



A Step Toward Understanding Health Care Trajectories of People Living With Dementia

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About this report

This report builds and expands on CIHI's 2018 report [Dementia in Canada](#) and focuses on the health care trajectories of people of all ages who are living with dementia. It is a collaborative project between the Canadian Institute for Health Information (CIHI) and the Public Health Agency of Canada (PHAC) that supports the implementation of the [national dementia strategy](#) through the [Enhanced Dementia Surveillance Initiative](#).

This report uses multiple CIHI data holdings to examine the clinical characteristics, caregiver factors and socio-demographic factors of people living with dementia and their health care trajectories, with a particular focus on home care and long-term care data. The analysis follows a group of people living with dementia for 5 years after their first record of dementia to understand their interactions with Canada's health care systems. It examines information of people from Newfoundland and Labrador, Ontario, Alberta and British Columbia — the provinces where there is nearly complete information for a broad range of health services. See [Appendix A: Methodology](#) for details.

The **key findings** include the following:

- Two-thirds of people living with dementia (67%) had the condition recorded for the first time in an encounter with a family doctor/general practitioner. Family doctors are crucial in providing various aspects of dementia care, but some may not feel well-resourced or prepared to manage dementia care in the community.
- People living with dementia follow different health care trajectories. These trajectories differ based on the person's health care needs and the supports available to them. The 4 main trajectories are described in this report.
- More than half of people living with dementia (58%) had publicly funded home care as part of their trajectory, and almost half of this group subsequently moved to a long-term care facility.
- Caregivers of people living with dementia are more likely to experience feelings of distress, anger or depression compared with those caring for people without dementia.
- Factors leading to an admission to a long-term care facility after receiving publicly funded home care include a combination of caregiver factors, deteriorating health of the person living with dementia and socio-demographic factors.
- Just less than 1 in 10 people living with dementia moved to a long-term care facility without receiving publicly funded home care. The time between the first record of dementia and the transition to a long-term care facility for this group was about 11 months shorter than for the group that received home care services. People in this group might have been receiving other services, such as short-term home care, assisted living or private services, and/or care from an unpaid caregiver.

- At least 1 in 4 people living with dementia in our study did not receive publicly funded home care and were not in a long-term care facility during the time studied in our analysis. People in this group were more likely to live in higher-income neighbourhoods and were slightly younger. This group also had one of the lowest rates of hospitalizations.
- 60% of people living with dementia who moved to long-term care were hospitalized in the 3 months before their move. However, only 12% were hospitalized in the 3 months after they moved to long-term care.
- People living with dementia and concurrent mental health and/or substance use disorders have challenges accessing home care services and transitioning to a long-term care facility.

It is important to note the following **factors that contribute to the interpretation of the findings** in this report:

- Dementia is a complex chronic condition with a variety of symptoms. As a result, it may not always be consistently captured and recorded in CIHI's databases. It was not possible to distinguish between the types of dementia in most CIHI databases. Further, it was not possible to explore mild cognitive impairment due to the challenges of coding this health condition.
- CIHI collects data on publicly funded long-term care facilities, home care services and drug claims only. This analysis focuses on long-stay home care, especially for people living in a private home.
- The analysis includes data from the COVID-19 pandemic period. The pandemic had broad impacts on health care use and therefore might have affected which services people accessed during that time, as well as their health outcomes.^{1,2} For example, we know that people residing in long-term care facilities were disproportionately affected by COVID-19 infections and deaths.³ In addition, data collection during the pandemic might have been affected.

We hope that this report will support planning and service provision by providing information about the challenges and needs of people living with dementia across care settings and of those who are providing care. The findings can also be used as a starting point for future analyses as the quality and availability of data improve over time.

Caregiver and health care provider stories

Caregivers — also called unpaid caregivers, informal caregivers, care partners or carers — are family members (spouses, children, in-laws, etc.), friends or neighbours who provide care to a person living with a condition or disability.

In Canada, caregivers of people living with dementia assist with general health care and health monitoring (68%), such as managing medications and scheduling appointments; finances (66%); activities of daily living (59%), such as feeding, dressing and personal care; and transportation (56%).⁴ They often juggle multiple responsibilities while caring for people living with dementia, including work, education and parenting, and they often do this without any formal support or financial compensation. Despite these challenges, caregivers also experience many positive aspects of caregiving.⁵

The findings of this report were given life by the stories of 4 people — caregivers and health care professionals who care or cared for people living with dementia. Through structured interviews, they talked about their experiences, emphasizing the crucial role of caregivers and the need to better support them. They shared stories about how they participated in all aspects of the life of a person living with dementia, from helping them with activities of daily living to connecting them with needed health care services.

Caregivers and health care professionals who shared their stories with us

Wendy Wu became the primary caregiver of her late in-laws, who both had dementia and multiple comorbidities, following her retirement. The family provided most of the care themselves with limited home care services, and her father-in-law ultimately moved into an assisted-living setting when his care needs became more complex. Wendy describes becoming a caregiver for someone living with dementia as “being dumped into the sea and learning how to swim.” Wendy is of East Asian descent and lives in a metropolitan area in Ontario.

Susan Palijan is a part-time university student, full-time employee and primary caregiver for her father, who has both dementia and a long history of mental health and substance use disorders. While Susan is the primary caregiver, her sister has been a strong support to her in his care. Susan’s father has been hospitalized more than 8 times in 18 months. Despite his increasingly complex care needs, he has refused home care services or to move to a long-term care facility. Susan has therefore managed his care largely on her own, while also facing stigma and a lack of coordination between services aimed at treating his dementia and other illnesses. Susan lives in an urban area in Ontario.

Sharla Cadwell is a registered nurse, wound care clinician and case manager. For the past 10 years, she has coordinated home care services for 2 rural communities while also running a lower-leg circulation clinic through Alberta Health Services. She works directly with home care clients — including those living with dementia, as well as their families and caregivers — to assess their needs, connect them with needed home care services and provide direct clinical care. As a care provider in a rural setting, Sharla says she frequently has to “be creative” to connect clients with specialized care services often located several hours’ drive from their homes. Sharla lives in a rural area in northern Alberta.

David Hood is a recently retired family physician. During his 4-decade career in family medicine, David treated many people living with dementia across their care trajectories. He was also a caregiver to his late parents and father-in-law, who all had dementia. David supported his parents as they moved into a retirement facility, and his mother as she ultimately moved into a locked ward offering specialized care for dementia. His caregiving experiences combined with his professional experience as a physician give David a unique perspective on both the strengths and weaknesses of health care systems in supporting people living with dementia and their caregivers. David lives in an urban area in Ontario.

Quotes from these 4 individuals are included throughout this report and represent their opinions, based on their own lived experiences. Their perspectives do not necessarily reflect the opinions of CIHI, PHAC or other caregivers or health care professionals, and represent only a few examples of caregiving experiences.

Introduction

Dementia in Canada

Dementia is an umbrella term that describes a set of symptoms affecting brain function. It is a chronic condition that usually gets more severe over time; it is often characterized by a decline in memory, planning, language and judgment, as well as by physical changes, like loss of coordination, loss of bladder control, weak and stiff muscles, and changes in mood and behaviour.⁶ There are several types of dementia, including Alzheimer's disease (the most common type), vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia. Dementia is not a normal part of aging, though it is more common in older individuals.

While the number of people living with dementia is growing in Canada, as reported by the [Canadian Chronic Disease Surveillance System \(CCDSS\)](#), the age-standardized prevalence of dementia has declined in the past 5 years. In 2020–2021,⁷ almost 477,000 Canadians age 65 and older were living with dementia (crude prevalence: 6.4%). More than 85,000 new cases of dementia were diagnosed that year among those 65 and older (crude incidence rate: 1,212 per 100,000). It is important to note that these numbers include only people who had a formal diagnosis with a health care provider, so the actual number of people living with dementia may be higher.

Dementia prevalence increases with age. In 2020–2021, among those age 80 and older, 17.9% had been diagnosed with dementia, compared with 2.4% of those age 65 to 79. Women are more affected by dementia than men and the gap increases with age; among those 80 and older, 19.8% of women have dementia compared with 15.1% of men.⁷

Dementia has a significant impact on health care systems. It is a complex condition, and health care service utilization may vary depending on multiple factors such as type of dementia, age at diagnosis and overall health. According to the [Alzheimer Society of Canada](#), total combined health care system costs and out-of-pocket costs of caring for people living with dementia were \$10.4 billion in 2016 and are projected to double by 2031. The [Spotlight from Ontario](#) describes the excess health care costs of dementia at various phases of the condition.

Given the complexity of the health care trajectories of people living with dementia, appropriate diagnosis and management are crucial for providing support and improving the quality of life for these individuals and their caregivers.

In 2019, Canada's [national dementia strategy](#) was released. The strategy includes 3 national objectives:

- Prevent dementia;
- Advance therapies and find a cure; and
- Improve the quality of life of people living with dementia and their caregivers.

Implementing the strategy relies on the efforts of many organizations and individuals across the country, including federal, provincial/territorial and local governments; advocacy groups; researchers; health care providers; and academics.

Federal investments in dementia research, surveillance, awareness initiatives, community-based projects and guidance are supporting the implementation of key elements of the strategy. This includes funding for the [Enhanced Dementia Surveillance Initiative](#) to address data gaps in the following areas:

- Dementia by cause, progression and stages;
- Socio-demographic, risk and protective factors; and
- Dementia caregivers.

This report presents the results of a collaboration between CIHI and PHAC, under the Enhanced Dementia Surveillance Initiative, to support the implementation of the national dementia strategy. PHAC provided funding to CIHI to support this work.

Main findings

The role of family doctors in dementia care

Family doctors are often the first point of contact with the health care system for people living with dementia. Diagnosis of dementia typically occurs during a medical consultation after symptoms such as memory problems, challenges with daily tasks and changes in personality and behaviour have been noticed by family members and are starting to affect the person's daily life.^{8–10} Delays in diagnosis and underdiagnosis^{11–13} are common and are related to multiple factors, such as uncertainty about the symptoms, stigma, denial, lack of informal network, normalization of symptoms, language barriers, fears of discrimination and primary care preference for a specialist to give a diagnosis.^{9, 10, 14}

Definitions

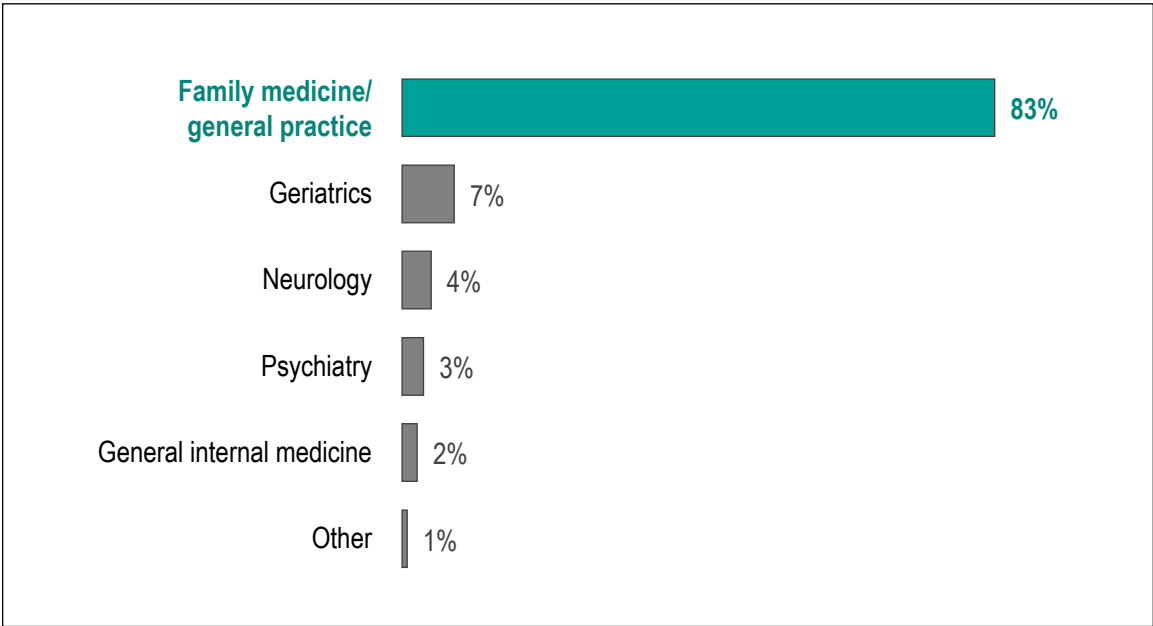
What does “first record of dementia” mean in our report?

Our study identified people who had a first record of dementia in 2017–2018 using dementia codes provided by health care providers at the time of billing, dementia codes recorded during a hospitalization or codes for anti-dementia drugs listed in prescription drug claims (whichever came first). Those who were identified through physician billings had 3 or more billing claims with dementia codes recorded within 2 years and a gap of at least 30 days between each claim. Also in our study, we used the date of first billing as the date of first record, which is different from CCDSS criteria,⁷ which uses the date of the third dementia code in physician billings. We then looked back 3 years to make sure that people in our cohort had no records of dementia prior to our defined first record of dementia in 2017–2018. We assumed that once a person had a recorded diagnostic code or prescription claim related to dementia, they would be living with dementia throughout the entire study period.

Overall, two-thirds of people living with dementia (67%) had the condition recorded for the first time by a family doctor/general practitioner.

In our analysis, 70% of people living with dementia had their first record of dementia in the community (e.g., doctor’s office, memory clinic). For this group, dementia was mostly recorded by family doctors (83%), while for a small percentage it was recorded by geriatricians (7%), neurologists (4%) or psychiatrists (3%) (Figure 1, Table B1). Other studies have found that general practitioners most commonly provide the diagnosis of dementia.⁹

Figure 1 Percentage of people living with dementia who had their first record of dementia in the community,* by physician specialty



Notes
* Excludes 25% with unknown location of first record of dementia.
Includes data from Newfoundland and Labrador, Ontario, Alberta and British Columbia.
Nurse practitioners accounted for 0.2% of diagnoses coded in the community.
Source
Patient-Level Physician Billing Repository, 2017–2018, Canadian Institute for Health Information.

Family doctors play crucial roles in coordinating care, referring people to community services, care planning, properly prescribing drugs and educating patients and caregivers about the condition’s progression. Their trusted relationships with patients enable them to practise a holistic approach to dementia care, considering contextual factors such as caregiver support, financial resources and access to support networks.¹⁵

However, family doctors may face numerous difficulties related to managing dementia care. These include not having enough time to assess the patient during consultation and, sometimes, a lack of specialized training required to accurately detect dementia.^{13, 16} The results of the 2022 Commonwealth Fund survey showed that, in Canada, only 35% of family doctors felt well-prepared to manage dementia care in the community, compared with the Commonwealth Fund average of 41%.¹⁷ The Canadian proportion had decreased significantly since 2019 (42%) and 2015 (41%). This may be in part due to broader issues affecting primary care during and after the COVID-19 pandemic, such as physician burnout, stress and high levels of administrative work.¹⁷

A health care provider perspective



It can take several months to get someone in to be assessed by a geriatrician unless they are in crisis. This means you will see a lot of diagnoses provided by family doctors. As a family doctor myself, I relied heavily on standardized written tests of cognition to diagnose dementia.

From my perspective, the biggest challenge is acceptance of the diagnosis by the person living with dementia and especially by their family. Those who accept it earlier and get involved in outreach programs tend to do better — both in terms of maintaining the functional level of the patient for longer, and giving a break to the caregiver.

— David, family physician and caregiver

While most people in our study who were living with dementia had a first record of dementia in the community, 30% had a first record of dementia in a hospital. Similar findings have been reported by other studies.¹⁸ This may indicate underdiagnosis in the community, where people living with dementia would ideally start their journey in the health care system rather than waiting until a health-related crisis causing hospitalization.

- People living with dementia in lower-income neighbourhoods were more likely to have a first record of dementia in hospital (34%) than those in higher-income neighbourhoods (27%). Other studies have reported that undetected dementia is higher among people with lower income¹² and that people with higher income were more likely to have an earlier diagnosis,¹⁹ which suggests that the latter group would consult with a physician earlier in the dementia trajectory.
- Regardless of where they had a first record of dementia, 3 in 4 people living with dementia were age 75 and older at the time dementia was first recorded. The mean age at a first record of dementia was 81 for women and 79 for men, which is comparable to other studies.²⁰

Timely and appropriate diagnosis helps people living with dementia and their caregivers access the resources and information they need to promote better quality of life through better symptom management, proper care, medication, social interventions and other supports. For caregivers, timely diagnosis and early involvement of their family doctor may help them navigate the health care system and better understand their caregiving roles, reducing burnout.

Caregiver perspectives



I think my mother-in-law was first diagnosed when she fainted and was admitted to hospital, likely because she hadn't been taking her medications correctly. Then we finally started to understand her situation. Prior to that, we weren't living with her. We just thought, "Oh, she's old. She's forgetful."

— **Wendy, caregiver of people living with dementia**

The diagnostic process took several years and multiple visits to physicians. My father received diagnoses of 4 different types of dementia depending on the care provider, making treatment very challenging. I felt that the stigma and added complexity of his concurrent other mental health and substance use conditions played a role in this delay.

— **Susan, caregiver of person living with dementia and concurrent mental health and substance use disorders**

Health care trajectories

After being diagnosed, people living with dementia will follow different trajectories in the health care system depending on the level of health care they need and the supports they have available.²¹ For example, they may live in a private home and receive help from an unpaid caregiver, a community organization (such as the Alzheimer Society or Meals on Wheels) and/or a direct care provider like a nurse, personal support worker or health care aide. Alternatively, they may move to a retirement home, assisted-living residence or long-term care facility where direct care is also provided.

People living with dementia are also likely to interact with other sectors of the health system and other health care professionals (e.g., hospitalizations, emergency department visits, family doctor and specialist visits).

Jurisdictions may have different types of support available for people living with dementia in the community. Alberta and British Columbia, for example, provide publicly funded or subsidized supportive living as an intermediate level of care between home care and long-term care. Our analysis does not identify results specifically for this type of supportive living.

Definitions

People receiving home care are defined in our study as those who were assessed with the interRAI Home Care (interRAI HC) or Resident Assessment Instrument–Home Care (RAI-HC) by a publicly funded home care provider in a setting other than a hospital to evaluate their health care needs and to either

- Develop a care plan as a **long-stay client** (i.e., clients requiring services in the home for 60+ days); or
- Assess whether they would be eligible for a long-term care placement.

In either case, most clients who are assessed receive some type of home care services. While most of them live in a private home, some could be living in a retirement home or assisted-living setting.

People who do not have a home care assessment (interRAI HC or RAI-HC) may still receive short-term home care services (short-stay client) that can be provided as an immediate/urgent time-limited intervention to assist with a post-surgery recovery, as end-of-life care or as time-limited care when their condition is expected to improve (e.g., rehabilitation). Short-stay home care clients and clients receiving private home care are not captured in our results.

People in a long-term care facility are defined in our study as those who were assessed with the interRAI Long-Term Care Facilities (interRAI LTCF) or Resident Assessment Instrument–Minimum Data Set 2.0 (RAI-MDS 2.0) in a publicly funded long-term care facility that provides 24-hour coverage by professional nursing staff and on-call physicians. Long-term care facilities can have different names across the country, such as nursing homes, residential care, continuing care and extended care. Jurisdictions that do not use interRAI assessments in long-term care facilities may use other data sources to identify people living with dementia in this setting (see [Spotlight from Quebec](#)).

Spotlight from Quebec: Validation of an algorithm to identify people age 65 and older living in long-term care facilities (CHSLD) using the Quebec Integrated Chronic Disease Surveillance System (QICDSS)

Results from the Institut national de santé publique du Québec

In Canada, more than 40% of people age 65 and older⁴⁴ who have been diagnosed with dementia live in long-term care facilities. The progression of dementia and service use patterns may differ depending on the setting in which people living with dementia live. Currently, data from surveillance systems in some provinces such as Quebec does not allow for direct estimates of the proportion of people living with dementia who live in long-term care facilities. We aimed to validate a previously developed algorithm⁴⁵ to identify people age 65 and older living in long-term care facilities in Quebec.

Method

We measured the validity (sensitivity, specificity, positive and negative predictive value) of an algorithm⁴⁵ developed to identify people age 65 and older living in a long-term care facility, compared with their residential postal code (reference population). 7 case definitions were then evaluated. The following validated algorithm was retained on the basis of sensitivity (96.77%), specificity (98.33%), and positive (93.57%) and negative (99.18%) predictive values. For each fiscal year, a person age 65 and older was considered to be living in a long-term care facility if they met at least one of the following criteria in the current fiscal year or the year before:

- Code for being institutionalized using data from the pharmaceutical services database; or
- Received a service billed by a physician in a long-term care facility using data from the physician claims database.

After identifying older people living in long-term care facilities, we used the CCDSS criteria to identify those living with dementia. We then compared demographic characteristics of people living with dementia in long-term care facilities with the characteristics of people living with dementia outside long-term care facilities.

Results: In total, there were 56,726 people age 65 and older in long-term care facilities in Quebec in 2016–2017. Among them, 70.6% were living with dementia.

Table 1 Characteristics of people age 65 and older living with dementia* and identified by the selected algorithm as living or not living in a long-term care facility, Quebec, 2016–2017[†]

Sex and age group	People 65+ diagnosed with dementia and living in a long-term care facility (%)	People 65+ diagnosed with dementia and not living in a long-term care facility (%)
Total	40,060 (100.0)	72,666 (100.0)
Women	26,956 (67.3)	46,192 (63.6)
Age 65–69	10,078 (2.3)	2,867 (4.0)
Age 70–74	2,192 (5.5)	6,197 (8.5)
Age 75–79	4,041 (10.1)	10,897 (15.0)
Age 80–84	6,915 (17.3)	16,097 (22.2)
Age 85+	25,834 (64.5)	36,608 (50.4)

Notes

* Dementia cases were identified using the CCDSS case definition.

† 2016–2017 was chosen because, at the time of the analyses, 2016 was the year of the last population census in Quebec.

Source

Quebec Integrated Chronic Disease Surveillance System.

Conclusion: Until specific databases on long-term care facilities are available, the validated algorithm can be used to identify and study people age 65 and older living in long-term care facilities.

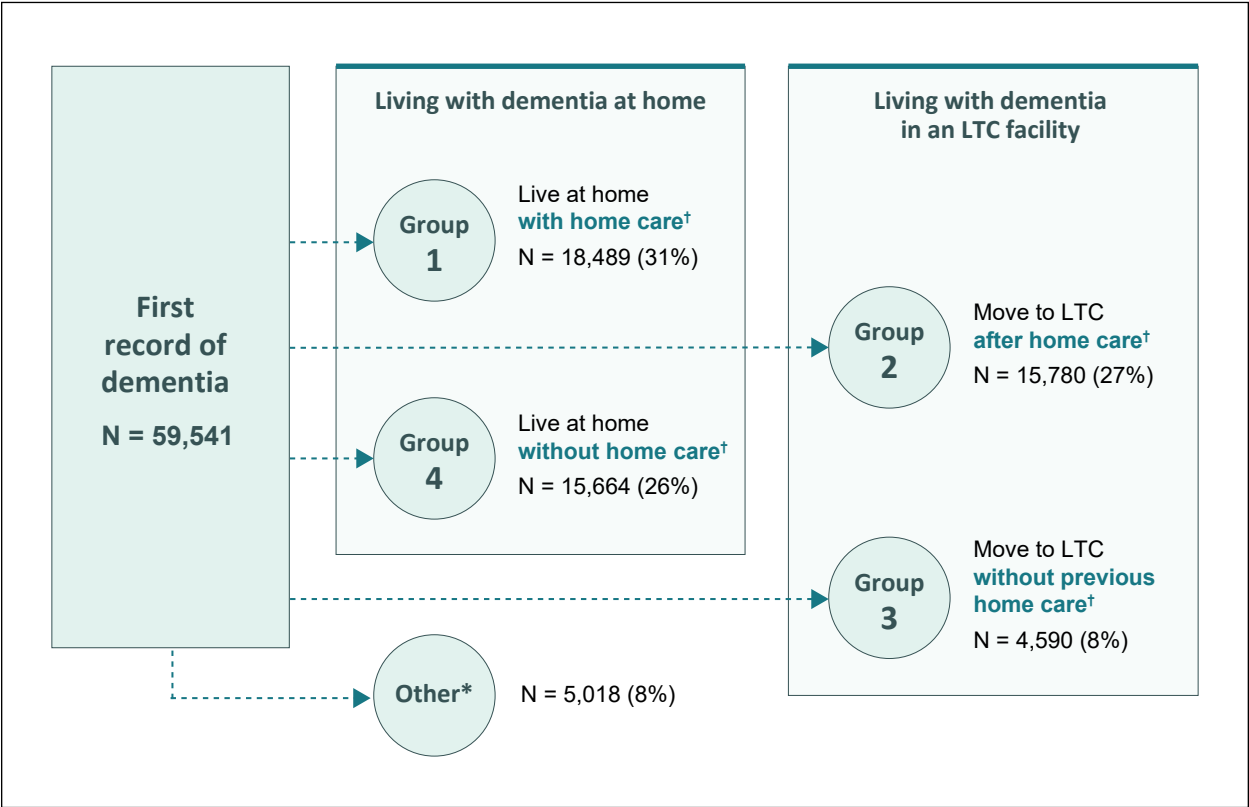
**Institut national
de santé publique**

Québec 

Description of the main care trajectories

We followed people living with dementia for 5 years from the time of their first record of dementia in 2017–2018 using assessments in home and long-term care settings. Figure 2 displays the care trajectories that were identified across 4 provinces.

Figure 2 Trajectories in the health care system after first record of dementia, Newfoundland and Labrador, Ontario, Alberta and British Columbia



Notes

* *Other* includes people living with dementia who had a first record of dementia while living in long-term care (N = 3,180, or 5%) and people living with dementia who moved to long-term care and had publicly funded home care prior to a first record of dementia (N = 1,838, or 3%). These groups are not described in this report.

† Publicly funded home care.

LTC: Long-term care.

Sources

Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Patient-Level Physician Billing Repository, Discharge Abstract Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System and National Prescription Drug Utilization Information System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

The 4 groups described below represent the trajectories of **92%** of people living with dementia:

- **Group 1: Live at home with home care** — People who lived at home and were supported by home care (31%)
- **Group 2: Move to long-term care after home care** — People who originally lived at home and were supported by home care but subsequently moved to a long-term care facility (27%)

In total, 58% of people living with dementia received home care after a first record of dementia. About 43% of them had home care assessments completed in the first 6 months after a first record of dementia, and 74% had dementia recorded for the first time by a primary care provider in the community. This demonstrates the important role of primary care providers in both early intervention and in coordinating home care services.²²

- **Group 3: Move to long-term care without previous home care** — People who moved to a long-term care facility without receiving publicly funded home care (8%)

This group was less likely to have dementia recorded for the first time by a primary care provider in the community (51%).

- **Group 4: Live at home without home care** — People who lived at home and were not supported by publicly funded long-stay home care and who did not move to a long-term care facility during the study period (26%). “At home” refers to any setting where people live other than a long-term care facility. It is typically represented by private homes.

A total of 71% of people in this group had dementia recorded for the first time by a primary care provider in the community.

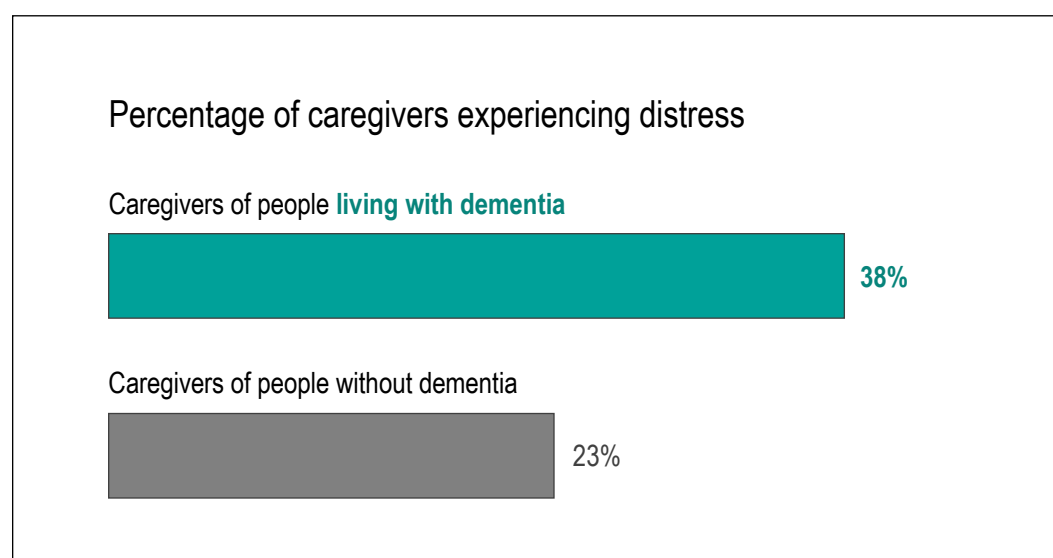
In total, 43% of people living with dementia were living in a long-term care facility at the end of our study.

Receiving care at home (groups 1 and 2)

Importance of caregivers

The majority of people who were living with dementia and receiving home care had caregivers (98%). About half of the caregivers (52%) were children or children-in-law. Caregiving for people living with dementia can be rewarding but also remarkably demanding, requiring caregivers to provide continual oversight of their loved ones' daily activities, as well as protective intervention when dealing with behaviours that can be a risk to the person's safety (e.g., getting lost).^{23, 24} Their caring responsibilities often affect the caregiver's own mental and physical well-being.²⁵ On average, caregivers of people living with dementia provided 24.5 hours of care per week, compared with 19.7 hours provided by caregivers of people without dementia. They were also more likely to experience feeling of distress, anger or depression.

Figure 3 Caregivers of people living with dementia were more likely to experience distress* compared with those caring for people without dementia



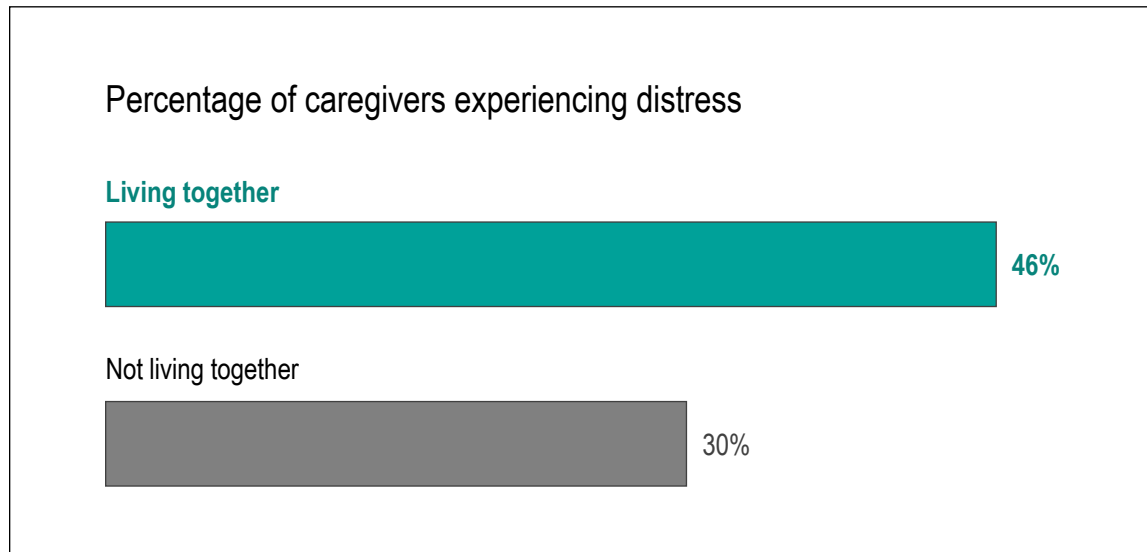
Note

* Distress refers to the interRAI HC/RAI-HC assessment item Primary informal helper/caregiver expresses feelings of distress, anger or depression.

Sources

Home Care Reporting System and Integrated interRAI Reporting System, 2017–2018 to 2019–2020, Canadian Institute for Health Information.

Figure 4 Among caregivers of people living with dementia, those living with the person they were caring for were more likely to experience distress*



Note

* Distress refers to the interRAI HC/RAI-HC assessment item Primary informal helper/caregiver expresses feelings of distress, anger or depression.

Sources

Home Care Reporting System and Integrated interRAI Reporting System, 2017–2018 to 2019–2020, Canadian Institute for Health Information.

Caregivers may also experience financial and employment difficulties,²⁶ particularly those caring for a person diagnosed with early-onset dementia.

What caregivers told us



Caregiving has become part of my identity as a result of caring for my parents — and despite the challenges, there have been positive impacts. This includes being able to give back to my parents, learning to be more adaptable and resilient in times of stress, and contributing to my personal growth and development.

— **Susan, caregiver of person living with dementia and concurrent mental health and substance use disorders**

Your stress is constantly there, because you know that this is a very slow, degenerating illness and you know you could be doing this for another 10 years, 15 years. There's no end in sight to the job you're doing. We are now part of a caregiver support group, helping to support other caregivers navigate the complex care environment.

— **Wendy, caregiver of people living with dementia**

Role of home care services

About half (54%) of the people living with dementia who received home care services remained in the community (group 1) while 46% were later admitted to a long-term care facility (group 2). Those who remained in the community may have been benefiting from increased services from either formal home care or unpaid caregivers. Another study of people living with dementia who stayed in the community found that the number of hours and services provided by home care increased over time, mostly for personal support and homemaking.²⁷ Publicly funded home care services for long-stay clients can provide support with activities of daily living (e.g., eating, personal care) as well as with more specialized care (e.g., nursing care, end-of-life care, physiotherapy).

As dementia progresses, behavioural and psychosocial symptoms (e.g., restlessness, agitation) and severe cognitive decline may become more challenging to manage at home, as people living with dementia may require constant supervision and may cause harm to themselves (e.g., person may get lost or injured) and/or to their caregiver.²⁸ Caregivers may feel unable to continue in their role due to this, but also due to other reasons such as competing responsibilities, their own health problems or an inability to provide additional hours of care, especially if additional support is not available. Home care services may not always address the needs of caregivers and/or of people living with dementia.²⁹

A caregiver and health care provider perspective



We [home care service] can offer supports like homemaking services, occupational therapy, nursing services . . . well, if the positions are staffed. But it's crucial that you have some family or informal support system, too, because home care is not always there and the support is going to be minimal, really.

— Sharla, home care nurse

I think that what we got is the most they can give us — 5 hours with a personal support worker per week. That's nowhere near what's needed to support them.

— Wendy, caregiver of people living with dementia

Transitioning to a long-term care facility after receiving home care (group 2)

In many cases, a transition to long-term care — where 24/7 support is available and provided by trained staff — is an appropriate option for people living with dementia and their caregiver(s).³⁰

In our analysis, transitions from home care to a long-term care facility were associated with

- Poor mental well-being of caregivers;
- Deteriorating clinical status of people living with dementia;
- Hospitalizations;
- Living in a lower-income neighbourhood;
- People living with dementia having English as a primary language; and
- Living in a rural/remote area.

We used logistic regression modelling to assess the likelihood of a person living with dementia and receiving home care being admitted to a long-term care facility during our study period, considering a variety of factors. The results are reported as odds ratios (Table B2). For instance, an odds ratio (OR) of 1.4 for “caregivers experiencing distress, anger or depression” means that caregivers of people living with dementia who moved to a long-term care facility had 40% higher odds of experiencing these feelings compared with caregivers of people living with dementia who received home care and who did not move to a long-term care facility during our study period.

We are reporting the top 12 factors that predict transitions of people living with dementia from home to a long-term care facility (OR≥1.2, p<0.05).

Caregiver factors

People living with dementia had higher oddsⁱ of being admitted to a long-term care facility if their caregivers

- Experienced distress, anger or depression (OR 1.4);
- Did not live with them (OR 1.4); or
- Felt unable to continue in their role (OR 1.2).

Home care and community support services may provide resources to assist with activities of daily living and help caregivers cope with distress. However, home care services that aren’t well-coordinated or that don’t provide consistent, well-trained staff can add to the stress experienced by people living with dementia and their caregivers.³¹

i. Compared with people living with dementia whose caregivers did not have these factors.

Clinical factors

Clinical characteristics of people living with dementia were also associated with transitions to long-term care facilities. For example, people living with dementia with the following characteristics (at the time of admission to publicly funded home care) had higher odds of moving to a long-term care facility during our study period compared with people living with dementia not experiencing the same issues:

- Moderate to very severe cognitive impairment (OR 1.7);
- Hospitalization within 1 year after home care assessment (OR 1.5);
- Frequent wandering (OR 1.4); or
- Severe hearing impairment (OR 1.4).

As shown in other studies,³² behaviours that require constant vigilance from caregivers and that pose a danger to the people living with dementia, such as frequently getting lost, can increase caregiver distress and lead to an admission to long-term care.³³

Equity and socio-demographic factors

Our findings also show the importance of equity and socio-demographic factors to transitioning to a long-term care facility. People living with dementia had higher odds of moving to a long-term care facility if they

- Had English as their primary language (OR 1.5);
- Lived in a rural/remote area (OR 1.5);
- Were age 85 or older (OR 1.4);
- Were a widow/widower (OR 1.3); or
- Lived in a lower-income neighbourhood (OR 1.2).

Caregivers from cultures that do not speak English as their primary language may feel more strongly about relying on home-based care due to a cultural preference or a lack of long-term care facilities that address cultural differences and diversity (e.g., staff who speak different languages, different types of food).²⁹

People living with dementia in rural areas may have less access to formal care and resources in the community, and those with lower income may not be able to afford out-of-pocket home care services that could help them stay at home longer.³⁴

A caregiver and health care provider perspective



In our culture, I think, if you send your parents to assisted living or long-term care, you really are frowned upon. It can also be very hard to find Mandarin-speaking care providers, which is another barrier.

As my father-in-law's health deteriorated, he was getting up 4 or 5 times each night and needing assistance to go to washroom. None of us were able to rest at night and my husband almost had a car accident because he was sleep-deprived. We finally decided to send him to an assisted-living home, and to this day we are still living with caregiver's guilt. However, I knew from my volunteer work with the Alzheimer Society that those facilities are there to help, and it doesn't always make sense to try to do it all on your own.

— **Wendy, caregiver of people living with dementia**

In the rural communities here, we do see lots of issues with being short-staffed and not having the resources people might need to stay a little bit longer at home. Then, once someone with dementia is placed in long-term care, they may end up 2 or 3 hours away from their community to get the level of care they need . . . it's just so far away for the family to be as involved.

— **Sharla, home care nurse**

Transitioning to a long-term care facility without receiving home care (group 3)

About 8% of people living with dementia who moved to a long-term care facility after a first record of dementia did not receive home care firstⁱⁱ (group 3). They could have been receiving care from unpaid caregivers and/or services from assisted-living models, private home care providers or community support organizations that do not submit data to CIHI. About 19% of people who had their first encounter in Alberta are in group 3 compared with 6% from other provinces. This may be because designated supportive living models represent a substantial part of the continuing care services offered in this province.

In addition, people living with dementia may not receive home care for various reasons. Results from the Canadian Community Health Survey³⁵ show that the most frequently reported barrier to obtaining home care is the availability of services, followed by personal characteristics such as language, not knowing where to go or not getting around to it, costs, and not being eligible or their doctor thinking it was not necessary. People may also decline home care services due to concerns about privacy, personal safety, previous negative experiences or lack of understanding of services provided.³⁶

In our analysis, we compared group 3 (move to long-term care without previous home care) with group 2 (move to long-term care after home care) by looking at their first assessment completed in a long-term care facility. The most notable difference was the interval between a first record of dementia and the admission to a long-term care facility:ⁱⁱⁱ group 3 moved to a long-term care facility 11 months earlier than group 2 on average, suggesting that home care could have helped them stay at home longer. Key clinical characteristics — such as level of cognitive impairment and dependence in activities of daily living — were similar between the groups. Lack of contextual information — such as caregiver support before long-term care admission — limits our understanding of factors associated with an earlier admission to long-term care for group 3.

ii. Not receiving home care means not receiving publicly funded long-stay home care (long-stay clients).

iii. Long-term care admission date was estimated based on the date of the first assessment in long-term care. This assessment happens within 14 days of admission as a standard practice.

Living at home without home care (group 4)

At least 1 in 4 people who had a first record of dementia in 2017–2018 were not receiving home care^{iv} or living in a long-term care facility for the duration of our analysis.

This group was more likely to live in higher-income neighbourhoods.

37% of people in group 4 lived in higher-income neighbourhoods (fourth or fifth neighbourhood income quintile) — this proportion was the highest among all trajectories (Table B3). This group might also have been healthier and/or in the earlier stages of dementia (they were age 76 on average at the time of the first record of dementia compared with age 80 for all people living with dementia). Compared with people living with dementia in other groups, within 12 months after a first record of dementia, this group had a lower rate of hospitalization (46% versus 54%).

It's also important to note that this group could have been receiving care from unpaid caregivers or services that are not captured by our data, such as short-term home care services, community support services (e.g., Alzheimer Society) or private home care paid for out of pocket. An Ontario-based study found that individuals with higher income were more likely to use private home care services.³¹ They could also have been in supportive or assisted living, especially in the provinces where this type of service is commonly available.

A caregiver and health care provider perspective



Publicly funded home care services are so short-staffed, but there are lots of private agencies around if people can afford them. And then if the person needs to be in a retirement home, they could be looking at paying thousands of dollars per month. It's just totally inaccessible for people who have lower incomes unless they are able to access the few subsidized beds that are available. Things have to get really bad before you can qualify for long-term care, which is subsidized, and the wait-list for that can be 2 to 3 years.

— **David, family physician and caregiver**

Publicly funded home care staff change. You might have a new person coming in every time, and then you have to start the training all over again — this is what she likes, this is not. In the end, it was easier for me to hire someone privately because then at least we would get a consistent person.

— **Wendy, caregiver of people living with dementia**

^{iv}. Not receiving home care means not receiving publicly funded long-stay home care (long-stay clients).

Role of hospitalizations in health care trajectories

Hospitalizations often play an important role in determining a person's care trajectory, as they typically coincide with significant changes in the person's health status and care needs.

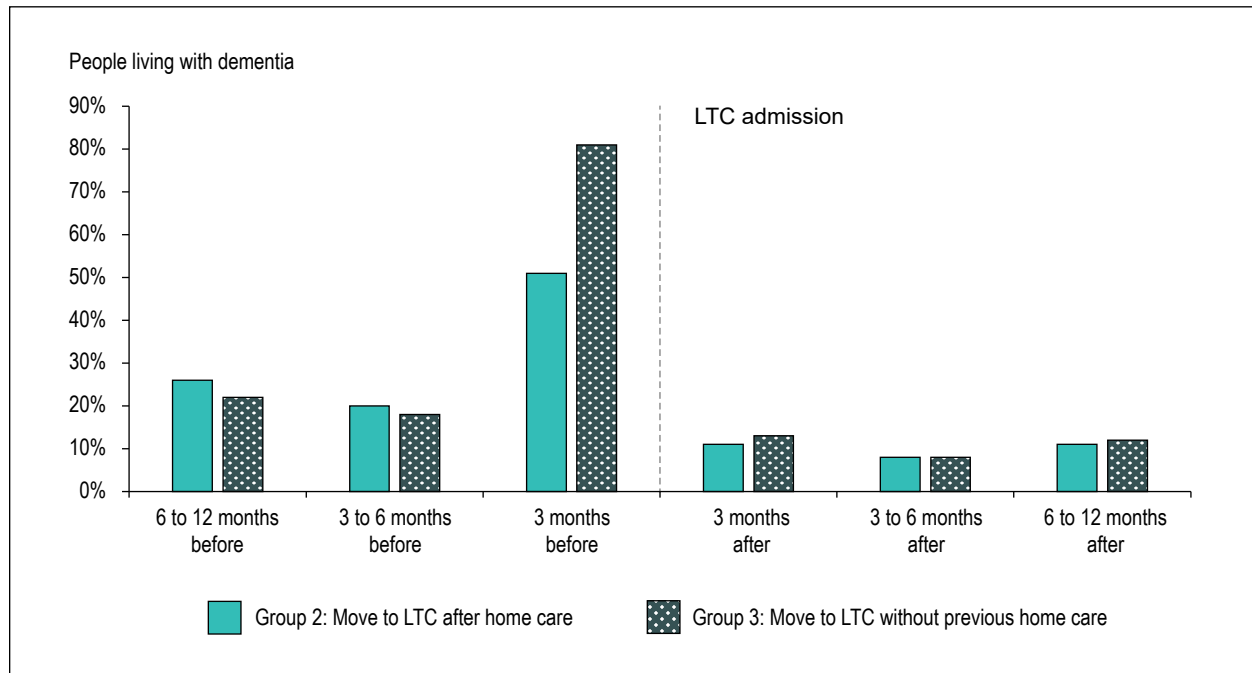
In our analysis, hospitalizations often preceded both the start of home care services and transition to a long-term care facility.

In the 3 months prior to starting home care, more than one-third (37%) of people living with dementia were hospitalized at least once. The most common main diagnoses recorded during these hospitalizations were unspecified dementia (4.0%), congestive heart failure (3.6%) and urinary tract infections (3.5%).

Hospitalization was even more common among people transitioning to long-term care facilities. While hospitalizations prior to home care admission were often related to health care problems that are common to all older adults, the main diagnoses recorded during hospitalizations in the 3 months prior to a long-term care admission were more likely to be associated with dementia: unspecified dementia (11.9%), waiting for admission to another facility (6.0%; see box [Alternate level of care](#)) and delirium superimposed on dementia (4.0%).

People living with dementia without previous home care were more likely to be hospitalized prior to their long-term care admission than those who had received home care: 81% of people in group 3 (move to long-term care without previous home care) and 51% of people in group 2 (move to long-term care after home care) had a hospitalization in the 3 months before their long-term care admission (Figure 5).

Figure 5 Percentage of people living with dementia who had at least one hospitalization before or after long-term care admission, groups 2 and 3



Note

LTC: Long-term care.

Sources

Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Discharge Abstract Database, Ontario Mental Health Reporting System and National Ambulatory Care Reporting System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

Medical characteristics are generally the main factors causing a hospitalization, but other reasons — such as low continuity of community physician care, insufficient home care services and a lack of caregiver support — may also play a significant role.^{37, 38} While in hospital, people living with dementia may be assessed to determine whether they require additional supports after discharge, such as home care or placement in a long-term care facility. If it is determined that they will need these additional services going forward, the person may spend additional time in hospital waiting for a space in the required program (see box [Alternate level of care](#)).

Alternate level of care

Alternate level of care (ALC) is a designation for patients who occupy an acute care hospital bed but do not require the intensity of services provided in acute care. Commonly, patients in ALC are awaiting transfer to another care unit or facility. The wait time can vary due to limited availability of resources.

Most people living with dementia who are designated ALC are awaiting placement in a long-term care facility to manage their symptoms.³⁹ Coordinating patient flow from hospital to long-term care facility has been a recurring issue, and extended ALC days can further compromise the health status of a person living with dementia.⁴⁰ interRAI assessments of physical assistance needs and cognitive status can facilitate faster placement.

Using 2022–2023 acute care data from all provinces and territories, we found that 30% of hospitalizations for people living with dementia age 65 and older who were hospitalized had ALC days, compared with 7% of hospitalizations for people the same age without dementia. Interestingly, people living with dementia who were younger had more ALC days: the average ALC length of stay was 42 days for those age 65 to 74, 32 days for those age 75 to 84, 29 days for those age 85 to 94 and 25 days for those age 95 and older. This may mean that it is more difficult to find appropriate supports in the community for younger people living with dementia.

A caregiver and health care provider perspective



The majority of our clients with dementia get referred to us [home care services] from a doctor's office or the hospital setting, often in a crisis situation like an acute delirium related to an infection or some other worsening condition.

— Sharla, home care nurse

When someone is in hospital and showing signs of severe impairment, you can't send them home alone. There needs to be somebody there to look after them, and if there isn't you can't discharge them. So you may end up with some ALC days.

— David, family physician and caregiver

People living with dementia and concurrent mental health and/or substance use disorders have even more challenges accessing home care or long-term care.

In our analysis, people living with dementia and concurrent mental health and/or substance use disorders were more likely to have part of their hospital stay recorded as ALC before starting home care or transitioning to a long-term care facility compared with people living with dementia without those disorders. In addition, their ALC lengths of stay were longer (Table 2).

Table 2 Alternate level of care days among people living with dementia with and without mental health and/or substance use disorders, last hospitalization before a care transition

People living with dementia	Last hospitalization before home care admission		Last hospitalization before long-term care admission	
	Percentage with ALC days	Number of ALC days (median)	Percentage with ALC days	Number of ALC days (median)
With concurrent mental health and/or substance use disorders	35%	14 days	81%	40 days
Without concurrent mental health and/or substance use disorders	27%	9 days	74%	27 days

Notes

ALC: Alternate level of care.

Mental health and/or substance use disorders include substance-related disorders, schizophrenic and psychotic disorders, mood disorders, anxiety disorders, personality disorders and other/unknown mental health disorders. Neurocognitive disorders are excluded.

Sources

Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Discharge Abstract Database, Ontario Mental Health Reporting System and National Ambulatory Care Reporting System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

It is commonly found that mental health and/or substance use disorders are heavily correlated with social isolation, lack of education, homelessness and excessive alcohol consumption.⁴¹ These risk factors likely impact the health status of people living with dementia by exacerbating the decline of cognitive and functional abilities.⁴² The added complexity of these comorbid conditions, as well as their associated stigma, seems to be a barrier to continuous care. In-hospital programs or an effective discharge plan that is connected with community-wide services may help people living with dementia and concurrent mental health conditions^{37, 39} avoid repeat hospitalizations.

A caregiver and health care provider perspective



I feel like we have to navigate 3 separate health care systems to get support for my father's dementia, mental health disorders and substance use disorders. But you can't just take one diagnosis from the other. They are all connected. It's very stressful and hard to navigate.

— Susan, caregiver of person living with dementia and concurrent mental health and substance use disorders

With dementia and concurrent mental health disorders, things are just compounded. In some cases, clients may have burned their bridges with family. Then it's a real challenge for us because there's nobody in between to help us get connected with that client or to make sure that they are going to their appointments and so on.

— Sharla, home care nurse

Living with dementia in long-term care

While the transition to a long-term care facility is often associated with negative emotions, such as a fear of losing one's independence, it may also bring some positive changes and a sense of relief for both people living with dementia and their families.⁴³ For example, our study shows that about 33% of people diagnosed with dementia who moved to long-term care after home care (group 2) experienced an improvement in cognition.

A health care provider perspective



We do see that, sometimes, clients going into long-term care will improve in that setting. They're getting their medications on time. They have a routine. The food is there. They're mingling a little bit, socializing. Everything is in place, supporting them.

— Sharla, home care nurse

A decline in hospitalization rates was also noted after admission to long-term care for people living with dementia, regardless of whether they received home care before admission (Figure 5). This may be because the preventive services, continuity of care and chronic condition management provided in long-term care have an impact on hospitalizations.³⁸

A recent study from B.C. (see [Spotlight from British Columbia](#)) reported a decrease in acute care and mental health hospitalization rates, as well as an increase in family physician and general practitioner visits, over the 2 years after long-term care admission. The study suggests that more frequent visits with physicians and specialists in long-term care facilities reduce the need for hospital-based care for people living with dementia.

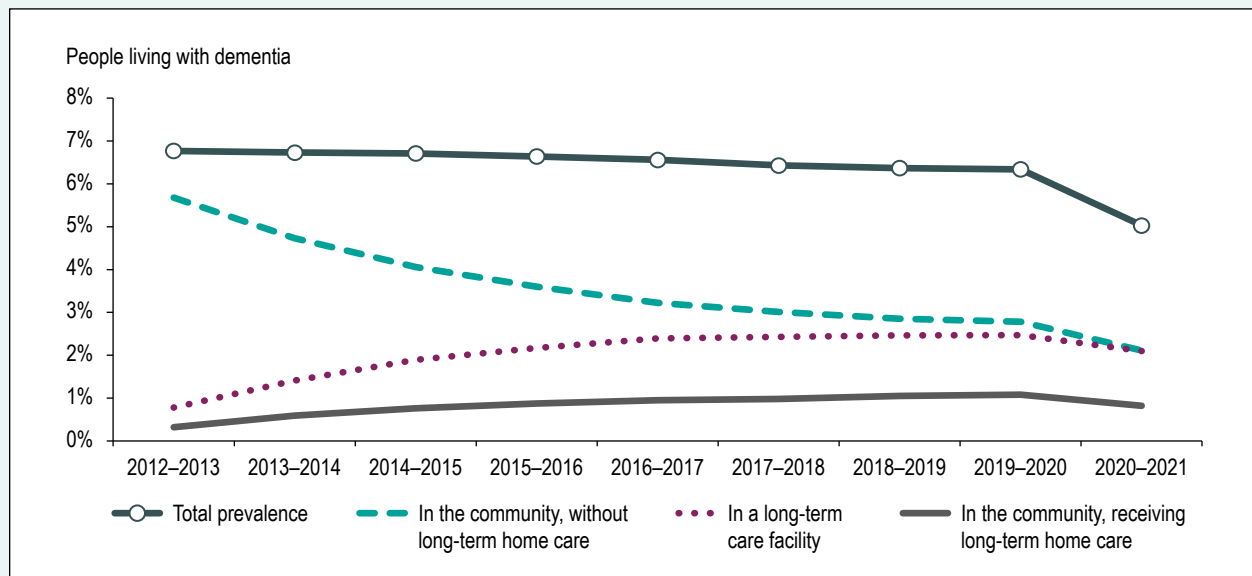
Spotlight from British Columbia: Prevalence of dementia in B.C. by living circumstance, and health care service use before and after transition to long-term care

Results from the Office of the Provincial Health Officer

The percentage of British Columbians living with dementia, including Alzheimer's disease, has been declining over the past decade. In recent years there has also been a shift in the living environment of individuals with dementia.

As shown in Figure 6, the prevalence of British Columbians living with dementia has decreased over time. The proportion of those living with dementia in the community who are not receiving publicly funded long-term home care services (i.e., those expected to require services for 60+ days) is also declining. In contrast, the prevalence of people living with dementia who are receiving long-term home care services and those living in long-term care facilities increased from 2012–2013 to 2019–2020. In 2020–2021, coinciding with the first year of the COVID-19 pandemic, dementia prevalence in all categories apparently decreased compared with prior years, likely due to direct and indirect effects of the COVID-19 pandemic.

Figure 6 Prevalence of people living with dementia (percentage of total B.C. population), according to living circumstances, by fiscal year, 2012–2013 to 2020–2021



Sources

Continuing Care Reporting System and Home Care Reporting System, 2012–2013 to 2020–2021, Canadian Institute for Health Information.

British Columbia Provincial Health Insurance Registry, 2012–2013 to 2020–2021.

Canadian Chronic Disease Surveillance System, 2012–2013 to 2020–2021.

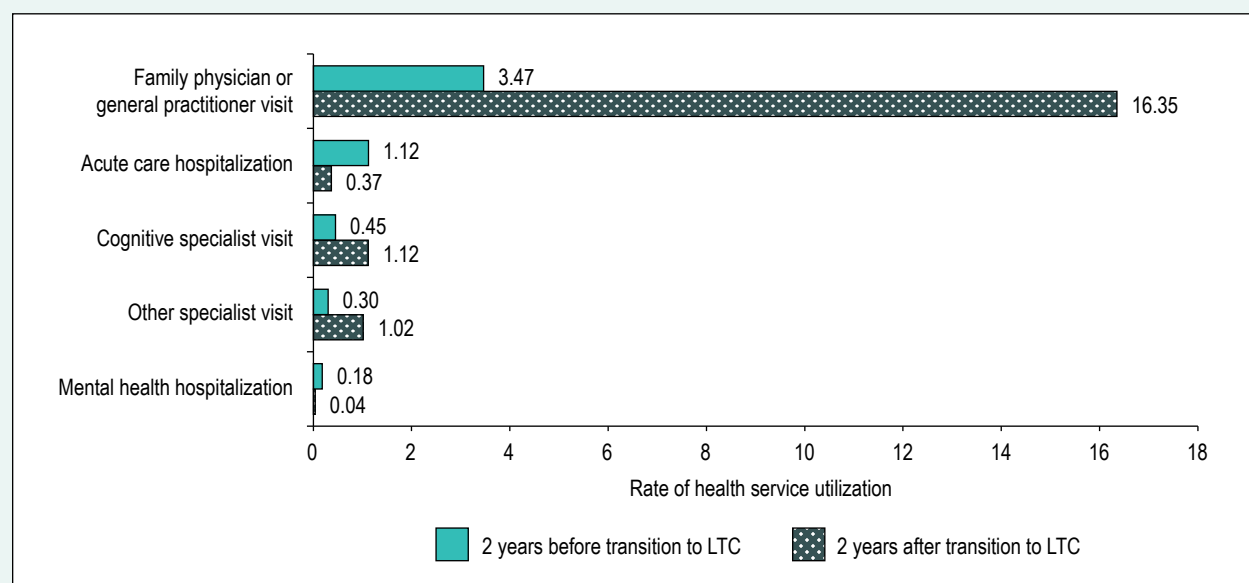
Changing trends in the living environment of individuals living with dementia has effects on the frequency of medical care and hospitalizations they experience, as shown in Figure 7.

Among both males and females, hospitalization rates in the 2 years after transition to long-term care (compared with the 2 years before) appear to decline for both acute care hospitalizations (from 1.1 visits to 0.4 visits per person-year) and mental health hospitalizations (from 0.2 visits to 0.04 visits per person-year).

In contrast, rates of family physician and general practitioner visits appear to increase 4.7-fold, with an average of 3.5 visits per year in the 2 years before moving to long-term care versus 16.4 visits per year in the 2 years after the transition. On average, specialist visit rates with cognitive and other specialists increase by 2.5-fold and 3.4-fold, respectively.

This suggests that more frequent visits with physicians and specialists in long-term care settings reduces the need for hospital-based care among people living with dementia.

Figure 7 Health service utilization (rates per person-year) among individuals living with dementia 2 years before versus 2 years after transitioning to long-term care



Notes

LTC: Long-term care.

Cognitive specialists include neurologists, geriatricians and psychiatrists.

Collection and analysis of dementia case data by the B.C. Office of the Provincial Health Officer was supported by PHAC. Dementia cases were identified using the CCDSS case definition.¹

Sources

Continuing Care Reporting System and Discharge Abstract Database, Canadian Institute for Health Information.

British Columbia Medical Services Plan Physician Claims Database and British Columbia Provincial Health Insurance Registry.

Canadian Chronic Disease Surveillance System.

People receiving publicly funded long-term home care services (i.e., those expected to require services for 60+ days) were identified through the Home Care Reporting System, and those living in long-term care facilities (i.e., hospital-based and residential continuing care facilities that provide 24-hour nursing care) were identified through the Continuing Care Reporting System.

Hospitalizations were identified using hospitalization records from the Discharge Abstract Database, and physician visits were identified using physician billing records from the medical service plan.

This analysis includes B.C. residents age 65 and older living with dementia who transitioned to a long-term care facility between April 1, 2014, and March 31, 2019.

More information about these results is available upon request at hlth.cdrwg@gov.bc.ca.



Office of the
Provincial Health Officer

Spotlight from Ontario: Excess health care costs attributable to dementia

Results from the Ottawa Hospital Research Institute

The direct costs of publicly paid health care services for people living with dementia in Ontario compared with costs for similar people without dementia are described here in 2018 Canadian dollars. Following the approach outlined by Bronskill et al.,⁴⁶ people living with dementia (cases) were matched to similar people without dementia (controls) using factors including age, sex, income, comorbidities and residence in a long-term care facility; direct costs were estimated per Wodchis et al.⁴⁷ Indirect costs not directly related to patient care, costs incurred by the patient and family, and insurance compensation paid by third-party payers are not included.

Average annual per-person health care spending for people living with dementia is consistently higher than spending for similar people without dementia across all phases of the condition (Table 3). Health care spending is highest in the year prior to death and is generally higher for males living with dementia than for females living with dementia. Much of the excess costs associated with dementia are from hospital admissions and long-term care (Figure 8).

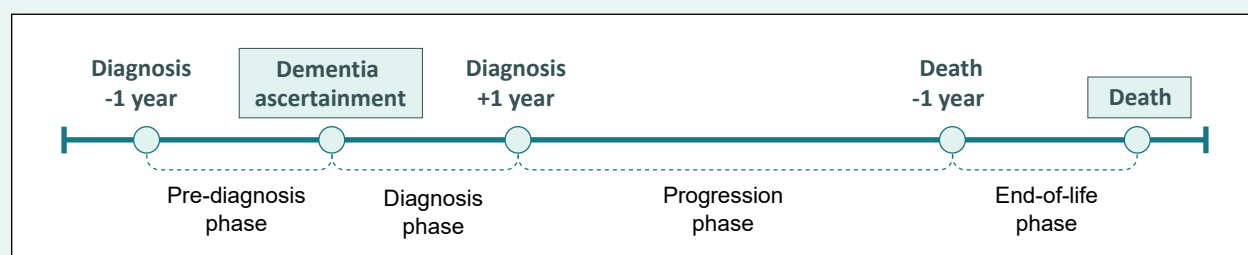


Table 3 Excess average annual per-person health care spending associated with dementia in Ontario by phase

Sex	Presence/absence of dementia	Pre-diagnosis phase	Diagnosis phase	Progression phase	End-of-life phase
Female	Dementia	\$21,011	\$32,086	\$30,194	\$91,859
	No dementia	\$18,479	\$12,933	\$13,806	\$66,375
	Excess costs	\$2,532	\$19,153	\$16,388	\$25,485
Male	Dementia	\$21,999	\$33,674	\$29,100	\$108,460
	No dementia	\$19,321	\$14,021	\$14,807	\$76,847
	Excess costs	\$2,679	\$19,653	\$14,293	\$31,613

Sources

Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2013–2014 to 2021–2022, Canadian Institute for Health Information.

Ontario Health Insurance Plan Database, Ontario Drug Benefit Program Database and Registered Persons Database, 2013–2014 to 2021–2022, Government of Ontario.

Pre-diagnosis and diagnosis

In both the year prior to the first record of dementia and in the year following, more is spent on health care for those living with dementia than is spent on similar people without dementia (Table 3). Most of this excess cost is associated with hospital admissions (Figure 8).

Progression

In the time between 1 year after the first record of dementia and 1 year prior to death, which we refer to as the dementia progression phase, annual health care costs for people living with dementia are approximately twice those for similar people without dementia (Table 3).

Among females, much of the excess cost associated with dementia during the progression phase is associated with long-term care — an excess of \$13,447 is spent on those living with dementia, compared with those without. Home care also accounts for a large proportion of the cost among females in the progression phase, with an excess \$1,416 spent on those living with dementia.

Among males, excess costs associated with dementia during the progression phase are also associated with long-term care, as well as with hospital admissions. An excess of \$9,153 per year is spent on long-term care and \$3,155 on hospital admissions for males living with dementia compared with those without dementia (Figure 8).

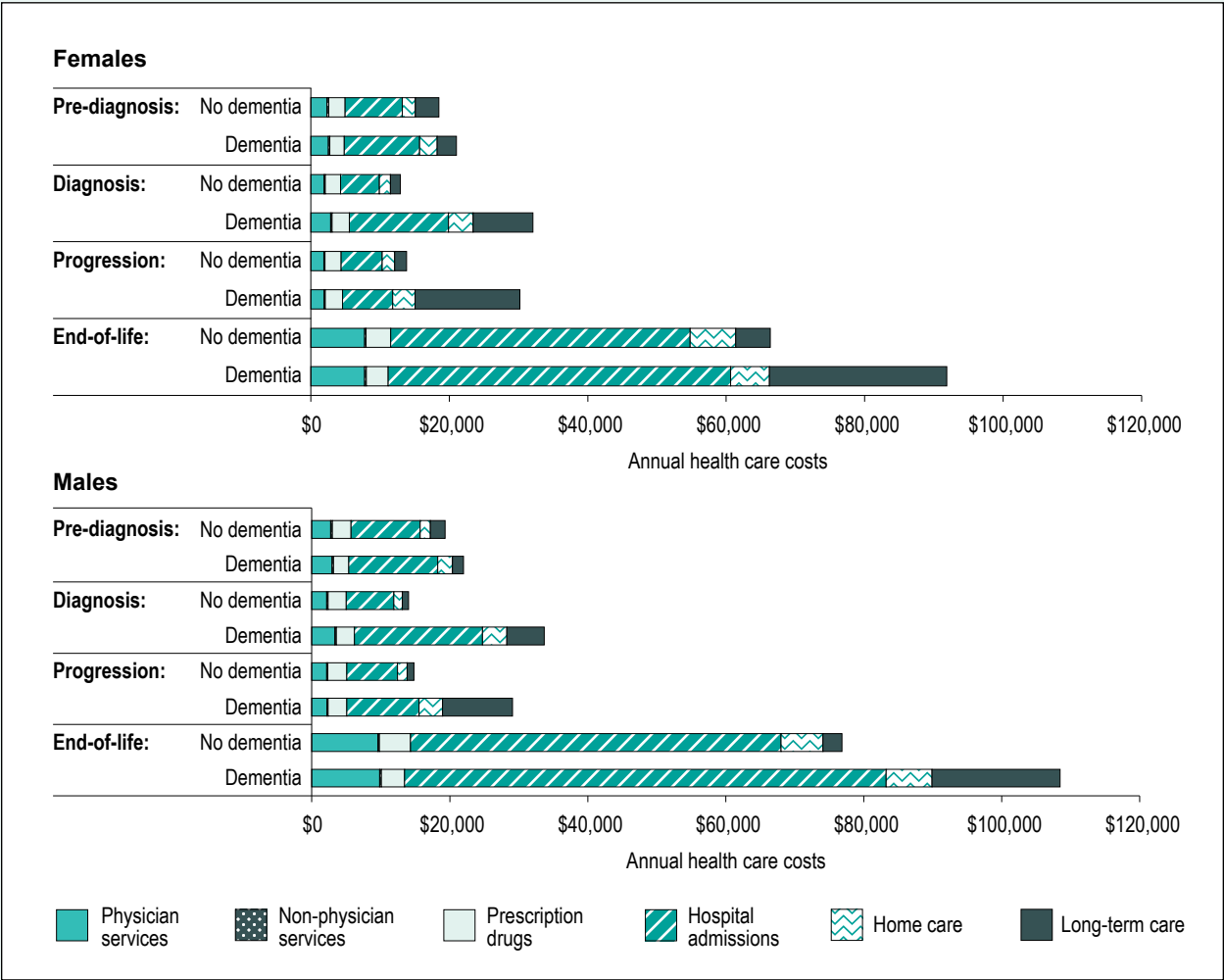
End-of-life

In the year prior to death, dementia is associated with \$25,485 in excess health care costs among females and \$31,613 in excess health care costs among males (Table 3).

Among females, most of the excess cost associated with dementia during the last year of life is for long-term care — an excess of \$20,612 is spent on those living with dementia, compared with those without the condition. The cost of hospital admissions also contributes to excess costs among females, with an additional \$6,232 spent on those living with dementia.

Among males, an additional \$15,827 is spent on long-term care in the last year of life for those living with dementia compared with those without dementia. Hospital admissions also account for a large proportion of excess cost among males, with an excess of \$16,086 spent on those living with dementia (Figure 8).

Figure 8 Average annual direct health care costs for females and males living with dementia and for similar people without dementia, by phase of condition and health care sector, Ontario (2018 Canadian dollars)



Sources
Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2013–2014 to 2021–2022, Canadian Institute for Health Information.
Ontario Health Insurance Plan Database, Ontario Drug Benefit Program Database and Registered Persons Database, 2013–2014 to 2021–2022, Government of Ontario.

The Spotlight from Ontario study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC). Data sets were linked using unique encoded identifiers and analyzed at ICES. This analysis used data adapted from the Statistics Canada Postal Code^{OM} Conversion File, which is based on data licensed from Canada Post Corporation, and/or data adapted from the MOH Postal Code Conversion File, which contains data copied under licence from Canada Post Corporation and Statistics Canada. Parts of this material are based on data and/or information compiled and provided by the Ontario MOH and CIHI. The analyses, conclusions, opinions and statements expressed herein are solely those of the Ottawa Hospital Research Institute authors and do not reflect those of the funders or data sources; no endorsement is intended or should be inferred.

More information about these results is available upon request at stafisher@ohri.ca.



Conclusion

As the Canadian population ages and the number of people living with dementia grows, it is crucial to understand their complex care needs.

Our analysis shows that this group is not homogeneous and that people living with dementia can follow various health care trajectories. Often, the trajectory they follow is a result of their health care needs and the supports they have in the community, mostly from family members and friends who provide care at home.

We hope that this report will be a step toward understanding the variety of health care trajectories that people living with dementia and their caregivers may follow. We also hope that it will help to inform service provision and policy planning to support people living with dementia and caregivers to follow the trajectory that provides the best care for their unique needs.

Appendices

Appendix A: Methodology

Data overview

Table A1 Data sources used to identify people living with dementia and to follow their care trajectories over time

Care setting	Data holding
Home care and long-term care	Home Care Reporting System (HCRS)
	Continuing Care Reporting System (CCRS)
	Integrated interRAI Reporting System (IRRS)
Acute care hospitalizations and day surgeries in general and psychiatric hospitals	Discharge Abstract Database (DAD)
	Ontario Mental Health Reporting System (OMHRS)
	National Ambulatory Care Reporting System (NACRS)
Physician billing	Patient-Level Physician Billing (PLPB) Repository
Prescription medications	National Prescription Drug Utilization Information System (NPDUIS)

Definition of dementia

- People living with dementia were identified using the CCDSS methodology described in [Dementia in Canada — Methodology Notes](#) (page 5), with the following exceptions:
 - Cases were also identified in the home care and long-term care databases using codes listed in [Dementia in Canada — Methodology Notes](#) (Table 1) and in Table A2 (i.e., IRRS codes).
 - The definition of dementia was not restricted to people age 65 and older in all data holdings.
- Specific codes used to identify dementia in each database are listed in [Dementia in Canada — Methodology Notes](#) (Table 1), as well as in Table A2.

Table A2 Codes used to identify dementia

Data holding	Description	Variables/codes
Integrated interRAI Reporting System (IRRS)	Alzheimer's disease/ other dementia	interRAI Home Care and interRAI Long-Term Care Facilities Variables and response values: I1c = 1, 2, 3 or I1d = 1, 2, 3, where 1 = primary diagnosis/diagnoses for current stay, 2 = diagnosis present, receiving active treatment and 3 = diagnosis present, monitored but no active treatment
Patient-Level Physician Billing (PLPB) Repository	Senile and presenile organic psychotic conditions/other cerebral degenerations	ICD-9: 290, 331 For Saskatchewan: 290, 331, 298
Ontario Mental Health Reporting System (OMHRS)	Alzheimer's disease/ dementia	DSM-V: 0461, 2900, 2901, 2902, 2903, 2904, 2941, 2942, 3310, 3311, 3315

Note

These codes are in addition to the ones listed in [Dementia in Canada — Methodology Notes](#) (Table 1).

Inclusion and exclusion criteria

- All analyses:
 - Health care number must be valid.
 - Exclude home care assessments submitted to CCRS that were completed in hospital and in complex continuing care.
- Spotlight from Ontario:
 - Dementia patients identified using home care and long-term care assessments from IRRS must also have a Cognitive Performance Scale score of 2+.
 - Exclude people who were not Ontario residents.
 - Exclude those who had no contact with the Ontario health care system for 7 or more years.
 - Costing analyses are limited to those age 65 and older.
- Care trajectories analysis:
 - Person must have had a diagnosis of dementia coded in the hospital or physician billing data, or a relevant drug prescription recorded in a pharmaceutical claim, in 2017–2018.
 - Person must not have met the definition of dementia in any care setting, including home care and long-term care settings, between 2014–2015 and 2016–2017.
 - Data must be submitted by, and have a health care number issued by, Newfoundland and Labrador, Ontario, Alberta or British Columbia.
 - These provinces were included because they had complete or near-complete coverage across the data sources over the study period (2014–2015 to 2022–2023).

For detailed information on the methodology for this report, contact us at help@cihi.ca.

First record of dementia location and physician specialties

Location of physician visits leading to a first record of dementia is identified based on the facility information submitted to the PLPB Repository. Due to a lack of a pan-Canadian standard for PLPB data, there are notable variations in data elements and coding practices across provinces. For this reason, caution is needed when interpreting results from the PLPB data.

Physician specialty is determined based on the primary provider's service code information from the DAD and provincial specialty code information from the PLPB Repository. For the PLPB Repository, provincial specialty codes are mapped to the national specialty codes to minimize code differences between provinces.

Data coverage and gaps

- In most cases, CIHI collects data on publicly funded health care services. Private home care and long-term care services, as well as prescription drug claims paid for out of pocket or by a private insurance plan, are generally not captured.
- Not all provinces/territories and individual health regions submit data to the CIHI data holdings used for the analysis. In addition, CIHI has incomplete coverage of data on assisted-living settings that are more common in some provinces such as Alberta.
- Canada's continuing care systems are administered uniquely within each province and territory; for more information, please see CIHI's [*Seniors in Transition: Exploring Pathways Across the Care Continuum — Methodology Notes*](#). This means that there are jurisdictional differences in the publicly funded services available to people living with dementia, as well as when/whether home care and long-term care assessments are completed and submitted to CIHI. At the time of writing, CIHI is transitioning toward a new standard for collecting home care and long-term care data and decommissioning the legacy reporting systems. Jurisdictions across Canada are at different stages of this transition process. Therefore, data for this report was derived from both the new reporting system (IRRS) and the legacy systems (HCRS and CCRS). Decisions on how to map data elements between these systems were informed by both data analysis and clinical expertise.
- For specific information on coverage, the transition to the new reporting standards and other data quality considerations for each individual data holding used in this analysis, please refer to the metadata pages for each data holding on [cihi.ca](https://www.cihi.ca).

It is important to note that several factors can affect when a record of dementia first appears in the administrative data. Some examples are listed below:

- Since a definitive diagnosis of dementia is usually complex, requiring multiple tests to rule out potential causes of cognitive decline, it may take several visits to a primary care provider before the diagnosis is confirmed and appears in the data. Furthermore, it is possible that the dementia code may not be recorded in cases where a person has another main reason for the physician visit.
- Dementia may not be recorded in the hospital setting if it is not related to main reason for the hospitalization.

Appendix B: Supplementary data

Table B1 Percentage of people living with dementia who had their diagnosis first recorded in the community or hospital,* by physician specialty

Physician specialty	In the community	In hospital	Overall*
Family medicine/general practice	83%	51%	67%
Geriatrics	7%	14%	13%
General internal medicine	2%	17%	7%
Psychiatry	3%	7%	5%
Neurology	4%	2%	4%
Other	1%	9%	3%

Notes

* Excludes 25% with unknown location of first record of dementia.

Includes data from Newfoundland and Labrador, Ontario, Alberta and British Columbia.

Sources

Patient-Level Physician Billing Repository and Discharge Abstract Database, 2017–2018, Canadian Institute for Health Information.

Table B2 Factors predicting long-term care admission among people living with dementia and receiving home care

Factors related to long-term care admission	Odds ratio	95% Wald confidence limits	
Moderate to very severe cognitive impairment	1.75	1.52	2.00
Living in a rural/remote area	1.50	1.38	1.62
Speaks English as their primary language	1.47	1.37	1.58
Hospitalization within 1 year after home care assessment*	1.46	1.39	1.55
Age 85 and older	1.45	1.36	1.53
Frequently wanders (e.g., gets lost)	1.44	1.28	1.62
Caregiver experiences distress, anger or depression	1.42	1.33	1.51
Caregiver did not live with the person living with dementia	1.40	1.31	1.49
Severe hearing impairment	1.36	1.25	1.47
Widow/widower at the time of home care admission	1.26	1.18	1.35
Lives in a lower-income neighbourhood	1.22	1.15	1.30
Caregiver unable to continue in their role	1.24	1.16	1.33

Note

* But before long-term care admission for people living with dementia in group 2.

Sources

Home Care Reporting System, Continuing Care Reporting System and Integrated interRAI Reporting System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

Table B3 Health care trajectories after first record of dementia by age, sex, neighbourhood income quintile and rurality

Demographic characteristics	Group 1: Live at home with home care	Group 2: Move to LTC after home care	Group 3: Move to LTC without previous home care	Group 4: Live at home without home care	Overall
Age at the first record of dementia diagnosis					
Age <65	4%	4%	7%	15%	8%
Age 65–74	16%	15%	17%	22%	17%
Age 75–84	40%	38%	36%	35%	37%
Age 85–94	36%	38%	36%	24%	34%
Age 95+	4%	5%	5%	3%	5%
Sex					
Female	56%	62%	52%	51%	57%
Male	43%	38%	48%	49%	43%
Neighbourhood income quintile*					
Quintile 1 (lowest income)	24%	28%	30%	22%	26%
Quintile 2	22%	23%	23%	21%	22%
Quintile 3	19%	19%	18%	20%	19%
Quintile 4	17%	16%	15%	18%	17%
Quintile 5 (highest income)	17%	15%	14%	19%	16%
Urban or rural/remote residency*					
Rural/remote	12%	15%	15%	12%	13%
Urban	88%	85%	85%	88%	87%

Notes

* Patients with missing or invalid postal codes were excluded.

LTC: Long-term care.

Sources

Discharge Abstract Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System, Patient-Level Physician Billing Repository and National Prescription Drug Utilization Information System, 2017–2018, Canadian Institute for Health Information.

Additional tables are available upon request. Please email us at help@cihi.ca.

Appendix C: Text alternatives for figures

Text alternative for Figure 1: Percentage of people living with dementia who had their first record of dementia in the community,* by physician specialty

Physician specialty	Percentage diagnosed in the community
Family medicine/general practice	83%
Geriatrics	7%
Neurology	4%
Psychiatry	3%
General internal medicine	2%
Other	1%

Notes

* Excludes 25% with unknown location of first record of dementia.

Includes data from Newfoundland and Labrador, Ontario, Alberta and British Columbia.

Nurse practitioners accounted for 0.2% of diagnoses coded in the community.

Source

Patient-Level Physician Billing Repository, 2017–2018, Canadian Institute for Health Information.

Text alternative for Figure 2: Trajectories in the health care system after first record of dementia, Newfoundland and Labrador, Ontario, Alberta and British Columbia

59,541 people in our study had a first record of dementia in 2017–2018. Group 1 (N = 18,489, or 31%) lived at home with publicly funded home care. Group 2 (N = 15,780, or 27%) moved to long-term care after receiving publicly funded home care. Group 3 (N = 4,590, or 8%) moved to long-term care without receiving publicly funded home care. Group 4 (N = 15,664, or 26%) lived at home without receiving publicly funded home care. An other group included 5,018 people (8%;* see the notes below).

Notes

* *Other* includes people living with dementia who had a first record of dementia while living in long-term care (N = 3,180, or 5%) and people living with dementia who moved to long-term care and had publicly funded home care prior to a first record of dementia (N = 1,838, or 3%). These groups are not described in this report.

LTC: Long-term care.

Sources

Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Patient-Level Physician Billing Repository, Discharge Abstract Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System and National Prescription Drug Utilization Information System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

Text alternative for Figure 3: Caregivers of people living with dementia were more likely to experience distress* compared with those caring for people without dementia

Type of caregiver	Percentage experiencing distress
Caregivers of people living with dementia	38%
Caregivers of people without dementia	23%

Note

* Distress refers to the interRAI HC/RAI-HC assessment item Primary informal helper/caregiver expresses feelings of distress, anger or depression.

Sources

Home Care Reporting System and Integrated interRAI Reporting System, 2017–2018 to 2019–2020, Canadian Institute for Health Information.

Text alternative for Figure 4: Among caregivers of people living with dementia, those living with the person they were caring for were more likely to experience distress*

Type of caregiver	Percentage experiencing distress
Living together	46%
Not living together	30%

Note

* Distress refers to the interRAI HC/RAI-HC assessment item Primary informal helper/caregiver expresses feelings of distress, anger or depression.

Sources

Home Care Reporting System and Integrated interRAI Reporting System, 2017–2018 to 2019–2020, Canadian Institute for Health Information.

Text alternative for Figure 5: Percentage of people living with dementia who had at least one hospitalization before or after long-term care admission, groups 2 and 3

Group	6 to 12 months before LTC admission	3 to 6 months before LTC admission	3 months before LTC admission	3 months after LTC admission	3 to 6 months after LTC admission	6 to 12 months after LTC admission
Group 2: Move to LTC after home care	26%	20%	51%	11%	8%	11%
Group 3: Move to LTC without previous home care	22%	18%	81%	13%	8%	12%

Note

LTC: Long-term care.

Sources

Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Discharge Abstract Database, Ontario Mental Health Reporting System and National Ambulatory Care Reporting System, 2017–2018 to 2022–2023, Canadian Institute for Health Information.

Text alternative for Figure 6: Prevalence of people living with dementia (percentage of total B.C. population), according to living circumstances, by fiscal year, 2012–2013 to 2020–2021

Year	Living with dementia (total prevalence)	Living with dementia in the community, without long-term home care	Living with dementia in the community, receiving long-term home care	Living with dementia in a long-term care facility
2012–2013	6.77%	5.68%	0.32%	0.78%
2013–2014	6.73%	4.73%	0.59%	1.41%
2014–2015	6.71%	4.06%	0.76%	1.89%
2015–2016	6.64%	3.60%	0.87%	2.17%
2016–2017	6.56%	3.22%	0.95%	2.39%
2017–2018	6.43%	3.01%	0.98%	2.43%
2018–2019	6.37%	2.85%	1.05%	2.46%
2019–2020	6.34%	2.78%	1.08%	2.47%
2020–2021	5.03%	2.11%	0.82%	2.10%

Sources

Continuing Care Reporting System and Home Care Reporting System, 2012–2013 to 2020–2021, Canadian Institute for Health Information.

British Columbia Provincial Health Insurance Registry, 2012–2013 to 2020–2021.

Canadian Chronic Disease Surveillance System, 2012–2013 to 2020–2021.

Text alternative for Figure 7: Health service utilization (rates per person-year) among individuals living with dementia 2 years before versus 2 years after transitioning to long-term care

Outcome	2 years before transition to LTC	2 years after transition to LTC
Acute care hospitalization	1.12	0.37
Mental health hospitalization	0.18	0.04
Family physician or general practitioner visit	3.47	16.35
Cognitive specialist visit	0.45	1.12
Other specialist visit	0.30	1.02

Notes

LTC: Long-term care.

Cognitive specialists include neurologists, geriatricians and psychiatrists.

Collection and analysis of dementia case data by the B.C. Office of the Provincial Health Officer was supported by PHAC. Dementia cases were identified using the CCDSS case definition.¹

Sources

Continuing Care Reporting System and Discharge Abstract Database, Canadian Institute for Health Information.

British Columbia Medical Services Plan Physician Claims Database and British Columbia Provincial Health Insurance Registry.

Canadian Chronic Disease Surveillance System.

Text alternative for Figure 8: Average annual direct health care costs for females and males living with dementia and for similar people without dementia, by phase of condition and health care sector, Ontario (2018 Canadian dollars)

Females

Phase of condition	Population	Physician services	Non-physician services	Prescription drugs	Hospital admissions	Home care	Long-term care
Pre-diagnosis	Dementia	\$2,509.04	\$231.85	\$2,064.75	\$10,891.52	\$2,541.79	\$2,771.78
	No dementia	\$2,333.27	\$234.77	\$2,361.58	\$8,292.07	\$1,857.39	\$3,400.13
Diagnosis	Dementia	\$2,859.12	\$203.90	\$2,502.84	\$14,318.77	\$3,537.21	\$8,663.99
	No dementia	\$1,909.10	\$177.98	\$2,209.68	\$5,593.74	\$1,609.31	\$1,433.39
Progression	Dementia	\$1,929.32	\$147.47	\$2,483.42	\$7,257.00	\$3,245.61	\$15,131.51
	No dementia	\$1,882.30	\$139.52	\$2,357.75	\$5,912.21	\$1,829.93	\$1,684.19
End-of-life	Dementia	\$7,771.54	\$233.20	\$3,154.33	\$49,493.40	\$5,572.78	\$25,633.96
	No dementia	\$7,783.90	\$197.40	\$3,545.62	\$43,261.48	\$6,564.51	\$5,021.78

Males

Phase of condition	Population	Physician services	Non-physician services	Prescription drugs	Hospital admissions	Home care	Long-term care
Pre-diagnosis	Dementia	\$2,932.26	\$223.84	\$2,219.20	\$12,872.98	\$2,121.40	\$1,629.60
	No dementia	\$2,738.08	\$227.77	\$2,718.96	\$10,033.75	\$1,448.59	\$2,153.42
Diagnosis	Dementia	\$3,358.39	\$199.90	\$2,609.19	\$18,568.49	\$3,513.83	\$5,424.64
	No dementia	\$2,171.31	\$188.13	\$2,614.66	\$6,929.58	\$1,205.52	\$912.11
Progression	Dementia	\$2,213.88	\$153.04	\$2,686.41	\$10,503.17	\$3,379.82	\$10,163.78
	No dementia	\$2,167.18	\$152.88	\$2,756.62	\$7,348.49	\$1,371.66	\$1,010.59
End-of-life	Dementia	\$9,847.45	\$223.61	\$3,368.30	\$69,806.26	\$6,632.98	\$18,581.07
	No dementia	\$9,592.41	\$212.18	\$4,503.62	\$53,720.22	\$6,065.10	\$2,753.58

Sources

Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, 2013–2014 to 2021–2022, Canadian Institute for Health Information.

Ontario Health Insurance Plan Database, Ontario Drug Benefit Program Database and Registered Persons Database, 2013–2014 to 2021–2022, Government of Ontario.

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