



THIS IS LONG-TERM CARE 2019

The impact of dementia
New evidence about quality of care
The need for more staff



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The role of long-term care



In this report

As more residents need a higher level of care than in the past, there have been corresponding higher demands on long-term care homes. They have risen to the challenge.

Although more funding and staffing are unquestionably needed, staff in long-term care homes are continuously looking for new ways to improve the care they provide, and to enrich quality of life for their residents.

This report provides new evidence about the high quality of care in Ontario's long-term care homes, as well as key information and statistics about the resident population and how long-term care works.

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Ontario's long-term care homes provide care and support to more than 115,000 people and their families every year.¹ Long-term care homes provide 24/7 nursing care and supervision, primary medical care, help with daily activities and interests, and a safe, caring home environment.

The vast majority of people who live in long-term care have some form of cognitive impairment and physical frailty, along with chronic health conditions that have seriously compromised their health.¹ ●



An invaluable part of the health care system

As part of the health care system, long-term care homes are licensed and funded by the Ministry of Health and Long-Term Care to provide care for people who need a level of support beyond what is possible at home. Residents also pay a fee for their accommodation.

Although most of us hope to age at home indefinitely, it simply isn't possible for everyone, particularly for people with Alzheimer's disease and other forms of dementia. An estimated 70% of people with dementia will eventually need long-term care.²

"Dementia" is an umbrella term for a number of degenerative brain diseases which have many stages and symptoms beyond memory loss. As the disease progresses, these symptoms can be very challenging for families to manage at home. Long-term care homes offer the expertise in dementia and end-of-life care that individuals and their families need.

Seniors whose dementia has progressed to the middle or advanced stages are the core population in long-term care homes. Since 2010, the proportion of residents with dementia has been growing steadily, with two out of every three residents (64%) now affected by these diseases.¹ ●

Resident profile

90% have some form of cognitive impairment¹

86% need extensive help with activities such as eating or using the washroom¹

80% have neurological diseases^{1*}

76% have heart/circulation diseases^{1*}

64% have a diagnosis of dementia¹

62% have musculoskeletal diseases such as arthritis and osteoporosis^{1*}

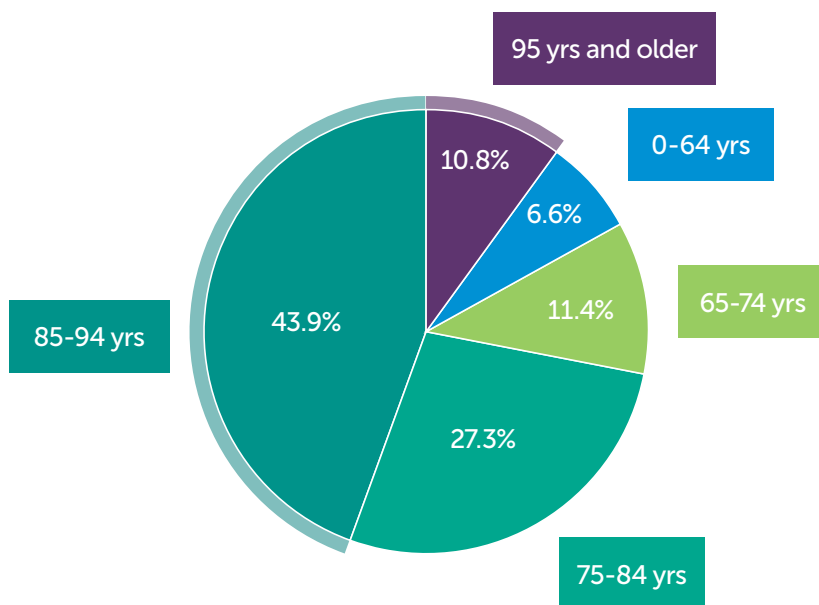
61% take 10 or more prescription medications³

40% need monitoring for an acute medical condition¹

21% have experienced a stroke¹

*Ontario's long-term care homes have the highest prevalence of these conditions in Canada, based on provinces and territories participating in the Canadian Institute for Health Information's Continuing Care Reporting System.¹

More than half of residents are over age 85



More than half of long-term care residents are over age 85, with a notable increase in the number of residents who are 95 years and older in the last five years.

Approximately one in six residents (18%) are younger than 75. Many of these younger residents have experienced a brain injury, stroke, and other conditions that require 24/7 care.¹

The changing profile of long-term care

Caring for seniors with higher needs

While long-term care homes have always cared for residents with a range of support needs, there has been a sharp increase in the proportion of residents with higher needs in recent years.

In 2010, the Ontario government began to put a larger focus on “aging at home” and set stricter criteria for admission to long-term care.

As a result, people are now coming to long-term care at a later stage of their cognitive and physical impairment, when their health is more likely to be unstable, they are more physically frail, and their care needs are higher.

The Ontario Long Term Care Association analyzed data which shows that since 2012:

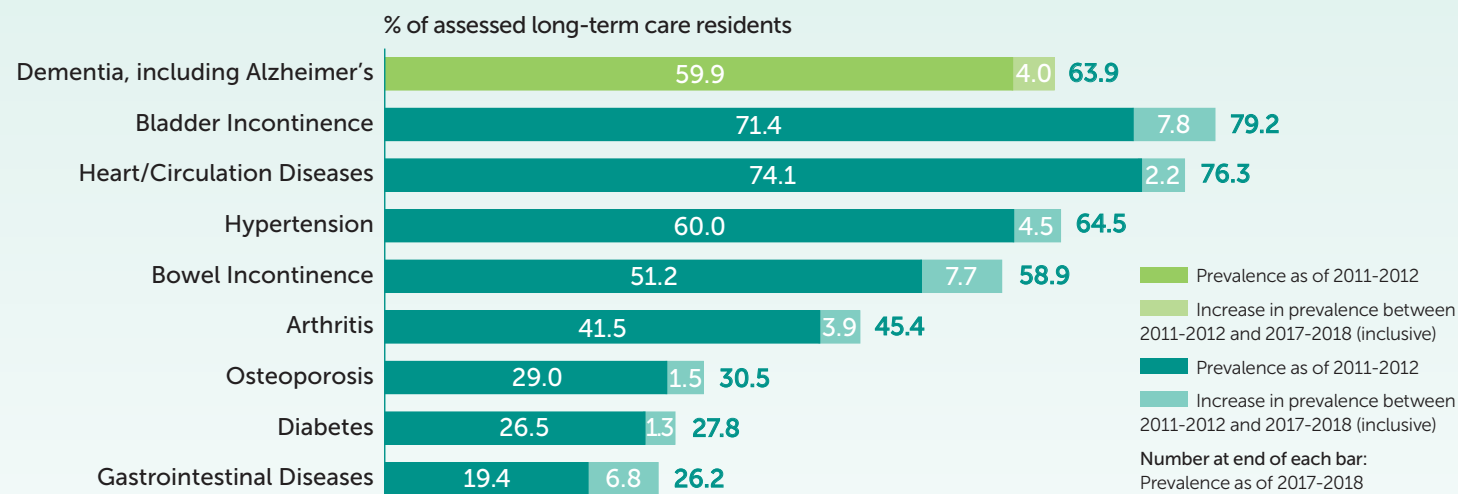
- there are now more residents in long-term care with a diagnosis of dementia;
- the prevalence of severe cognitive impairment has increased;
- more people need extensive or complete support with everyday activities such as getting dressed or feeding themselves; and
- the prevalence of bladder and bowel incontinence has notably increased.^{1,4}

These changes are interconnected. As dementia causes the brain to deteriorate, the organs and functions that it



directs deteriorate as well. When the disease progresses into middle and later stages, most people have lost the ability to communicate or understand communication, to interpret their environment, and to care for themselves. ●

Health conditions and care needs have increased since 2011-2012

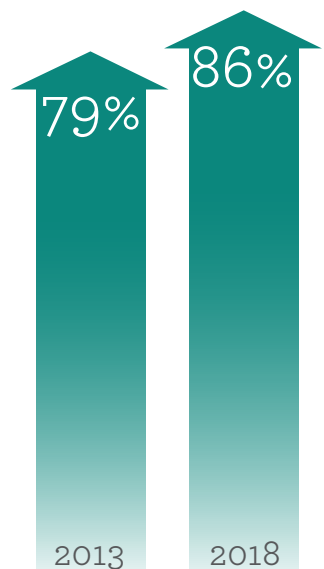


This graph shows the rise in the prevalence of selected health conditions among long-term care residents between 2011-2012 and 2017-2018. Increases across multiple conditions add up to a dramatic growth in the overall care needs for residents in long-term care.

As one example, the significant increase in the number of people experiencing bladder incontinence means that **more than 9,600 additional residents need care staff to help with toileting**, compared to 2011-2012.^{1,4} ●



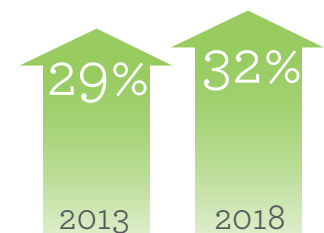
More residents need support with daily activities



The number of long-term care residents who need extensive or complete support with daily activities such as grooming, getting dressed, and eating has risen from 79% to 86% over the last five years. This represents **more than 9,000 additional people who need significant assistance.**^{1,5}



More residents have severe cognitive impairment



The percentage of residents who have severe cognitive impairment has risen from 29% to 32% over the last five years. This represents almost **5,000 more people who need more support with daily activities.**^{1,5}

What about more staff?

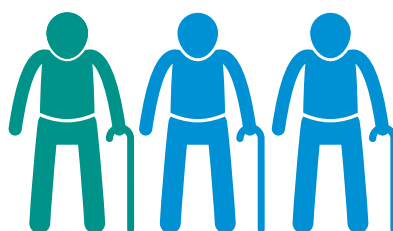
There are many different health care professionals in long-term care, each providing their expertise and care to help residents. But the largest group of frontline caregivers is personal support workers (PSWs), who help residents with the activities they cannot do independently.

As this report shows, the proportion of residents who need help has grown in the last five years and more staff are needed to help with their care.

The Ontario Long Term Care Association is asking the government to fund more frontline staff, as well as for the flexibility to use government funding to hire different types of support staff. More information on this important issue can be found on pages 8 and 9. ●



1 in 3 residents have severe cognitive impairment¹



2 out of 3 residents have dementia¹

Caring for people with dementia

64% of Ontario long-term care residents have a diagnosis of dementia¹



Ontario long-term care homes have the **2nd highest prevalence of dementia in Canada**¹

Understanding dementia

One of the tragedies of dementia is that it gradually destroys social skills and the ability to manage emotions. Many people with dementia can become easily irritated, suspicious, frightened, and upset. They may react reflexively by pushing or hitting, or by using angry and accusatory responses. Even something as simple as having hair combed can be confusing or frightening, triggering a negative reaction.

In addition, the majority of people with dementia will experience one or more behavioural symptoms related to the disease, which include activities such as pacing, wandering, hoarding, disrobing, and repetitive motions or speech. These symptoms – which often change through the course of someone’s disease – can be very distressing to the person experiencing them, as well as to those around them.

One of the important functions of long-term care homes is to help reduce or better manage dementia-related symptoms. The solution may be to learn to approach a resident differently, to change the environment, or to divert them to pleasurable memories or activities.

Working with the behavioural symptoms of dementia is an enormous but often unrecognized part of the work of long-term care staff. It is rewarding and meaningful work that has led to some outstanding successes, both in the care of individual residents and in reducing the severity of dementia-related behaviours across the province. ●

Reducing the distress of dementia-related symptoms

Most health care educational programs don’t offer in-depth information on how to care for people with dementia, or how to manage dementia-related symptoms. In the last decade, long-term care homes and the government have invested in new programs and training to help long-term care staff learn new information about dementia and behaviour management strategies for related behaviours.

Additional government funding, starting in 2011, has been another catalyst for this change. Behavioural Supports Ontario (BSO) is a provincial program that provides specially trained teams to help other staff learn new ways to manage and reduce behaviours. Many of these teams are embedded in long-term care homes, ensuring that additional staff with specialized skills are on site to help care for residents. There is evidence that BSO expertise and support in the care of people with dementia has helped to speed the pace of culture change in dementia care, reduce the use of restraints and antipsychotic drugs, and reduce the rate of aggressive behaviour.⁶ ●

A new era in dementia care

An important societal shift has been unfolding over the last decade, changing the way we think about dementia and what we expect from long-term care homes. Ontario’s long-term care homes have embraced this shift and are moving away from a medical model of care with fixed activities and schedules to a more flexible and personalized approach to care.

This way of providing care focuses on developing a sensitive understanding of each individual, their likes and dislikes, and what gives their lives meaning – even in the face of advanced dementia.

People who have dementia often need help tapping into the activities, memories, and relationships that provide them with a sense of purpose and meaning. Long-term care homes employ a variety of approaches such as personalized music, art, doll therapy, and animals to help improve mood, reduce pain, and reduce dementia-related behaviours. Residents are also included in everyday activities at their homes, such as helping to sweep floors or fold laundry. Involving residents in meaningful activities typically reduces dementia-related behaviours and enhances their quality of life. ●

Understanding aggressive behaviour

Nearly half of long-term care residents exhibit some form of aggressive behaviour.¹ Aggression in long-term care is defined as someone being verbally or physically abusive, socially disruptive, or resisting care and assistance.

In most cases this is not true aggression, but a response to something in the person's environment and an inability to interpret the situation correctly. For this reason, irritable outbursts, pushing or hitting, or other behavioural symptoms of dementia are often described as "responsive behaviours."

Since 2012, the prevalence of severe and very severe aggressive behaviour has gone down, and there are fewer residents resisting care from staff.^{1,4} This reflects the dedication of homes and their staff to working sensitively with residents around the behavioural symptoms of dementia. ●



45% of residents exhibit some form of aggressive behaviour¹



Hands-on care

As dementia progresses, people lose the ability to care for themselves. For example, they may no longer recognize when they need to use the washroom, or understand what utensils are for. Long-term care home staff provide physical support with eating, toileting, getting dressed, bathing, grooming and hygiene, and mobility. ●

70% of people with dementia living at home will eventually need long-term care²



Psychiatric conditions in long-term care

People with a dual diagnosis of dementia and a psychiatric condition often have severe struggles. Their care is usually very complex, requiring more staff time and specialized support. Very few homes have the resources to accept residents with psychiatric conditions.

In Ontario, more than 3,600 long-term care residents have a diagnosis of schizophrenia, the highest prevalence among long-term care homes in Canada. More than 2,500 residents are affected by bipolar disorder.¹ Many people with these conditions are admitted to long-term care homes because they also have a diagnosis of dementia. ●

80% of people with dementia experience behavioural or psychological symptoms during the course of their disease⁷



The need for more staff

Long-term care is a hidden jewel of a workplace for the right people. But right now, those staff need more support. There is currently a workforce shortage of personal support workers (PSWs), and in some areas there aren't enough nurses either.

In a 2018 survey of Ontario's long-term care homes, 80% of respondents said they had difficulty filling shifts, and 90% experienced challenges recruiting staff.⁸ Homes find themselves working short, working staff into overtime, and sometimes unable to fill the required shifts to provide care that residents need. The situation has reached a tipping point.

There are currently 79,000 long-term care beds in Ontario. The government has committed to an additional 15,000 beds within five years, and a further 15,000 within 10. Another 15,000 beds alone will need nearly 8,500 more care staff (full-time equivalents) than currently exist — an increase of 20%.⁹

Even more long-term care beds and staff will be needed as the baby boom generation ages and the prevalence of dementia increases. While long-term care homes are doing what they can to recruit, retain, and value their staff, Ontario needs a big picture approach. **It's time for a provincial workforce strategy that will help build the workforce for tomorrow.** ●



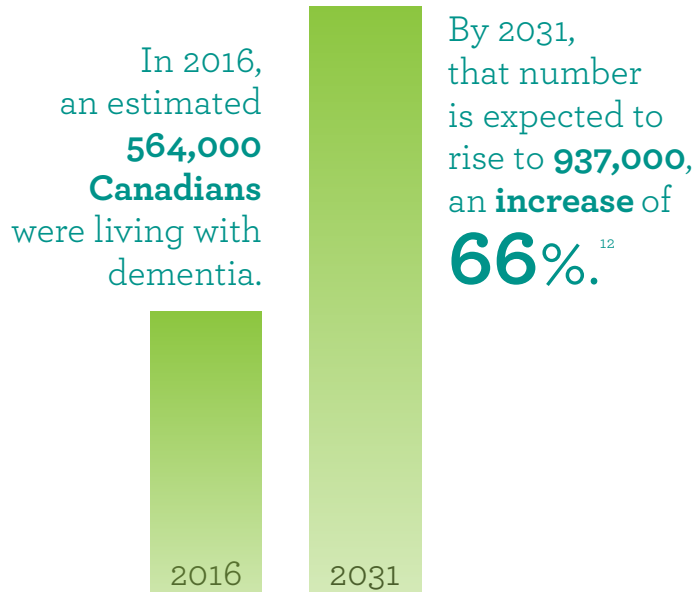
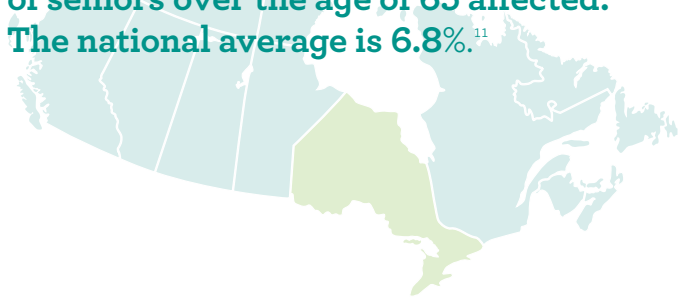
Currently 79,000 beds

20% more care staff*
will be needed for
15,000 more beds⁹

*Full-time positions or equivalent (FTE) of registered nurses, registered practical nurses, and personal support workers.

Over the **next 20 years** it is anticipated that there will be **more than twice as many seniors over the age of 75** and, by extension, a growth in the number who need long-term care support.¹⁰

Ontario has the highest prevalence of dementia in Canada, with **7.3% of seniors over the age of 65 affected. The national average is 6.8%.**¹¹



What's needed: Flexible staffing

Giving long-term care homes more flexibility in the type of staff they can hire would help homes to address staffing shortages and be more creative in the way they meet residents' needs.

Nearly 50% of personal support workers' current work is unrelated to direct resident care and could be done by other staff such as health care aides.¹³

This would help to ease the PSW shortage, but there are currently legislative and funding restrictions that discourage this type of flexibility.

Registered practical nurses (RPNs) could play a much larger role in long-term care. Nearly 40% of Ontario's RPNs are already employed in long-term care homes and provide the majority of nursing care.¹⁴

RPNs have the knowledge and skills required for providing all but the most complex care, and could take on some of the roles that currently only registered nurses (RNs) are allowed to do according to the *Long-Term Care Homes Act*. There is no shortage of registered practical nurses in the province, and many would be eager for this leadership opportunity. ●

What's needed: More funding for staff

Homes need an overall higher level of funding to ensure that they can hire enough staff – and the right mix of staff – for their residents' specific needs. This applies not only to funding for more direct care staff, but also for specialized mental health teams that help homes to reduce challenging behaviours and improve quality of life for residents with dementia and/or psychiatric conditions. ●

What's needed: A provincial strategy

A number of factors have come together to create a staffing shortage in long-term care, from the increased pressures on homes to a workforce that is generally older than in other areas of health care.

Long-term care homes need government support in areas such as grants to reduce tuition, rural and northern training programs, international recruitment, and a campaign to promote working in long-term care as a meaningful career choice for young Canadians.




By working together on a provincial staffing strategy, the government and long-term care homes can create a new generation of health care staff for the future. ●

New evidence of quality care

Ontario is a leader in reducing pain, restraints, and antipsychotics

Staff in Ontario's long-term care homes have made extraordinary efforts for their residents in reducing restraints, improving pain management, and reducing inappropriate antipsychotic use. ●

✔ In Canada, Ontario has the **lowest proportion of long-term care residents with pain or in physical restraints.**¹

		Percentage of residents	
		2010/11	2016/17
	Antipsychotics without psychosis	35.0%	20.4%
	Daily moderate or any severe pain	11.9%	5.6%
	Daily physical restraints	16.1%	5.1%

Reprinted with permission from *Measuring Up 2018*, Health Quality Ontario, 2018. Data source: Continuing Care Reporting System, provided by the Canadian Institute for Health Information.

✔ In the last five years, Ontario homes have shown the **fastest rate of decline in antipsychotic use and physical restraints in the country.**^{1,5}

The vast majority of homes do well on their inspections



Long-term care inspections

Long-term care homes operate according to the *Long-Term Care Homes Act*, one of the toughest pieces of nursing home legislation in the world. The legislation has more than 1,000 requirements, ranging from the posting of menus to prevention of abuse. Staff are proud of the care they provide, the relationships they build with residents, and the work they do to meet the stringent requirements of the Act. ●

A closer look at quality

Staff in long-term care homes want to ensure that they're providing the best possible care, but it's only since 2012 that data has been available publicly which allows homes to compare data about the care they're providing.

A number of key factors, such as the percentage of residents who are experiencing pain, who have pressure ulcers, or who are receiving antipsychotics, are widely believed to indicate whether long-term care homes are providing high-quality care.

These indicators are all reported individually on public websites. But until recently, there hasn't been any way to show how long-term care homes are doing overall, or how they are performing based on factors such as size or ownership.

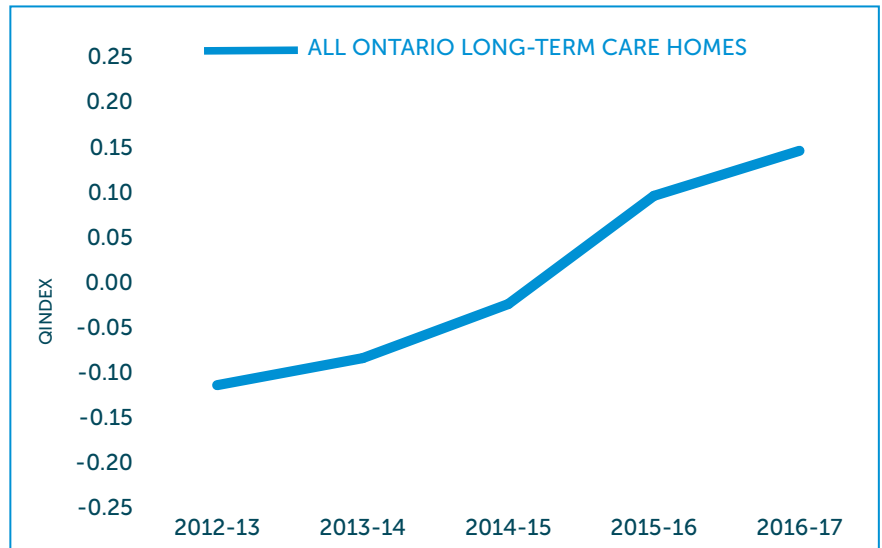
In 2018, the Ontario Long Term Care Association, in partnership with the University of Toronto, developed a new metric called the Qindex, a composite of nine quality indicators that shows overall performance and trends of quality improvement in long-term care.¹⁵



The Qindex shows that all types of long-term care homes are making significant improvements in quality of care. It also helps to identify some that may be struggling more than others. ●

Ontario long-term care homes show significant results in improving quality of care

About this figure: New evidence from the Qindex shows that long-term care homes across Ontario made great strides in improving quality of care over the five-year period between 2012-2013 and 2016-2017.¹⁵

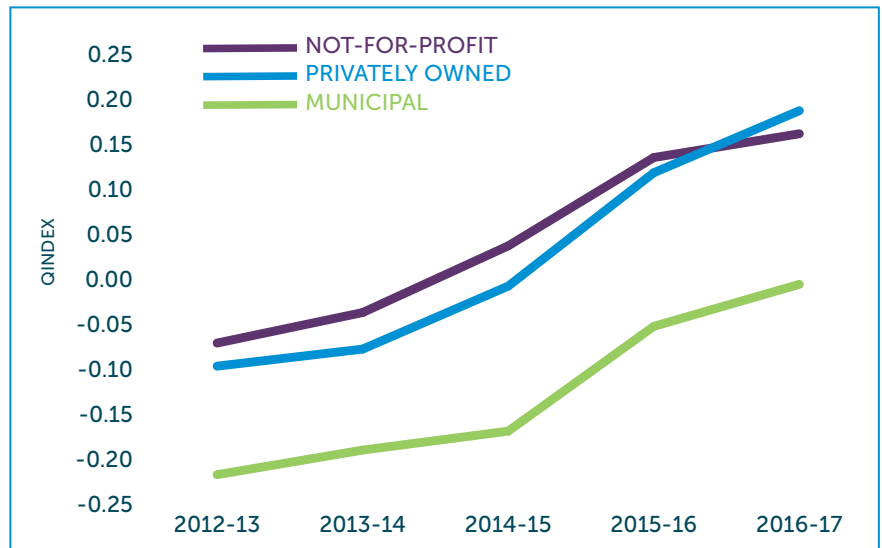


No differences in quality between privately owned and not-for-profit homes

About this figure: On average, there is no difference in quality of care between homes that are not-for-profit* or privately owned.

Although they too are improving, on average Ontario’s municipally run homes do not score as highly on quality of care as not-for-profit and privately owned homes.¹⁵

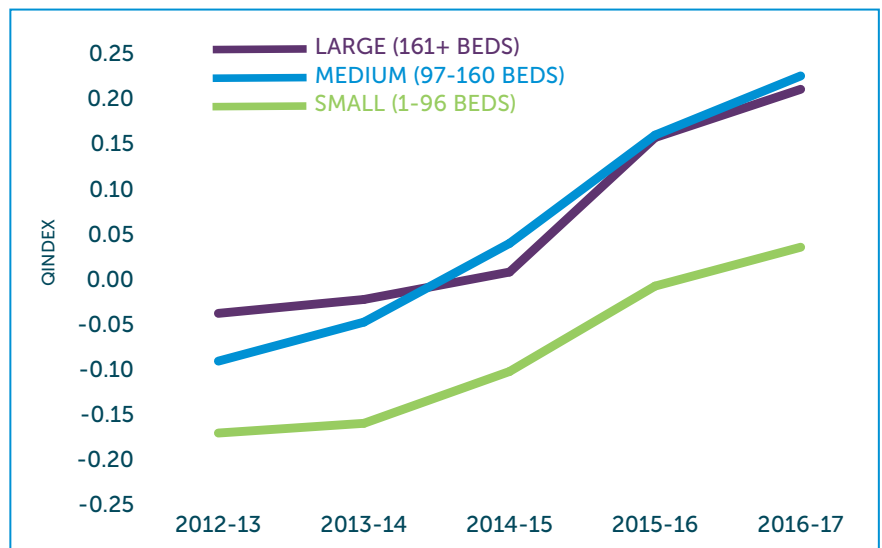
**includes homes with charitable designation*



Smaller homes need more support

About this figure: On average, small homes (96 beds or less) have significantly lower scores in quality of care.¹⁵ Although they are improving every year as well, they are not catching up to the gains in quality made by medium and large homes.

One reason may be staffing levels. The Ontario Long Term Care Association has asked the government for more funding for nursing and care staff in small homes, so that they can have a similar ratio of care staff to residents as larger homes.



How long-term care works

In Ontario, long-term care homes are regulated and funded by the provincial government. Government agencies determine who is eligible to be admitted to long-term care, and manage the wait lists.

Each home owner/operator is granted a license to operate by the provincial government. Homes are required to follow the requirements of the *Long-Term Care Homes Act*, one of the most stringent pieces of nursing home legislation in the world.

Long-term care funding

The provincial government provides funding for all the staff and supplies related to nursing and personal care, resident social and recreational programs and support services, and raw food (used to make meals).

In addition, long-term care homes receive other government funding for specific needs, such as falls prevention equipment.



Residents pay an accommodation fee to the long-term care home that is used to pay for expenses such as non-care staff, utilities, and mortgages, as well as building maintenance and major capital repairs (like a new roof).

The government sets the rate for resident fees and provides subsidies for residents as needed.

Long-term care homes account for every dollar



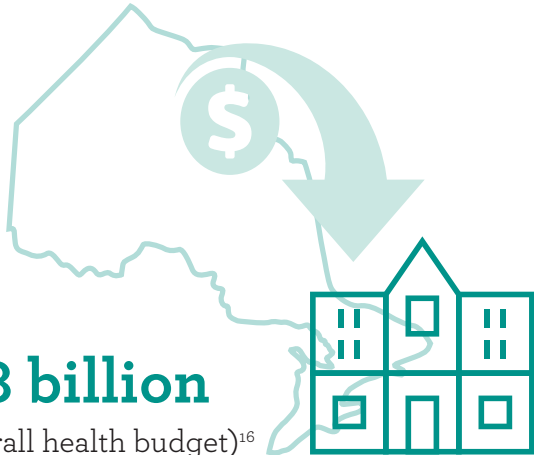
As part of their licensing agreement with the government, all funding provided to homes by the province must be rigorously accounted for, and can only be used for its specified purpose. Any unspent funds are returned to the government.

Funding from residents' fees is also accounted for, but the home is permitted to keep any surplus funds after expenses are paid.



Every long-term care home produces an audited annual report documenting the home's spending, which is then reviewed and audited again by the government. The final report is presented to each home's Residents' Council and Family Council and posted publicly in the home.

Provincial spending on long-term care



\$4.28 billion

(7% of overall health budget)¹⁶

Resident fees and other costs

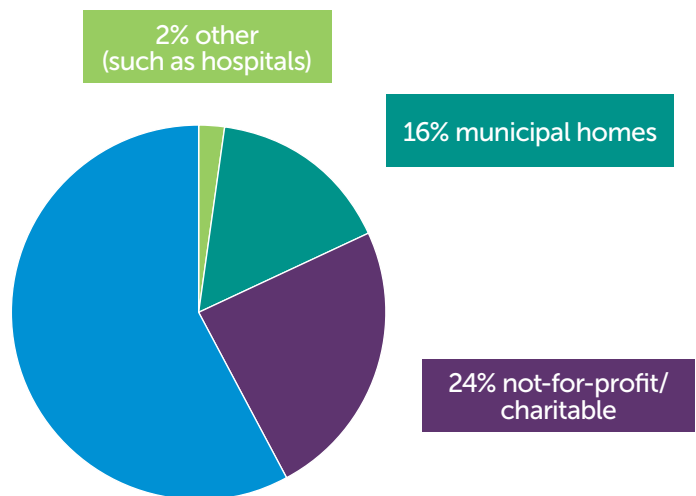
\$1,850 - \$2,640 per month, depending on whether the resident lives in a shared or private room, and whether it is a newer or older home.¹⁷

Residents also pay for services not covered by OHIP, such as dental care and transportation to outside appointments.

Who owns long-term care homes?

626 Long-term care homes in Ontario are owned and operated by individuals, family-owned businesses, private corporations, publicly traded companies, not-for-profits and charities, and municipal governments (municipalities are required by legislation to operate at least one long-term care home). Many homes are part of multi-home organizations, while others are stand-alone independent homes.¹⁸

58% privately owned



Rebuilding and renewing

300 homes renovated or rebuilt to current design standards by July 2025

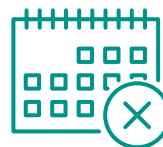
A program launched by the previous government provides funding to older homes to renovate or rebuild to modern design standards. **Almost half of the province's homes need to do this.** This funding has not been enough to cover the costs of rebuilding for many homes, and the current government is being asked to provide sufficient funding.

New homes built to modern design standards will have sprinklers in residents' rooms, more spacious common areas, and more private accommodations for residents.

This is particularly important for people with dementia, who can become easily stressed by incursions into their personal space.

Waiting for long-term care

35,000 people waiting for long-term care



Average wait time is about **5 months** (142 days). Some people wait much longer.¹⁸

Wait times vary based on the severity of the person's condition, the availability in a certain region, and whether the person wants to wait for a specific home. As of October 2018, there were nearly 35,000 people waiting in Ontario for a long-term care bed. The bottom line: **There simply aren't enough beds for the people who need them, something the government has recognized with its commitment for 30,000 more beds within the next decade.**

Supporting innovation

The way to meet the future needs of Ontario’s seniors is by evolving our current ways of doing business. Long-term care homes are actively driving innovation by leading and partnering to design and test new tools and technologies. These can improve quality of care and quality of life and reduce administrative tasks, giving staff more time to spend on resident care.

However, Ontario’s long-term care homes are one of the most heavily regulated, inspected, and controlled care settings in the world. This strict regulatory environment can make it very difficult for homes to try new ways of doing things.

Creating more flexibility in the existing regulatory and funding system — as well as providing new supports and encouragement for innovation — would allow more improvements to take flight. ●




Strategic Innovation Council


In 2017, the Ontario Long Term Care Association established a Strategic Innovation Council with thought leaders from academia, business, and government to look at what could be done to drive innovation in long-term care. The result was a dynamic 2018 report that is serving as a catalyst for innovation in the sector. *Accelerating Our Innovation Potential* is available at oltca.com. ●



What innovation can do

Innovation results in more effective, higher-quality care and quality of life. 

Residents’ and families’ expectations are higher, and innovations driven by empathy improve their experience. 

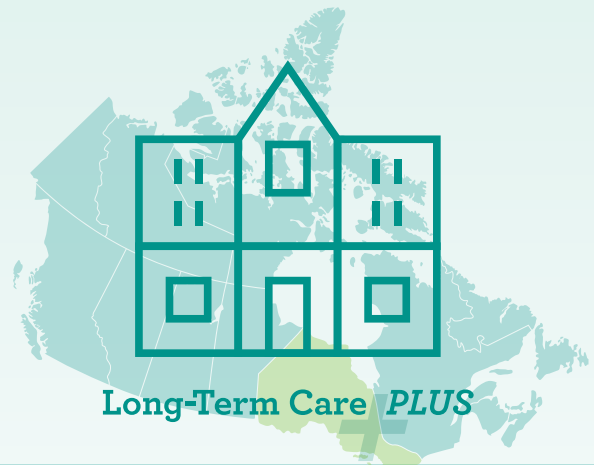
Health care dollars are tight, and innovation can find efficiencies.¹⁹ 

Long-Term Care Plus

A recent research study by the Ontario Long Term Care Association and the University of Toronto looked at several Ontario homes that are experimenting with new approaches to care that allow them to serve a broader population of seniors. These include seniors with psychiatric conditions whose care is too complicated for a traditional long-term care home to manage; seniors in the community with dementia who may be on the wait list for long-term care; and community seniors who need help accessing health care and support services.²⁰

This research is a first step in analyzing the potential of these new approaches and also the factors that have led to their success to date, such as strong leadership and additional funding.

For details and case studies, see the 2018 white paper, *Long-Term Care Plus: Realizing Innovative Models of Care for the Future*, available at oltca.com. ●



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About the Ontario Long Term Care Association

The Ontario Long Term Care Association is the largest association of long-term care providers in Canada and the only association that represents the full mix of long-term care operators — private, not-for-profit, charitable, and municipal.

The Association represents nearly 70% of Ontario's long-term care homes, located in communities across the province. Our members provide care and accommodation services to more than 79,000 residents annually.

For more information, please contact info@oltca.com.

Photo credits

The Association would like to thank the residents and staff of Kensington Health, the O'Neill Centre, and Trinity Village for the photos used in this report.



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