>19</sup> Home Care Ontario, p24

needed respite for families. The lack of equality in respite care options identified by the Auditor General of Ontario<sup>20</sup> must be addressed. As the circumstances warrant, overnight respite should be an additional option for families and implemented where possible as an add-on to the day program services to provide patients and family with continuity of premises and staff.

Palliative care should be available to all patients, including those with dementia. Symptom management for people with dementia can be complicated, and family caregivers who have witnessed a gradual change in overall condition may not distinguish between dementia and palliative needs. It is also critical that care be coordinated and that care directives be addressed early in the trajectory to ease decision-making when patients have lost the ability to eat, identify pain, hallucinate or have delusions.

Members of the team will benefit from additional education to better understand when to commence palliative care for the patient diagnosed with dementia.

## Recommendation

2. Frontline Home Care Providers must be provided with funds for staff training to better understand and provide care for people with dementia; and to provide replacement personnel when staff and families are receiving dementia care education.
6. Communities must work collectively to implement dementia-friendly services that are responsive and respectful of the complex challenges facing patients and families.

Efforts must be made to increase awareness and provide training to all levels of staff in the care of people with dementia throughout all stages of the illness, including palliative and end-of-life care. Above of all, education should be consistent and include family caregivers.

## FRAMEWORK ELEMENT: *Coordinated Care*

The goal of health care providers and of the health care system is to organize and deliver care in a cohesive manner so that patients and families experience consistent, reinforcing and informed service. It is important to reduce redundant processes. All members of the team must be respected

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<sup>20</sup> Auditor General, p78

and valued for their knowledge, as care in the home clearly builds on the contribution of others. In a well-coordinated care system, redundant requests for information by the health care team are reduced as much as possible.

From the patient's perspective, information must be shared. Patients and family caregivers have high expectations for accurate and timely access to their health information for themselves and the members of their care team. They need information, education and support to understand how they can be most useful and effective when a person with dementia is being discharged home. Patients and families must have knowledge of the full range of service options available to them, including services that can be purchased privately.

From the provider's viewpoint, care paths must be clear, efficient and available. Frontline Home Care Providers must be able to input and access patient information in the patient record so there is no delay in receiving vital, accurate and current patient information, thus improving continuity of care and better health outcomes for patients.<sup>21</sup>

The increasing use of antipsychotics by the elderly in the community<sup>22</sup> is a call to action for policy initiatives and services, such as home care behavioural support programming, to decrease inappropriate use in all seniors, including those with dementia.

From the system perspective, care must be appropriate, effective and efficient within and across health sectors. Health system partners must have equal access to information and

make every effort to ensure that care is seamless, that people are well informed and confident that the frontline home care delivery system, as a part of the broader health care system, is available and effective.

## Recommendation

3. Transitions between service providers must be strengthened through adequate funding to enable information exchange - electronically, orally and/or in person - to achieve continuity in approach and seamless care for patients and families.

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<sup>21</sup> Home Care Ontario, p11

<sup>22</sup> Ontario Drug Policy Research Network, p8

This requires, for example, that frontline Home Care Providers be linked into provincial portals to access and exchange patient information in real time. Programs should be linked where possible, such as extending a dementia day program to a program of overnight respite. Opportunities for care conferences and staff orientation prior to transfers of patients from one setting to the other should be encouraged to minimize disruption to the person with dementia.

## **FRAMEWORK ELEMENT: *Supports for Care Partners***

Family caregiving is crucial to keeping seniors at home and the important contributions of families must be recognized. While caregiving is a positive experience for many, family members can struggle to balance the competing demands of work, family and care for elders. When the person requiring care has dementia, the responsibility can quickly push families beyond their physical and emotional ability to cope. Caregivers experience losing their loved one first to the dementia, then potentially to the long-term care facility, and finally to death.

Families are integral to maintaining care at home and must be effectively supported. Of immediate importance is safeguarding the health and wellbeing of family caregivers by increasing the flexibility and availability of respite care. Research has shown that family counseling and mental/emotional health support for caregivers can reduce the rate of institutionalization for some groups of seniors with Alzheimer's disease.<sup>23</sup> The Reitman Centre CARERS Program (Coaching, Advocacy, Respice, Education, Relationship, and Simulation) has demonstrated improvements in measures of depression, task-oriented coping, mastery, and caregiver burden.<sup>24</sup>

The Caregiver ReCharge program in Mississauga-Halton is targeted specifically for high acuity/high needs individuals and the caregivers who care for them. The program is flexible to the caregiver's needs as the caregiver determines when they use their hours and for what purpose.<sup>25</sup> The Caregiver ReCharge program focuses on a person-centered experience and received the Minister's Medal to Honour Excellence in Health Quality and Safety in 2016.<sup>26</sup>

It is (also) vitally important that the health and wellbeing of the family caregiver is regularly assessed as distinct from the person with dementia. Frontline Home Care Providers have a privileged view of

<sup>23</sup> Mittelman et al

<sup>24</sup> Accreditation Canada (2013) The Reitman

<sup>25</sup> Mississauga Halton LHIN

<sup>26</sup> Ontario Newsroom

everyday life in the homes of their patients and families, when they are most natural and authentic in their emotional responses to stress. This often occurs when the impact of fatigue, worry and the strain of continuous caregiving is most evident. Home Care Providers witness firsthand the behaviours of patients that may be more controlled in public situations such as planned medical appointments. Caregivers' needs for support and help must be honoured and addressed. Accordingly, members of Home Care Ontario recommend increased hours of service and the autonomy to respond with additional care in the moment when the need is clear.

If an effective Caregiver Education Program was implemented, the number of community dwelling persons awaiting their first LTC home placement could decrease up to 17% in the Champlain LHIN. 692 more persons living with dementia in Champlain could be living well in the community.<sup>27</sup>

## Recommendation

### 4. Implementation of effective Caregiver Education Programs must be a priority.

Everyone, including caregivers, copes differently. Respecting differences and responding appropriately requires trained staff with the autonomy to do what is most helpful at the time. This should include the decision to stay longer in the home when required or respecting the caregiver's desire to accumulate hours for overnight care or for a holiday away.



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<sup>27</sup> MOHLTC (2017) Slide 11

## FRAMEWORK ELEMENT: *Well Trained Dementia Workforce*

It is imperative that specially trained caregivers are available to provide home care services to individuals with dementia. Staff need to be aware of the different types of dementia<sup>28</sup>, including the symptoms and impact on the brain in order to anticipate care needs and respond appropriately. This requires education and training and the time to provide service that is sensitive to responsive behaviours.

The current home care system has over-emphasized task oriented and time limited interventions. This has contributed to a staff that is focused on the function (e.g. the bath, the meal preparation) not the needs of the patient. This accountability to complete a task within the assigned timeframe is contrary to best practice and good patient care.<sup>29</sup> The result can be harmful to staff, patients and/or family caregivers – both physically and emotionally.

Typical home care occupational health and safety policy is that if a patient or other family member becomes violent, the worker will leave the home.<sup>30</sup>

When staff do not recognize a patient with dementia whose behaviours are escalating, or believe that they do not have the time to address the actions, they cannot appropriately respond. They complete the assigned tasks but may have to leave the patient and family in an escalated state, thus undoing any potential support that the visit may have provided.

An important approach to working with people with dementia is to be watchful and “go slow” – the antithesis of the typical fast paced, time-for-task goal of the current publicly-funded system that is designed to minimize cost and maximize the numbers of patients seen.

With the current funding priority in home care on increasing numbers of patients served and hours delivered, there has been a decline in support for continuing education and training. Creative education is necessary to support the home care work force and the family caregivers who cannot

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<sup>28</sup> Types of dementia include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, mixed dementia, Parkinson’s disease, Frontotemporal dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington’s disease and Wernicke-Korsakoff Syndrome.

<sup>29</sup> Following passage of Bill 41 in 2016, the Community Care Access Centres (CCACs) who administer and direct home care services are being transferred into the Local Health Integration Networks (LHINs) and home care service delivery will be transformed to support the province’s Patients First Strategy.

<sup>30</sup> Home Care Providers have specific processes for ensuring staff safety specific to the situation. The expectation is that staff will do their best to ensure the safety of the client before leaving. They will immediately contact their supervisor or emergency services/police depending on the circumstances.

guarantee regular attendance to events of any sort. A specialization program that educates health care staff on the best practices in dementia care needs to be established and implemented across the province. Criteria must be established for the assignment of dementia specialists to provide care in all health care settings. Dementia specialists in home care should be tiered by level of education and assigned to patients based on their clinical presentation. These staff, primarily PSWs, would be educated and equipped to work with patients, with the various types of dementia, in a responsive, compassionate and respectful way.

“The PSW came to help but let my husband nap (instead of encouraging activities). Thus, he was energetic and acting out after she was gone. He stayed up most of the night and today I am exhausted.”

## Recommendation

5. Enhanced training and a PSW specialization in dementia care must be designed and funded; and criteria established for the deployment of staff with additional expertise when caring for persons with dementia.

### **FRAMEWORK ELEMENT: *Awareness, Stigma and Brain Health***

Many persons with a dementia and their caregivers can become stigmatized and socially isolated. Many people in broader society can find it hard to understand the behaviours of people with dementia and do not know how to act. Because the behaviours of a person with dementia can be embarrassing and unpredictable, families are often reluctant to be seen in public. Persons with early stages of dementia lose the ability to drive and as the condition worsens are not able to take public transportation.

Family caregivers have increasingly less time to spend with friends outside of their responsibilities for their loved one and can also become excluded from mainstream activities, such as withdrawing from work outside the home. As in the past when society has feared a condition (e.g. cancer), dementia is often referred to euphemistically. This makes it hard for people with dementia and leads families to avoid admitting to the condition and obtaining treatment and support.

Organizations such as the Alzheimer’s Society of Ontario are doing important work to educate and thereby change the social norms regarding dementia. However much more needs to be done. Greater public awareness is needed not only to support those with dementia and those providing care but to educate and normalize dementia-friendly strategies across society. When successful, businesses will, as a matter of practice, create dementia friendly physical spaces; will first consider that a customer action, such as forgetting to pay, might be related to dementia instead of a crime. In the future, municipalities will have established and focused services, such as transportation, for people with dementia.

## Recommendation

6. Communities must work collectively to implement dementia-friendly services that are responsive and respectful of the complex challenges facing patients and families.

## Conclusion

Dementia is feared by many. Once the condition has been diagnosed, the entire family is impacted and often isolated and stigmatized. A Dementia Strategy for Ontario is vital to educating and changing the health care system and broader societal approaches to support those persons facing this health challenge. The patient/family-centred model of health care delivery, appropriate for all health care recipients, is particularly important for families coping with dementia.

Understanding that families are at their best when attending a health appointment, it is critical to draw on the observations and experiences of the frontline providers in the home who witness the families' coping mechanisms at their most natural and authentic.

## Ontario's Dementia Strategy must include the following recommendations:

1. The Home Care program must be structured so that the services can be responsive to the specific needs of the person and those of the family and family caregiver. The maximum funding for frontline publicly funded home care service for people with moderate to severe dementia should be increased to enable a bundle of up to 35 hours per week of flexible care.
2. Frontline Home Care Providers must be provided with funds for training of staff to better understand and provide care for people with dementia; and to provide replacement personnel when staff and families are receiving dementia care education.
3. Transitions between service providers must be strengthened through adequate funding to enable information exchange - electronically, orally and/or in person - to achieve continuity in approach and seamless care for patients and families.
4. Implementation of effective Caregiver Education Programs must be a priority.
5. Enhanced training and a home care PSW specialization in dementia care must be designed and funded; and criteria established for the deployment of staff with additional expertise when caring for persons with dementia.
6. Communities must work collectively to implement dementia-friendly services that are responsive and respectful of the complex challenges facing patients and families.

## About Home Care Ontario

Home Care Ontario, the voice of home care in Ontario™, is a member-based organization with a mandate to promote growth and development of the home care sector through advocacy, knowledge transfer, and member service. Home Care Ontario members include those engaged in and/or supportive of home-based health care. In Ontario, service provider organizations are responsible for providing nursing care, home support services, personal care, physiotherapy, occupational therapy, social work, dietetics, speech language therapy and medical equipment and supplies in the home to individuals of all ages. An estimated 58 million hours of publicly and privately purchased home care service is provided annually across the province.

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