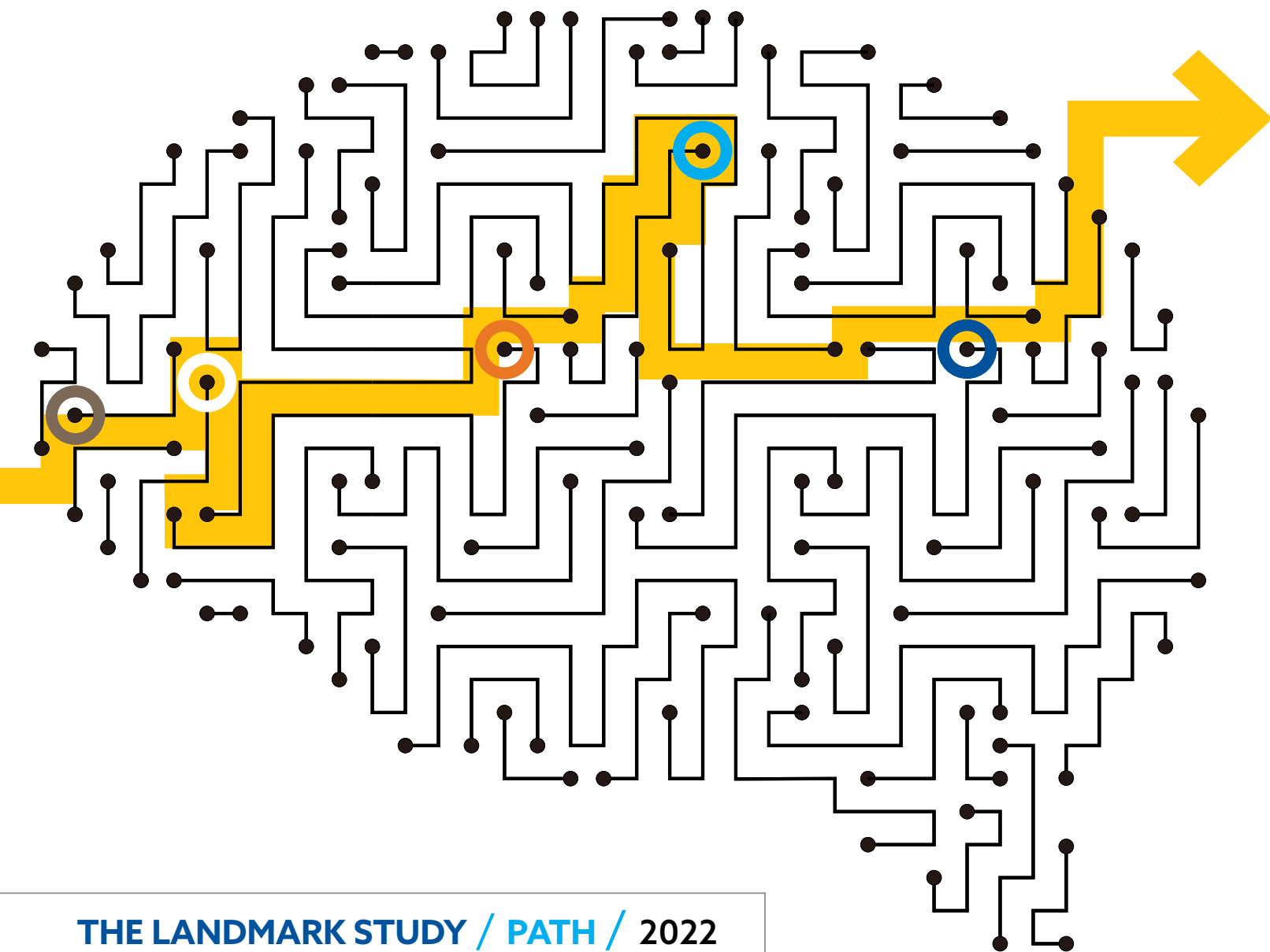


REPORT

1

NAVIGATING THE PATH FORWARD FOR DEMENTIA IN CANADA



THE LANDMARK STUDY / PATH / 2022

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The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society offers help for today through programs and services for people living with dementia and hope for tomorrow by funding research to find the cause and the cure.

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EXECUTIVE SUMMARY

In Canada, over 600,000 people from British Columbia to Nunavut to Newfoundland and Labrador are living with dementia. People who live with Alzheimer's dementia*, vascular dementia, and other forms of dementia (including young-onset dementia) and their family and friends are all deeply affected by the cognitive decline, memory loss, changes in mood and behaviour, and loss of functional abilities that can occur.

There is some hopeful news on reducing risk and delaying the onset of dementia. However, population aging in Canada means we will continue to see ongoing increases in the number of people affected by dementia. While we have made progress in the last decade to better address this brain condition, much more work needs to be done. With this report, we aim to achieve the following:

1. **Clarify the path forward.** The first objective of this report is to update public knowledge of dementia numbers across Canada and how we expect these counts to change over the next 30 years.
2. **Improve knowledge.** Dementia is a complex condition with many established risk factors. This report aims to break down the complexity and highlight key areas for risk reduction.
3. **Advocate for individuals, families, care partners, and service providers.** Most individuals who develop dementia do not face the challenge alone. Family, friends and neighbours often help support people living with dementia. The people contributing both formal and informal care need support and resources.
4. **Create action.** Inspire individuals, researchers, health-care providers, funding agencies, and the various levels of governments to support and work toward programs and policies that promote better brain health for all.
5. **Push for change.** There is a need for action: more dollars for research, changes to our care systems, recognizing and reducing discrimination, stigma and stereotypes, and implementing equitable solutions for the challenges that come with the onset of dementia.

** A note on word choice: "Alzheimer's disease" is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge. "Alzheimer's dementia" is the later stages of that same disease; during these stages, problems with thinking, memory, mood, behaviour and/or communication are evident.*

Data from the Landmark Study

The Landmark Study is a microsimulation study we undertook to project the number of people who will develop dementia over the next 30 years in Canada. The study uses the socio-economic statistical analysis platform from the Canadian Centre for Economic Analysis (CANCEA) to make these projections.

A microsimulation model is similar to the way simulation video games like SimCity work. Rather than setting up a city in a game and looking at how interactions and events occur over simulated time, our model uses publicly available data from Statistics Canada to create “agents” that are used as a statistical representation of persons living in Canada. Each agent is associated with several demographic characteristics, including age, sex, ethnicity and health status, which match those of the Canadian population.

The model can simulate the agents and their interactions over time as the agents age and pass through various health states, such as dementia diagnosis, risk factor exposure, hospitalization and death. This allows the model to provide estimates and forecasts of the rates of dementia in Canada over time and the care needs for people with dementia.

This model also lets us ask what might happen in Canada if the age at which dementia begins is delayed by 1, 5 or 10 years. This helps us understand the potential impact of effective dementia risk reduction efforts on a national level. More details about the methods of the Landmark Study model are found in the Appendix.

This report is the first of a series of three releases that will share our results.

In this first report, we cover the following areas:

- **Chapter 1:** The Current Direction of Dementia in Canada
- **Chapter 2:** The Need for Care—It’s Not an Individual Journey
- **Chapter 3:** The Power of Dementia Risk Reduction
- **Chapter 4:** Differences in Dementia Rates Across Regions of Canada
- **Chapter 5:** Finding the Best Path Forward

In the second report, we will provide additional focus on the people who will experience dementia in Canada over the next three decades:

- Differences between sexes
- Expected population shifts in the ethnicity of people living with dementia
- Young-onset dementia

In the final report, we will use the simulation model to examine the economic impact of dementia in Canada.



There is some hopeful news on reducing risk and delaying the onset of dementia. However, population aging in Canada means we will continue to see ongoing increases in the number of people affected by dementia.

The current direction of dementia in Canada

In 2020, it was estimated that there were 597,300 individuals living with dementia in Canada. By 2030, we can expect this number will reach close to 1 million. In terms of newly-diagnosed individuals per year—what epidemiologists call annual incidence—in 2020 there were 124,000 new cases of dementia diagnosed (10,333 per month; 348 per day; 15 every hour). By 2030, the annual incidence will rise to 187,000 new cases a year (15,583 per month; 512 per day; 21 every hour).

If we look further into the future, using the latest demographic trends from Statistics Canada combined with our Landmark Study model, we can also predict that the challenges that come with dementia in Canada will further intensify in the 2030s and 2040s. In terms of annual incidence, by the 2040s it is expected that over 250,000 individuals will develop dementia each year (20,833 per month; 685 per day; 29 every hour).

By 2050, the number of people living with dementia will almost triple the 2020 level, and over 1.7 million Canadians will be living with dementia.

The need for care—it's not an individual journey

Our study found that in 2020 there were 350,000 care partners for people with dementia. With an average of 26 hours of care per week, together this amounts to 470 million hours of care in a year. This number of hours is equivalent to 235,000 full-time jobs (40 hours per week with 2 weeks vacation)—a tremendous contribution of time and resources by care partners for people living with dementia in Canada.

If you translate these hours into dollar figures, even at a federal minimum wage of \$15.55 per hour, the care provided by family and friends is greater than \$7.3 billion dollars.

Our projections suggest that if not much changes in the current trends, by 2050 the number of care partners for people living with dementia will increase to over 1 million in Canada. This would be almost tripling (188% increase) the number of care partners over the 30-year period.

Given the large number of people living with dementia, and the level of care required, the number of hours provided by family could reach almost 1.4 billion hours annually by 2050. This is equivalent to over 690,000 full-time jobs.



The power of dementia risk reduction

The Landmark Study developed three hypothetical scenarios where the onset of dementia in Canadians was delayed by 1, 5 or 10 years. The goal of these scenarios is to demonstrate what the effect would be on the Canadian population if we were able to improve risk reduction efforts for dementia and delay its onset across our population.

All three hypothetical scenarios demonstrate the power of risk reduction. Even a delay of 1 year could result in almost 500,000 fewer new cases by 2050; this would make a huge difference in national dementia rates across the next three decades. If the onset of dementia could be delayed by 10 years, over 4 million new cases of dementia could be avoided by 2050.

Delaying the onset of dementia could also have an enormous impact on caregiving for people living with dementia in Canada. A 10-year delay could reduce the number of caregiving hours needed by almost 1 billion hours per year.



Differences in dementia rates across regions of Canada

All regions of Canada are expected to see an increase in the number of people with dementia if current trends continue. However, the growth in dementia cases will not be uniform across the country.

Dementia will affect the provinces differently over the next 30 years. Differences in age distributions, migration patterns, and the prevalence of risk factors combine to produce specific challenges, needs, and overall numbers of people living with dementia for each province. Unfortunately, insufficient data was available to study the Yukon, the Northwest Territories or Nunavut.



Finding the best path forward

Dementia will continue to be a growing issue in Canada, with the number of people living with some form of dementia projected to triple over the next 30 years. If current trends continue, all regions of the country will see a dramatic increase in the number of people with dementia and the demands placed on care partners.

While a cure or an effective treatment for dementia has not yet been discovered, a wide range of actions can be taken to optimize the dementia journey for people in Canada. The final chapter of the report highlights some of the actions that can lead to positive outcomes for people living with dementia and their care partners.

All people in Canada have a role to play in this challenge. As a result, recommendations in the report have been organized to address these perspectives: What can Alzheimer Societies do? What can health-care systems do? What can the federal, provincial/territorial and municipal levels of government do? What can researchers do? What can individual Canadians do? Across all of these lists, it is important that this work is done collaboratively with people living with dementia and their care partners.

ACKNOWLEDGEMENTS

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FOREWORD

Dr. Brian Goldman



Dementia is arguably the greatest health challenge of Canada's aging society. What makes it all the more daunting is not knowing the scale of the challenge and its impact on Canadians. The Landmark Study seeks to fill the data gap with a microsimulation study whose intent is to project the number of people who will develop dementia in Canada by the year 2050, and assess the impact of factors such as age, sex, ethnicity, health status and geography.

The numbers generated by this report are staggering.

By the year 2050, more than 1.7 million Canadians are expected to be living with dementia, with an average of 685 individuals being diagnosed each day. All told, that translates into an estimated 6.3 million Canadians diagnosed, living with and eventually dying of dementia over the next 30 years. Women with dementia will continue to outnumber men diagnosed with this condition. It's up to researchers to find out why.

The impact of dementia on Canada's health-care system will be huge. In Canada, family doctors and nurse practitioners are primarily responsible for diagnosing and providing health care for persons with dementia. If projections are correct, the demand for primary care services will grow even as fewer medical students are choosing family medicine as a career. Within the offices and clinics of primary care providers, patients with dementia will require a disproportionate share of their time. The provinces and territories need to incentivize family doctors and nurse practitioners to provide customized care to these highly complex patients.

It is imperative that we make our best efforts to delay the onset of dementia, if not prevent it outright. As the Landmark Study reveals, there are many things Canadians can do to improve their health and reduce the impact of dementia. These include being physically and socially active; following a healthy diet; challenging one's brain by engaging in games, reading, learning new languages, hobbies and skills; managing stress; quitting smoking; limiting alcohol consumption; and preventing head injuries by wearing a helmet. Canadians also need to partner with their health-care provider to manage blood pressure and diabetes.

The Landmark Study shows us how impactful these measures can be in aggregate. Delaying the onset of dementia by 1 year would avoid nearly 500,000 cases of dementia over the next 30 years in Canada. Delaying the onset by 10 years would effectively avoid more than 4 million cases.

Dementia has a disproportionate impact on loved ones. I know this personally because I helped care for my mother when she had dementia. Now, just eight years following her death, I have once again found myself providing essential care for a close family member. In the years ahead, I will not be exceptional. The Landmark Study reveals that by the year 2050, more than 1 million Canadians will serve as care partners to people with dementia. The care they provide will be equivalent to more than 1.4 billion hours per year or 690,000 full-time jobs.

Care partners, as the Landmark Study calls them, are often taken for granted by our society. To enable them to carry out the tasks expected of them, we need to support them financially and emotionally, and give them the training they need to do the work properly. Caregiving is stressful, which means we need to provide them with respite care as needed.

The Landmark Study gives us a roadmap to follow over the next 30 years. There is much that we can and should do to begin the journey.

Brian Goldman, MD

THE CURRENT DIRECTION OF DEMENTIA IN CANADA

By 2050, 1.7 million
Canadians will be
living with dementia,
almost triple the
number in 2020

In 2010, the Alzheimer Society of Canada produced the Rising Tide report, which brought attention to the dementia epidemic that was beginning to rise in the Canadian population. At the time, just under half a million people in Canada lived with Alzheimer's dementia* or other dementias, and many more family members, friends, and neighbours were being affected through their "informal" caregiving roles.

[The Rising Tide report](#) called for a national plan to prepare for and mitigate the challenge of dementia in Canadian society. In 2019, the federal government produced A Dementia Strategy for Canada. This strategy, along with its annual updates, can be found on the [Government of Canada website](#).

The federal dementia strategy has been a great step toward better managing dementia in Canada. But the findings of our new Landmark Study, some of which are detailed in this report, demonstrate that we must take further action now if we are to meet the challenge of the surge in dementia that has already begun in Canada.

The data suggests that:

- | | | |
|--|--|--|
| <ul style="list-style-type: none">● Every day in 2022, an average of over 350 people in Canada are diagnosed with dementia (from the Landmark Study findings). | <ul style="list-style-type: none">● For every person in Canada who has dementia, a family member or friend will spend an average of 26 hours a week caring for them. | <ul style="list-style-type: none">● Billions of dollars are spent on health-care costs and out-of-pocket individual and care partner expenses in supporting people living with dementia in Canada. |
|--|--|--|

** A note on word choice: "Alzheimer's disease" is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge. "Alzheimer's dementia" is the later stages of that same disease; during these stages, problems with thinking, memory, mood, behaviour and/or communication are evident.*

Additional gaps show that:

- We have an incomplete understanding of risk and protective factors for dementia development and the progression of dementia—more needs to be done. This is especially important as there is no known cure for dementia.
- The home care and long-term care systems in Canada are already under strain and facing multiple crises, with urgent need to remodel dementia care.
- While many care partners report the positive aspects of providing care, care partners of all ages and types (spouses, children, friends, neighbours) too frequently experience challenges, including financial hardship, burnout, depression and isolation.

Based on projections from the Landmark Study, the impact of these challenges will grow—not only in the number of people experiencing them, but also in their severity. Canada’s health-care and long-term care systems are already struggling, and the expected rise in the number of Canadians affected by dementia will exacerbate these difficulties. COVID-19 highlighted some of the pre-existing challenges in these systems, which will only increase if we continue to do things as we have done in the past (e.g., underfunding health care).

Although we have a better sense of risk factors for dementia than we did 10 years ago, the social will, social action, and social support needed to act on this knowledge are still lacking. We expect that this report will make a further case to encourage change.



What is dementia?

Dementia is a word that describes a set of symptoms caused by specific disruptions to healthy brain functioning that reduce a person’s ability to perform everyday activities. These symptoms can include (but are not limited to) memory loss, difficulties with attention, problem solving and language; changes in mood and behaviour; and issues with vision, balance, and movement. There are several different subtypes of dementia. Some of the more commonly seen types are outlined in **Box 1**. We now know that many people with dementia often have features of more than one type.

What’s the difference?

Alzheimer’s disease

“Alzheimer’s disease” is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication or behaviour emerge.

Alzheimer’s dementia

“Alzheimer’s dementia” is a later stage of that same disease; during this stage, problems with thinking, memory, mood, behaviour and/or communication are evident.

Box 1. Types of dementia

	DEMENTIA TYPE	DESCRIPTION
1	ALZHEIMER'S DEMENTIA	Alzheimer's dementia is the result of damaged brain cells causing thinking and memory to worsen over time. It is often considered the most common type of dementia and its hallmark brain changes include amyloid plaques and neurofibrillary tangles.
2	VASCULAR DEMENTIA	Vascular dementia happens when the brain's blood supply is blocked or damaged, causing brain cells to be damaged too. This leads to problems with thinking and moving. This is considered the second most common type of dementia after Alzheimer's dementia.
3	FRONTOTEMPORAL DEMENTIA	Frontotemporal dementia is a group of rarer disorders that usually begin by affecting the frontal and temporal areas of the brain. Initial symptoms involve changes in personality and behaviour, or changes in language comprehension or expression, but other changes, including problems with movement, can occur later.
4	LEWY BODY DEMENTIA	Lewy body dementia is caused by abnormal deposits of the protein alpha-synuclein called "Lewy bodies" inside the brain's nerve cells. Lewy body dementia shares many features with Parkinson's disease and can arise in persons with established Parkinson's disease.
5	MIXED DEMENTIA	The term "mixed pathologies" is used when multiple factors appear to be contributing to a person's dementia. When this happens, it is known as mixed dementia. The older someone is, the more likely it is that multiple disease processes in their brains are leading to their dementia symptoms.
6	YOUNG-ONSET DEMENTIA	This term is used when dementia occurs in people under the age of 65. Middle-aged (and even younger) adults can develop dementia due to various disorders, including Alzheimer's disease. These types of dementia are more likely to be genetic.

While age is the primary factor associated with the onset of dementia, dementia is not a normal part of aging. Many people experience some cognitive changes as they get older, but only a small percentage develop dementia that progresses from mild to severe over a number of years. Nonetheless, Canada’s population is quickly aging—in just 5 years (2016 – 2021), the percentage of Canadians over the age of 65 rose from 16.9% to 19.0% (Statistics Canada, 2022a). We can expect a corresponding rise in the number of older adults experiencing some form of dementia.

We still have an incomplete understanding of the mechanisms that lead to dementia, but researchers have pinpointed several risk factors that increase the chance that someone will develop dementia. Importantly, some factors can be changed or modified to delay or reduce the risk of developing dementia. These factors affect people differently across their life course (i.e., from birth to middle age to older age). Select examples are listed in **Box 2**.

Box 2. Select risk factors for dementia

RISK FACTORS THAT CANNOT BE CHANGED		
● Age ● Sex ● Genetics		
RISK FACTORS THAT CAN BE CHANGED OR MODIFIED		
EARLY LIFE (UP TO AGE 45)	MIDLIFE (AGE 45 TO 65)	LATER LIFE (AGE 65 AND OLDER)
● Less education is associated with greater risk of dementia	● Hypertension ● High alcohol intake ● Obesity ● Hearing loss ● Traumatic brain injury	● Smoking ● Depression ● Social isolation ● Physical inactivity ● Air pollution ● Diabetes

Note: Risk factors are organized by whether they can be modified and evidence of effects across the life course. Information is from the 2020 report of the Lancet Commission on dementia prevention, intervention, and care (Livingston et al., 2020).

Of the list of risk factors for dementia, age remains the most important. While it is not considered a direct cause of dementia, it is closely associated with risk of dementia onset. For example, most (but not all) people who develop dementia are over the age of 65. After the age of 65, the risk of dementia approximately doubles every five years. After the age of 85, nearly one in every four Canadians has been diagnosed with dementia.

As expected, with the size of our older population increasing quickly, population aging plays a strong role in what the Landmark Study projects for the expected number of people living with dementia in Canada over the next 30 years.

A million Canadians with dementia by 2030

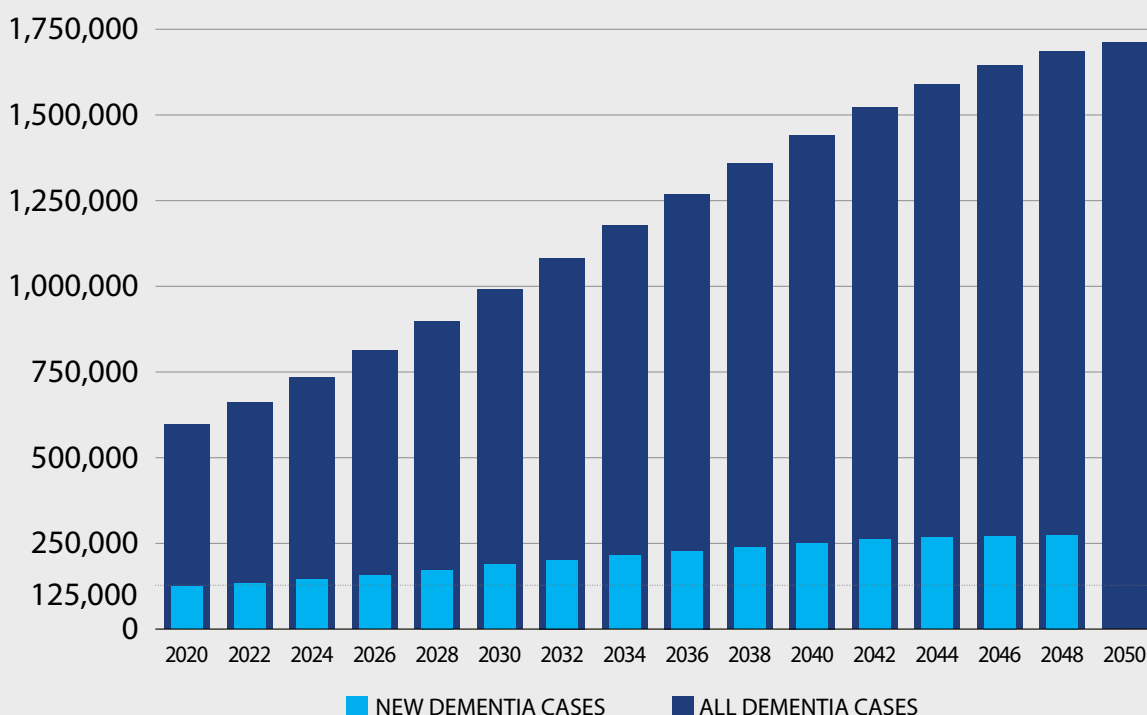
In 2020, it was estimated that there were 597,300 individuals living with dementia in Canada. By 2030, we can expect this number will reach close to 1 million (Figure 1). In terms of new cases per year—what epidemiologists call annual incidence—in 2020 there were 124,000 new cases of dementia diagnosed (10,333 per month; 348 per day; 15 every hour). **By 2030, the annual incidence will rise to 187,000 new cases a year (15,583 per month; 512 per day; 21 every hour).**

These expected changes mean that, compared with 2020 numbers, **by 2030 we can expect a 51% increase in the number of new cases per year and an overall increase of 65% in the number of Canadians living with dementia (597,300 → 990,600).**

These short-term estimates for higher numbers of individuals living with dementia in 2030 indicate a pressing need to increase levels of health and social care—by our health and long-term care systems, home care, and family/friend care partners. Can our current systems handle this increase? How can we best meet this challenge across these levels of care?

We hope that the Landmark Study will inspire both immediate and long-term actions to meet the needs of the growing number of people in Canada living with dementia.

Figure 1. Number of people living with dementia and the number of new cases of dementia per year in Canada, 2020 to 2050



20,000+ Canadians will be diagnosed every month in the 2040s

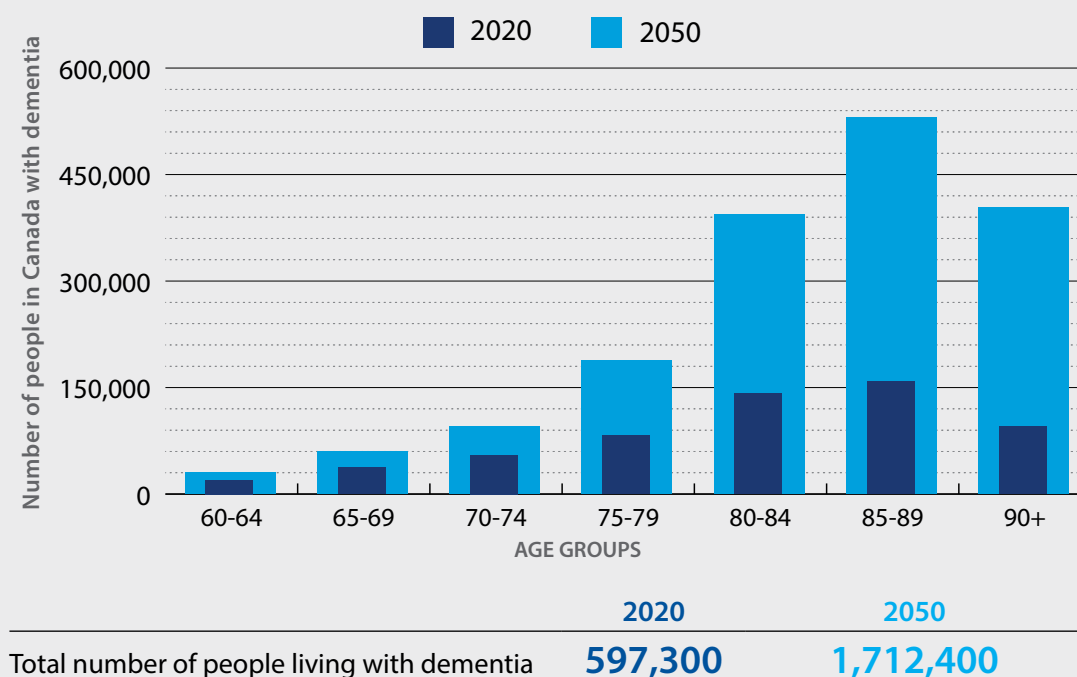
If we look further into the future, using the latest demographic trends from Statistics Canada combined with our Landmark Study model, we can also predict that the challenges that come with dementia in Canada will further intensify in the 2030s and 2040s.

In terms of annual incidence, **by the 2040s it is expected that over 250,000 individuals will develop dementia each year (20,833 per month; 685 per day; 29 every hour).**

By 2050, the number of people living with dementia will almost triple the 2020 level, and over 1.7 million Canadians will be living with dementia (Figure 1).

While about 1.6% of the Canadian population in 2020 had dementia, this number is expected to increase to 3.6% by 2050. Over this 30-year period, over 6.3 million individuals would develop dementia (Table 1).

Figure 2. Number of people in Canada with dementia by age group, 2020 and 2050



Note: People under age 60 can also develop dementia. This topic will be covered further in the second report from the Landmark Study.

Table 1. Estimates for the total number of new cases of dementia by decade in Canada, 2020–2049

	2020 – 2029	2030 – 2039	2040 – 2049	TOTAL NEW CASES
NEW CASES	1,495,300	2,167,300	2,665,600	6,328,200

Increasing age is the primary risk factor for dementia

The increasing number of people in Canada living with dementia is primarily a function of an aging population. Dementia will steadily become more common as the “baby boomer” cohort (the large group of people born between 1946 and 1965) ages into their eighties and nineties.

In 2020, 8.4% of Canadians over 65 had some form of dementia. By 2050, when all the surviving baby boomer generation is 85 or older, the percentage of Canadians over 65 living with dementia is expected to increase to 13.2% (**Table 2**).

The largest estimated increases in dementia are in the older age groups, with the number of people over 85 with dementia expected to increase almost 30% faster than the overall number of cases in the population. According to the latest Statistics Canada reports (2022a), the number of Canadians over the age of 85 is expected to triple by 2046, which directly relates to some of the projections made by this study. **Figure 2** shows a comparison of dementia numbers for 2020 with expected numbers for 2050, according to different age groups.

Table 2. Estimates of the number of people age 65+ in Canada with dementia by sex, 2020 to 2050

YEAR	NUMBER OF PEOPLE (65+)					% OF POPULATION (65+)		
	FEMALE	MALE	TOTAL	FEMALE %	MALE %	FEMALE	MALE	TOTAL
2020	352,300	217,300	569,600	61.8%	38.2%	9.7%	6.9%	8.4%
2030	592,700	363,200	955,900	62.0%	38.0%	11.1%	7.8%	9.6%
2040	880,700	523,000	1,403,700	62.7%	37.3%	14.0%	9.8%	12.1%
2050	1,053,200	616,000	1,669,200	63.1%	36.9%	15.3%	10.6%	13.2%
INCREASE FROM 2020	700,900	398,700	1,099,700	1.3%	-1.3%	5.6%	3.7%	4.8%

Alzheimer's dementia will remain the most common dementia

Alzheimer's dementia will continue to be the dominant type of dementia in Canada in the coming decades, with over 1.1 million people affected by 2050. Projections of people living with vascular dementia have been estimated to be 460,000 in 2050, while 300,000 people are forecast to live with other forms of dementia by 2050 (Table 3).

We know that multiple diseases or conditions can affect the brain at the same time, resulting in what is called “mixed dementia.” Many scientists think mixed pathologies are truly the most common cause of dementia.

Often, an older adult's brain might have the neurofibrillary tangles and amyloid plaques typical of Alzheimer's dementia, but their brain may also show evidence of blood vessel damage, stiff and clogged arteries, changes to the white matter, cell loss, and accumulation of various other abnormal proteins. These “mixed pathologies” would be associated with both Alzheimer's dementia and vascular dementia.

Determining the type of dementia a person might have by looking at physical changes in the brain is complex. This is especially true in the oldest groups of people; for them, many types of symptoms and injuries to brain structures have had time to accumulate.

Researchers are working on this problem by using ever-improving imaging technologies to examine the brains of people living with dementia, and by studying the brains of people that have been donated for scientific research after they have died. With these approaches, among others, researchers will continue to grow our understanding of how a brain can become damaged—and how such damage might relate to the symptoms and signs of dementia.

Table 3. Estimates for the number of people with dementia by type, 2020 and 2050

YEAR	ALZHEIMER'S DEMENTIA	VASCULAR DEMENTIA	OTHER DEMENTIA
2020	368,200	156,400	116,800
2050	1,116,600	458,800	300,300
INCREASE FROM 2020	203%	193%	157%

Note: A person may have multiple types of dementia, so the sum of the individual types will be more than the total number of people with dementia.

More females than males are living with dementia

The number of females experiencing dementia is projected to continue to be significantly greater than the number of males (**Figure 3**). In 2020, an estimated 61.8% of persons living with dementia (352,000) in Canada were female. This gap between the sexes is projected to grow slightly to 63.1% in 2050.

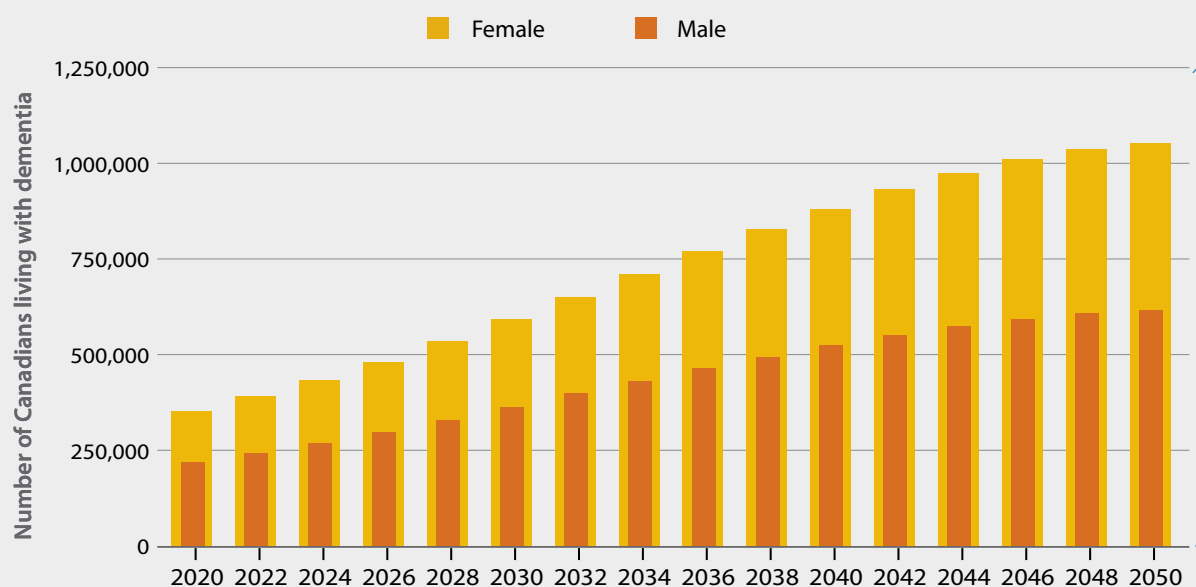
Canada isn't alone in this trend. When we look at dementia rates from around the world, women experience dementia more often than men by a considerable margin.

Women tend to live longer than men and increased age leads to an increased risk of dementia, but other factors are also likely contributing. These include biological factors such as sex differences in hormones; brain structure; health conditions causing inflammation; genetics; and frailty, which also tends to be higher in women than in men (Andrew & Tierney, 2018).

Further, this divide in dementia risk between the sexes may be driven by other factors: sex differences in cognitive abilities on the standard clinical tests used to diagnose dementia; gendered social roles that influence how clinicians judge losses of abilities; and different opportunities in education and occupation throughout the life course.

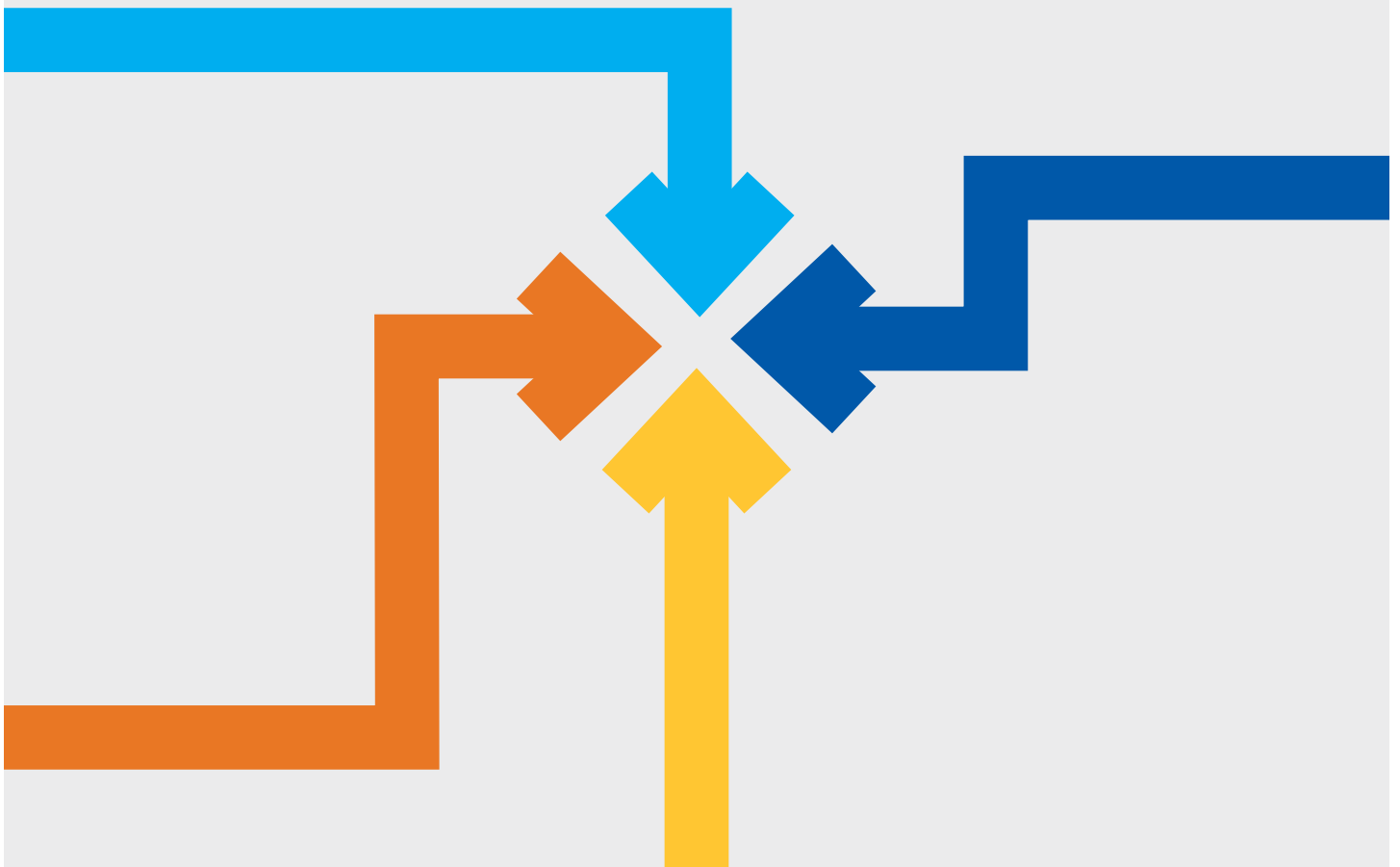
These sex and gender differences are further complicated when these factors interact and change as people get older. Much more attention to sex and gender differences in dementia is needed if we are to fully understand dementia and improve our ability to address it for all Canadians. As the number of Canadians living with dementia increases, it will become of growing importance to address other population diversity—socio-economic status, race, ethnicity, language and disability. Further to this point on diversity, dementia research and the current available services are also lacking when it comes to many minority groups in Canada.

Figure 3. Number of people with dementia in Canada by sex, 2020 to 2050



THE NEED FOR CARE—IT'S NOT AN INDIVIDUAL JOURNEY

By 2050 the number of care partners for people living with dementia could increase to over 1 million in Canada if current trends don't change.



In Canada, most people living with dementia reside at home. In 2015 and 2016, 69% of seniors with dementia under the age of 80, and 58% of those over 80, lived in the community and outside of the long-term care systems (Canadian Institute for Health Information [CIHI], 2018a).

Most older adults in Canada want to maintain their independence and remain in their communities for as long as possible. But people living with advancing dementia often cannot manage their lives on their own. In addition to the care provided by health and social care professionals (including the Alzheimer Societies), most people with dementia living at home will rely on the care and support of care partners. These family members, friends and other volunteers who support the person living with dementia are commonly referred to as “informal caregivers.” This term is used because informal caregivers are not paid while providing this support.

Due to the progressive nature of most dementias, people with dementia who live at home will eventually need increasing levels of medical and social support, which may ultimately present challenges to their family and friends who act as care partners. Canadian statistics (CIHI, 2018b) have shown that for people living with dementia:

- 1 in 4 require a lot of help for activities of daily living (e.g., eating, dressing, personal hygiene)
- 1 in 4 exhibit various behavioural changes (e.g., anger, delusions, getting lost, restlessness, hallucinations, paranoia)
- 1 in 4 have symptoms of depression
- 1 in 4 were admitted to hospital at least once in the last three months
- 1 in 5 have been to an emergency room in the last three months



Who are care partners?

Care partners are family members, neighbours or friends who provide ongoing care to another person in need of support.

Most care partners for persons living with dementia are adult children. Of those providing dementia care in the home, 58% are children and 32% are spouses, while the remaining 10% include other family, friends or community members (CIHI, 2018b). Statistics also show that women do the majority of the unpaid caregiving for people living with dementia (Statistics Canada, 2022b).

The role of care partners for people with dementia

Care partners for people with dementia provide an average of 26 hours of caregiving per week compared to 17 hours per week for older adults with other health issues (CIHI, 2018b). The number of care hours is related to the severity of the dementia, caregiver characteristics, and changes in mood, personality and behaviour. These factors are also related to medical care costs and costs to society as a whole (Angeles et al., 2021).

Areas of care that are commonly done by care partners can include:

- assistance with everyday activities (like household chores, meals and personal hygiene)
- support for medical care (such as arranging, coordinating and attending appointments; dispensing medications)
- supporting changes in mood, personality and behaviour that can occur for some people living with dementia
- providing psychological support, companionship, and advocacy in general

Further details for these types of supports can be found in Table 4.

Care partners for people with dementia provide an average of 26 hours of caregiving per week compared to 17 hours per week for older adults with other health issues (CIHI, 2018b).

Every care partner comes to their role with different resources, skills and needs. And the role of the care partner changes across the different stages of dementia (Huang et al., 2015). Changes occur in various ways:

- types of activities of support
- alignment of knowledge and skills with the activities and challenges of care
- volume of care and support provided
- amount of pressure, stress, and tension

Care partners who are family members or friends, many of them women in the middle stages of their lives, may step away from their jobs, lose out on career transitions, and miss out on time with their children and spouses to care for the person living with dementia.

Middle-aged Canadians who find themselves caring for an aging parent with dementia while still raising their own children are commonly described as the “Sandwich Generation”—a whole generation caring for both the young and the old. Having the responsibility to care for both your children and your parents can lead to care partners feeling overwhelmed, stressed, and at a higher risk for burnout. Perhaps a better term for this group might be “Squeezed Generation,” as those with aging parents and young children must cope with the heavy pressure of trying to manage everyone’s needs, often contributing to their own health problems and burnout.

Table 4. Types of support provided by care partners

TYPE OF SUPPORT	DETAILS
Assistance with day-to-day core activities (i.e., instrumental activities of daily living)	Helping with household chores, shopping, preparing meals, transportation, medical appointments, finances, legal affairs, managing medications, and communication.
Assistance with self care activities (i.e., activities of daily living)	Helping with bathing, dressing, grooming, meals, walking, standing up or moving between bed and chair, toileting, and managing incontinence.
Managing support and home care services	Finding and using support services (e.g., day programs, art and music therapy), hiring and supervising others who provide support (personal support workers), and making arrangements for home care services.
Supporting changes in mood, personality and behaviour	Supporting changes in mood, personality and behaviour, including getting lost, depression, frustration, anxiety, repetitive activity and nighttime/ sleep disturbances.
Other types of support	Conducting overall household management; navigating family issues; managing other diseases or health issues; providing companionship, emotional support, social support, and other health-care support.

Note: This list does not include all responsibilities of care partners which may include their employment, taking care of children, and maintaining their own health and well-being.

Care partner health and stress

While many care partners find their experiences rewarding, it is also important to recognize that the caregiving role can have a negative impact on the health and quality of life of the care partner.

Studies have shown that caring for a person with dementia can be more stressful than caring for a person with a physical disability (Ory et al., 1999). Care partners often become secondary patients due to the risks to both physical and emotional health that can come with providing hours of care for a family member or friend with dementia (Richardson, 2013; Zhu et al., 2014).

Data from the Canadian Institute for Health Information (2018b) reports that:

- 45% of care partners providing care to people living with dementia exhibit symptoms of distress. This is almost twice the rate compared to care partners of older adults with health conditions other than dementia (26%).
- 21% of care partners feel unable to continue their caring activities due to stress.

The factors that are associated with care partner stress vary across individuals as well as across the progression of dementia (Bergvall et al., 2011; Pinquart & Sorensen, 2003). These factors can include:

- the number of hours of care provided
- the severity of personality, mood or behaviour changes of the care recipient
- the health status of the care provider and their external circumstances or stressors
- the level of dependence for completing functional activities of the care recipient
- the severity of cognitive impairment of the care recipient

Looking ahead with the Landmark Study, the increased number of people living with dementia will lead to a demand for an increased number of dementia care partners—this will add additional stress to the health-care system as many care partners are challenged to maintain their own health as well as that of the person they support.

Informal caregiving equals 235,000 unpaid full-time jobs

Our study found that in 2020 there were 350,000 care partners for people with dementia. With an average of 26 hours of care per week, together this amounts to 470 million hours of care in a year. **This number of hours is equivalent to 235,000 full-time jobs (40 hours per week with 2 weeks vacation)—a tremendous contribution of time and resources by care partners for people living with dementia in Canada.**

If you translate these hours into dollar figures, even at a federal minimum wage of \$15.55 per hour, the care provided by family and friends is worth greater than \$7.3 billion dollars.

Of these care partners, approximately 54% were women. There was considerable variation in age groups:

- 12% were over 65
- 44% were 45–65
- 14% were 35–45
- 30% were under 35

Many working-age adults are providing care to persons living with dementia (307,000 under the age of 65 in 2020). With an average number of 26 hours per week spent caregiving, this role clearly affects a care partner's ability to fully participate in the workforce and represents a large economic impact in Canada.



Over 1 million care partners for people living with dementia by 2050

Our projections suggest that if not much changes in the current trends, by 2050 the number of care partners for people living with dementia will increase to over 1 million in Canada. This would be almost tripling (188% increase) the number of care partners over the 30-year period. (For more details, refer to Table 5.)

In the next 30 years, we expect a large increase in the number of middle-aged people (age 45–65) caring for people living with dementia. In 2020, the estimated number of care partners age 45 to 65 was 155,000. By 2050, this number is expected to almost triple to 449,000, an increase of 190% (Figure 4).

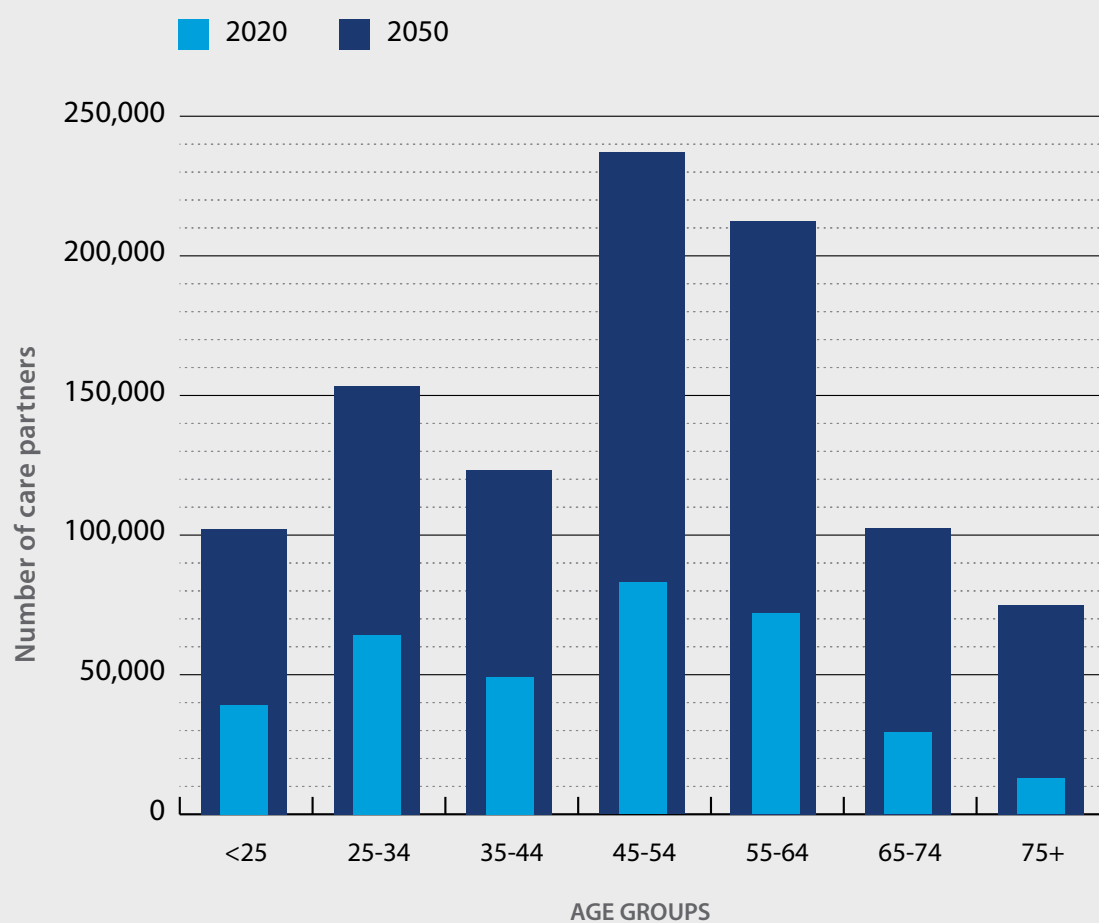
This large increase in the need for middle-aged care partners will have a direct impact on the workforce in Canada and on the Canadian economy. Both the health and careers of many care partners across Canada will be affected by dementia if the current trends prevail.

In addition to the growing impact on middle-aged Canadians, there is also an expected increase in older age groups where partners are providing care to their spouses while managing their own health challenges as they get older. This can lead to increased stress and exacerbation of the care partner's own health issues (Statistics Canada, 2020). A growing number of care partners are also younger than 35. For them, dementia caregiving may coincide and compete with completing secondary or post-secondary education, launching a career, and starting a family.

Table 5. Number of care partners for people living with dementia in Canada, 2020 and 2050

YEAR	NUMBER OF CARE PARTNERS		
	MALE	FEMALE	TOTAL
2020	160,200	189,400	349,600
2050	467,100	538,800	1,005,800
% INCREASE BY 2050	192%	184%	188%

Figure 4. Age distribution of care partners for people living with dementia in Canada, 2020 and 2050




Unpaid caregiving impact equal to 690,000 full-time jobs in 2050

Given the projected increases in the number of people living with dementia, and the level of care required, the number of hours provided by family and friends could reach almost 1.4 billion hours annually by 2050 (Table 6). This is equivalent to over 690,000 full-time jobs.

Since we depend so much in Canada on these care partners, we must optimize available resources and supports so they can best manage the role they have taken on. This support is the responsibility of everyone, from health-care providers to Alzheimer Societies and all levels of government.

Table 6. Number of caregiving hours for people living with dementia in Canada, 2020 and 2050

YEAR	NUMBER OF CAREGIVING HOURS		
	MALE	FEMALE	TOTAL
2020	194,000,000	278,600,000	472,600,000
2050	579,900,000	805,800,000	1,385,700,000
% INCREASE BY 2050	199%	189%	193%



THE POWER OF DEMENTIA RISK REDUCTION

If the onset of dementia could be delayed by 10 years, over 4 million new cases of dementia in Canada could be avoided by 2050.

Dementia is often described as a public health challenge about which nothing can be done because it is due to the aging of the population—but this is false. Research has demonstrated that there are actions that can be taken that may help reduce the risk of developing dementia. While some risk factors like age, sex at birth and genetics cannot be changed, others can. These are known as modifiable risk factors.

Non-modifiable risk factors for dementia are factors that may increase your chance of developing dementia and that cannot be changed. Examples include age, sex at birth, and genetics. Age is the strongest known risk factor for dementia. Females are at an increased risk of developing dementia, and there are at least 75 genes that are associated with an increased risk of developing Alzheimer's dementia* (Bellenguez et al., 2022).

Modifiable risk factors include a range of lifestyle or behavioural factors (diet, exercise, social activities), as well as heart health, intellectual activities, and protecting your brain from injuries that can help reduce the risk of developing dementia. While we might not be able to cure dementia in the near future, by reducing lifetime exposure to modifiable risk factors we may be able to delay or even prevent dementia from occurring in many people.

The 2020 report of the Lancet Commission on Dementia Prevention, Intervention, and Care identified 12 modifiable risk factors that account for about 40% of dementia worldwide (Livingston et al., 2020). The report's authors also took a life-course approach to identify specific actions that can be done over a lifetime. Examples of these actions are outlined in Figure 5.

In the past decade, we have seen further progress in our understanding of the risk factors for dementia. The evidence clearly suggests that the risk for late-life cognitive decline and dementia can be addressed by preventative actions. The list of modifiable risk factors continues to grow with new research, yet significant gaps in knowledge remain, including differences across geographic locations, ethnic and cultural diversity, changes across the life course, biological mechanisms, and interactions between factors (Anstey et al., 2020). Newer risk factors not included in earlier papers include sleep disturbance, atrial fibrillation, anxiety, cancer, carotid atherosclerosis, inflammatory markers, metabolic syndrome, peripheral artery disease, renal disease, serum uric acid, stroke, and pesticides (Anstey et al., 2019).

While there is a growing list of risk factors that can be labelled as modifiable, many Canadians may not be able to make these positive changes due to their personal situation and resources. These factors are only truly modifiable if the proper supports are provided by our communities, public health agencies, and other governmental organizations.

* **A note on word choice:** "Alzheimer's disease" is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge. "Alzheimer's dementia" is the later stages of that same disease; during these stages, problems with thinking, memory, mood, behaviour and/or communication are evident.

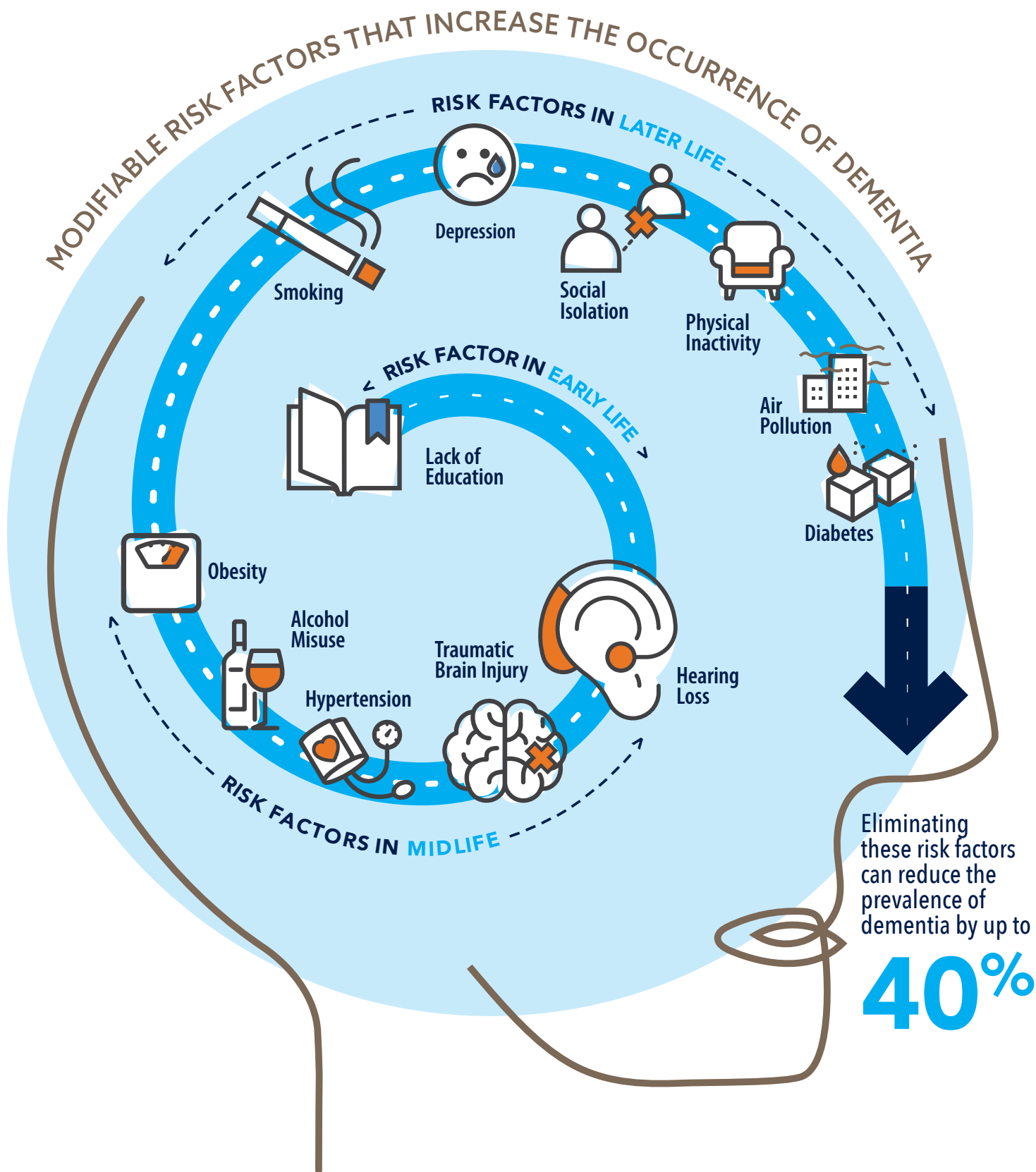


Figure 5. The twelve modifiable risk factors shown above contribute to increased dementia risk (Livingston et al., 2020). Addressing these modifiable risk factors can reduce the prevalence of dementia in Canada.

Studies have demonstrated that the more health deficits you have, the higher the risk for developing dementia. This line of research shows that a person's overall health (and frailty level) is important to consider in understanding their dementia risk.

Combinations of risk factors tend to increase with age

Many of the risk factors associated with dementia onset are also closely tied to aging. As people grow older, they are at higher risk of developing a wide range of health issues, many of which have been linked to an increased risk of dementia.

In fact, dementia seldom travels alone; health conditions often occur together as people get older. In other words, “the problems of old age come as a package” (Fontana et al., 2014). This is demonstrated by the common occurrence of multimorbidity—the presence of more than one chronic condition—in older Canadians. Using data from the Canadian Chronic Disease Surveillance System, analysts have demonstrated that over 50% of Canadians over the age of 70 have two or more chronic conditions.

Scientists have only just begun to study how having multiple risk factors raises the chance of developing dementia rather than just examining individual factors on their own. A 2019 study that reviewed the current scientific literature demonstrated that having three or more risk factors doubles the risk of developing dementia (Peters et al., 2019). The evidence that overlapping or multiple risk factors further raises dementia risk is very strong. If the goal is to minimize dementia risk for an individual, all risk factor exposures must be minimized across their lifetime.

Researchers are also understanding more about the relationship between frailty and dementia. “Frailty” is used to describe a state of vulnerability when faced with a stressor. Frailty increases with the accumulation of multiple health deficits that can occur as we age. These deficits include symptoms, abnormal laboratory values, disease states, and disabilities (Clegg et al., 2013).

Studies have demonstrated that the more health deficits you have, the higher the risk for developing dementia (Ward et al., 2022). This line of research shows that a person's overall health (and frailty level) is important to consider in understanding their dementia risk.

Recent research has begun to examine how overall health and frailty may be linked to a person's ability to withstand changes in the brain that come with aging. This is an active area of research that may lead to a better understanding of brain health and resiliency in relation to Alzheimer's disease.

Promoting brain health

Brain health is related to both the integrity and biological functions of the brain, and also to the mental and cognitive functions that the brain produces (Stern, 2012). With aging, brains have to cope with numerous biological challenges that come from use over the years, along with a range of neurological disorders that can arise with time.

In contrast to the risk factors outlined above, epidemiological studies have found that there are also “protective factors” when it comes to dementia risk. These factors include a range of healthy habits that have been shown to reduce the risk of cognitive decline and dementia through actively influencing brain health.

Having more education, being physically active, staying connected with social activities, and eating healthy are just a few of the ways to improve brain health and protect against dementia risk. Refer to **Box 3** for additional actions that can be taken to improve brain health.



Reducing more than one risk factor is key

Many researchers recommend multimodal interventions as the most likely way to delay the onset of dementia.

Multimodal interventions do not focus on just a single risk factor or one aspect of a person’s life. Instead, they work to address multiple risk factors for dementia in a single health promotion program.

One leading example of this work is the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (Ngandu et al., 2015). Researcher Miia Kivipelto and their team found success by creating an intervention that addressed diet, exercise, cognitive training and vascular risk monitoring. They found that this approach could improve or maintain cognitive functioning in older adults.

Based on the success of this research, a global network of 16 similar projects has been developed. Here in Canada, we have CAN-Thumbs Up—The Canadian Therapeutic Platform Trial for Multidomain Interventions to Prevent Dementia. The Alzheimer Society partially funded this work which is focused on lifestyle and dementia risk factors in the Canadian context. Recruitment began in 2022 for their Brain Health Support Program Intervention, and more information can be found on the Canadian Consortium on Neurodegeneration in Aging website (ccna-ccnv.ca).

Box 3. Twelve actions for a healthier brain at any age

- 1** **Be physically active each day.** Reduce sedentary time and move more. This can include all types of physical activities, including walking, running, weightlifting, gardening, yoga, tai chi, swimming, dancing, biking, team sports and yard work.
- 2** **Protect your heart.** Monitor your blood pressure, cholesterol and diabetes closely. What's good for the heart is also good for the brain.
- 3** **Stay socially active.** Make sure to be engaged with friends and family. Maintain your social network and stay connected.
- 4** **Manage your medical conditions.** Keep on top of your overall health. This is directly linked to your brain health and your ability to avoid dementia as you get older.
- 5** **Challenge your thinking.** Take on mental leisure activities that you enjoy. Always try to learn new things, no matter what your age.
- 6** **Get a good night's sleep every night.** Try to sleep over 6 to 8 hours each night to help maintain your brain health.
- 7** **Have depression treated.** Remember that depression is more than just feeling down. Seek help to improve the functioning of your brain.
- 8** **Avoid excessive alcohol intake.** Limit your intake of wine, beer and other alcoholic beverages.
- 9** **Maintain your hearing.** Use hearing aids if you need them. Protect your hearing from loud noises.
- 10** **Find meaning in life.** Find a purpose to get out of bed each day. This is associated with better brain health and reduced dementia risk.
- 11** **Avoid all types of head injury.** Steer clear of activities where you might put your brain at risk of harm.
- 12** **Adopt healthy behaviours.** Make healthy food choices, reduce avoidable stress, quit or reduce smoking, and get regular check-ups with your doctor. All these actions will positively affect your brain health.

High-risk individuals versus whole-population approaches to risk reduction

When focusing on risk factors for dementia, interventions and actions are often examined through the lens of the individual. It is important to learn about what individuals can do for themselves and what health-care providers can do to support individual health during the aging process.

However, there also needs to be some focus on what can be done at a population level in Canada to address the challenge of dementia. While we might not be able to completely prevent dementia, the science is quite clear that dementia risk can be modified. From a population perspective, this is of key importance, as even the slightest delays in dementia onset can have a huge influence on national statistics.

At the population level, there are two broad approaches to dementia risk reduction:

1. The high-risk approach directs interventions at people identified as being at a higher risk of dementia. This targeted approach uses education and interventions to help people respond to their elevated risk.
2. The whole-population approach aims to reduce everyone's risk across society. This could include actions such as new legislation, investments in infrastructure, and other broad approaches at a community, provincial or federal level.

Most risk reduction activities take the high-risk approach, with interventions designed to focus on older individuals at the greatest risk of developing dementia. However, if we only focus on at-risk individuals, it is unlikely that we will be able to significantly reduce the overall strain of dementia across Canada in the long-term due to the following reasons (Walsh et al., 2022):

1. Dementia and its modifiable risk factors are very common in Canada. At-risk approaches will miss a large number of people who will go on to develop the condition.
2. Dementia occurs as the result of cumulative exposure to multiple risk factors across the life course. Whole-population approaches that influence the environments in which people live, work and play have greater potential to reduce overall dementia risk.
3. Dementia has been shown to be closely associated with socio-economic status. Whole-population approaches could be designed to reduce inequalities and engage people of all backgrounds.

High-risk and whole-population approaches are complementary, and both are needed if we are to effectively tackle the challenge of dementia in Canada.

Even a small delay in dementia onset across Canada can make a significant difference nationally

The Landmark Study developed three hypothetical scenarios where the onset of dementia in Canadians is delayed by 1, 5 or 10 years. The goal of these scenarios is to demonstrate what the effect would be on the Canadian population if we were able to improve risk reduction efforts for dementia and delay its onset across our population.

For these three scenarios, we made no specific assumptions about how to achieve such reductions (i.e., change in risk factors). These scenarios are essentially adjustments to the simulation model where the risk of dementia onset is shifted for everyone. The goal of these hypothetical scenarios is to understand what the population-level effects might be if we had successful population-level interventions.

All three hypothetical scenarios demonstrate the power of risk reduction at a national level. **Even a delay of 1 year could result in almost 500,000 fewer new cases by 2050; this would make a huge difference in national dementia rates over the next three decades (Table 7). If the onset of dementia could be delayed by 10 years, over 4 million new cases of dementia could be avoided by 2050 (Table 7).**

In the scenario with a 10-year delay, there would be slightly fewer people living with dementia in 2050 compared to 2020 (Table 8). While a 10-year shift in onset may seem unreasonable based on the science at this time, it is not impossible. Some research has already demonstrated that maintaining a cognitively active lifestyle in old age (e.g., reading, visiting libraries, writing, playing games) may delay the onset of Alzheimer's dementia by as much as 5 years (Wilson et al., 2021).

Delaying the onset of dementia could also have an enormous impact on caregiving for people living with dementia in Canada (Table 9). A 10-year delay could reduce the number of caregiving hours needed by almost 1 billion hours per year (Figure 7).

Table 7. The number of individuals in Canada who would avoid dementia across the three scenarios where dementia onset is delayed by 1, 5 or 10 years

	1-YEAR DELAY (FEWER CASES)	5-YEAR DELAY (FEWER CASES)	10-YEAR DELAY (FEWER CASES)
ALZHEIMER'S DEMENTIA	236,800	1,128,400	2,039,700
VASCULAR DEMENTIA	118,900	538,800	955,700
OTHER DEMENTIA	138,400	620,500	1,035,300
TOTAL CASES DELAYED	494,000	2,287,800	4,030,700

Figure 6. Impact of delaying dementia onset on the projected number of people with dementia in Canada in 2050

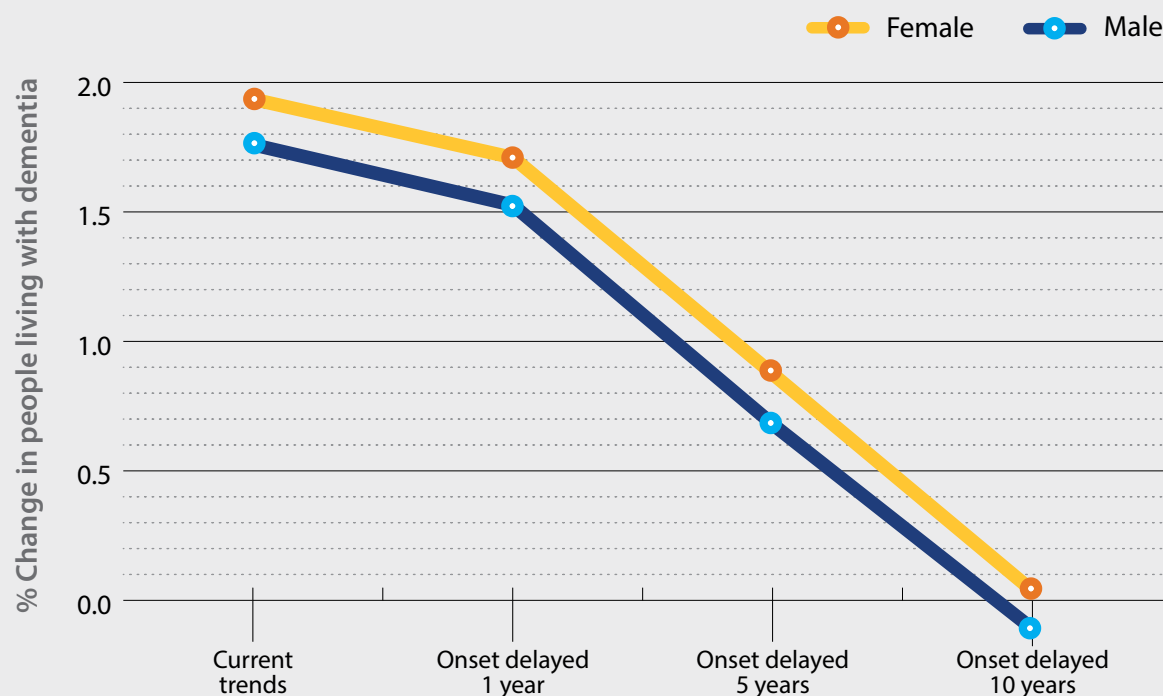


Table 8. Impact of delaying dementia onset on the projected number of people with dementia in Canada*

NUMBER OF PEOPLE WITH ANY DEMENTIA				% INCREASE BY 2050		
	MALE	FEMALE	BOTH	MALE	FEMALE	TOTAL
Current trends						
2020	230,900	366,400	597,300	176%	193%	187%
2050	637,100	1,075,300	1,712,400			
Dementia onset delayed 1 year						
2020	226,900	360,500	587,400	153%	171%	164%
2050	573,100	976,900	1,550,000			
Dementia onset delayed 5 years						
2020	214,000	341,500	555,500	68%	87%	80%
2050	359,400	639,700	999,100			
Dementia onset delayed 10 years						
2020	204,800	326,700	530,400	-11%	4%	-2%
2050	182,000	339,300	519,400			

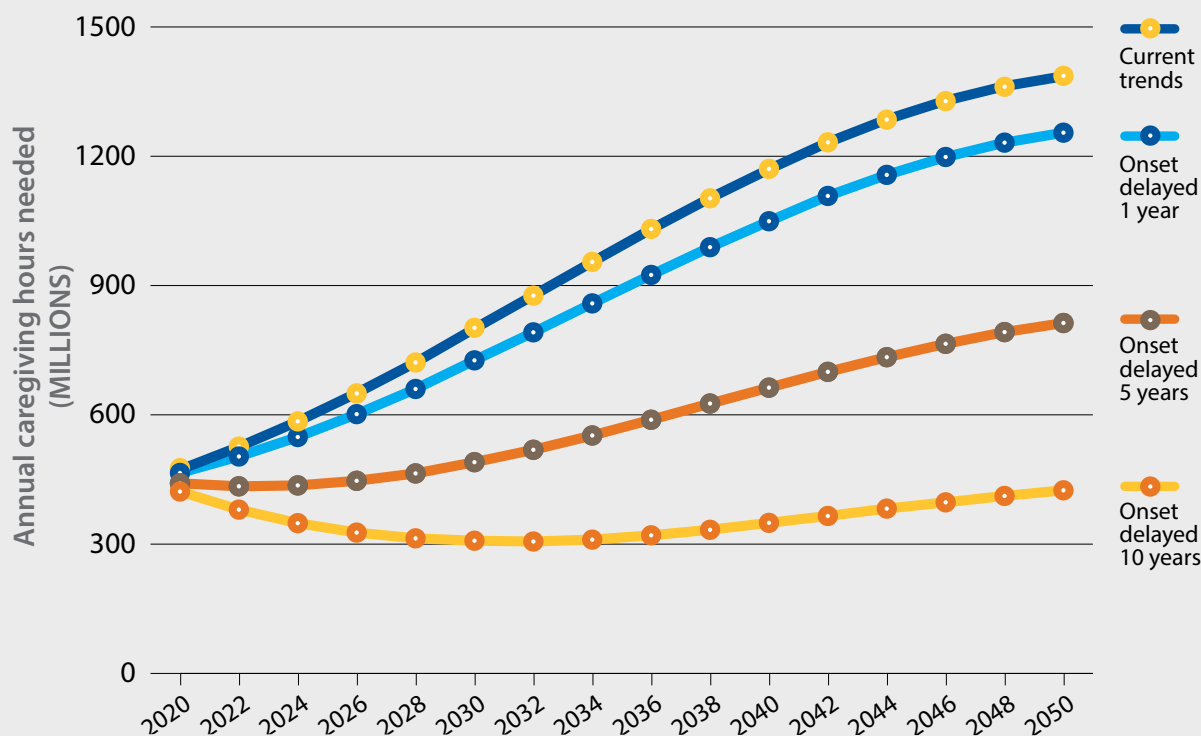
*Note: Numbers show current trends and the three scenarios where dementia onset is delayed by 1, 5 or 10 years.

Table 9. Impact of delaying dementia onset on the projected number of care partners in Canada*

NUMBER OF CARE PARTNERS				% INCREASE BY 2050		
	MALE	FEMALE	BOTH	MALE	FEMALE	TOTAL
Current trends						
2020	160,200	189,400	349,600	192%	184%	188%
2050	467,100	538,800	1,005,800			
Dementia onset delayed 1 year						
2020	157,700	186,400	344,100	168%	162%	165%
2050	422,900	487,700	910,600			
Dementia onset delayed 5 years						
2020	149,500	176,700	326,300	83%	79%	81%
2050	274,000	315,900	589,800			
Dementia onset delayed 10 years						
2020	143,100	169,100	312,200	0%	-3%	-1%
2050	143,100	164,900	308,000			

*Note: Numbers show current trends and the three scenarios where dementia onset is delayed by 1, 5 or 10 years.

Figure 7. Impact of delaying the onset of dementia on the number of unpaid caregiving hours needed in Canada, 2020 to 2050





DIFFERENCES IN DEMENTIA RATES ACROSS REGIONS OF CANADA

The growth in
dementia cases
will not be uniform
across the country.

All regions of Canada are expected to see an increase in the number of people with dementia if current trends continue. However, the growth in dementia cases will not be uniform across the country.

Dementia will affect the provinces differently over the next 30 years. Differences in age distributions, migration patterns, and the prevalence of risk factors combine to produce specific challenges, needs, and overall numbers of people living with dementia for each province. Unfortunately, insufficient data was available to study the Yukon, the Northwest Territories, or Nunavut.

Based on the data that was used for the Landmark Study, the expected percentage increases of people living with dementia vary considerably across the 10 provinces (Figure 8).

Largest percentage increases will occur in Ontario, Alberta, and British Columbia

Faster growing and younger provinces, such as Ontario, Quebec, British Columbia and Alberta, will have the most significant increases in dementia by 2050 (**Figure 8, Table 10**). Ontario, with a 202% increase over the three decades, is projected to have the most new cases by 2050: 1.5 million new cases of Alzheimer's dementia*; 680,000 new cases of vascular dementia; and 780,000 new cases of other types of dementia.

Alberta and British Columbia are expected to have greater percentage increases in people living with dementia. Alberta will see a 286% increase in the number of people living with dementia from 2020 to 2050. For British Columbia, this increase will be 218%. These large increases in Ontario, Alberta, and British Columbia are driven by higher growth rates and faster-aging populations than other provinces (**Figure 9**).

Quebec is expected to have the second-highest increase in the number of people with dementia (2020: 147,000 people living with dementia; 2050: 360,200), but stands to be below the national average in terms of percentage increase over the three decades (Quebec: 145% increase from 2020–2050; Canada: 187%).

While the Atlantic provinces have, on average, older populations than other parts of the country, their much slower population growth limits the rate of dementia growth. However, substantial growth in dementia numbers is still expected from 2020 to 2050:

- New Brunswick → 89% increase
- Prince Edward Island → 138% increase
- Nova Scotia → 87% increase
- Newfoundland and Labrador → 73% increase

** A note on word choice: "Alzheimer's disease" is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge. "Alzheimer's dementia" is the later stages of that same disease; during these stages, problems with thinking, memory, mood, behaviour and/or communication are evident.*

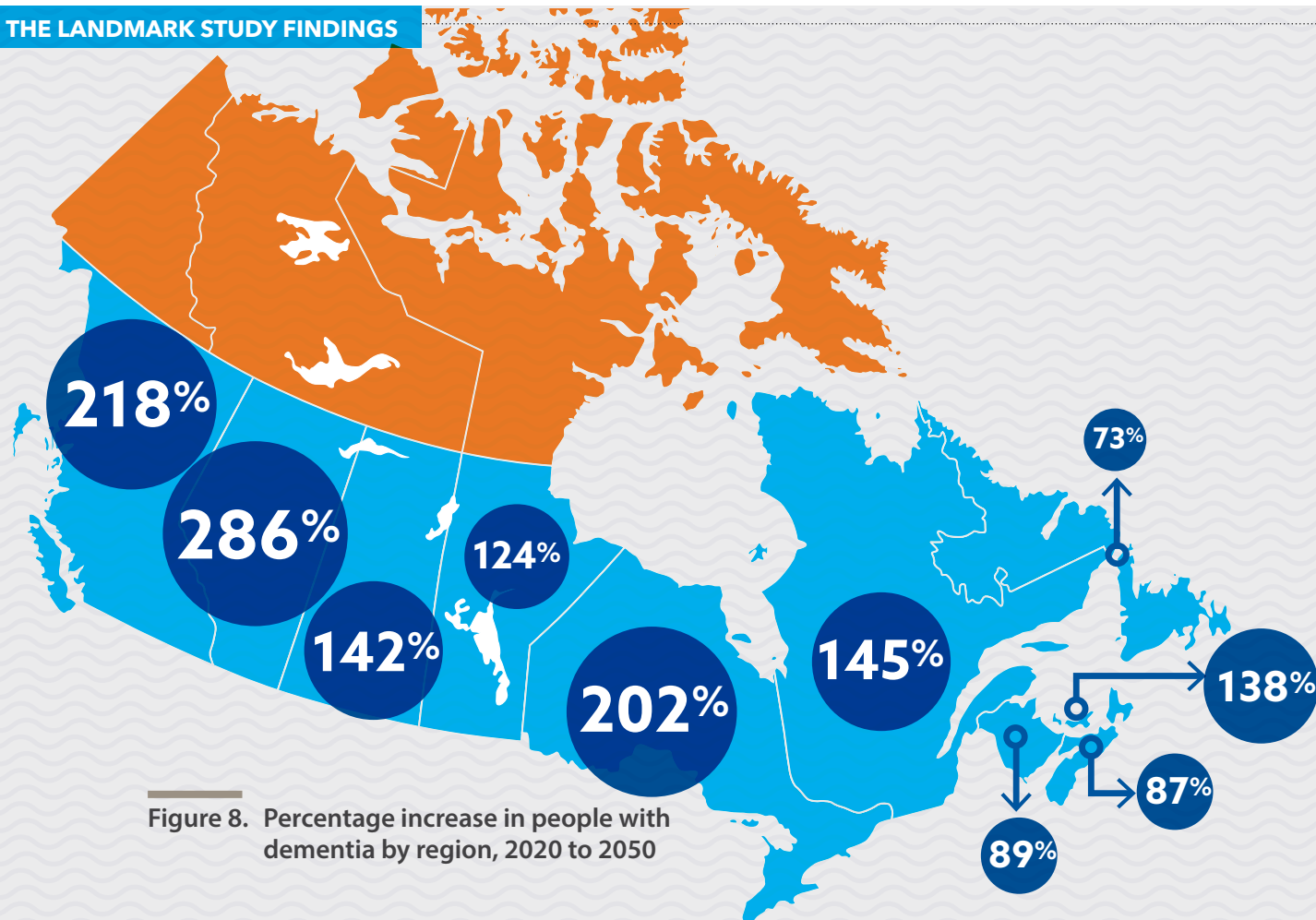
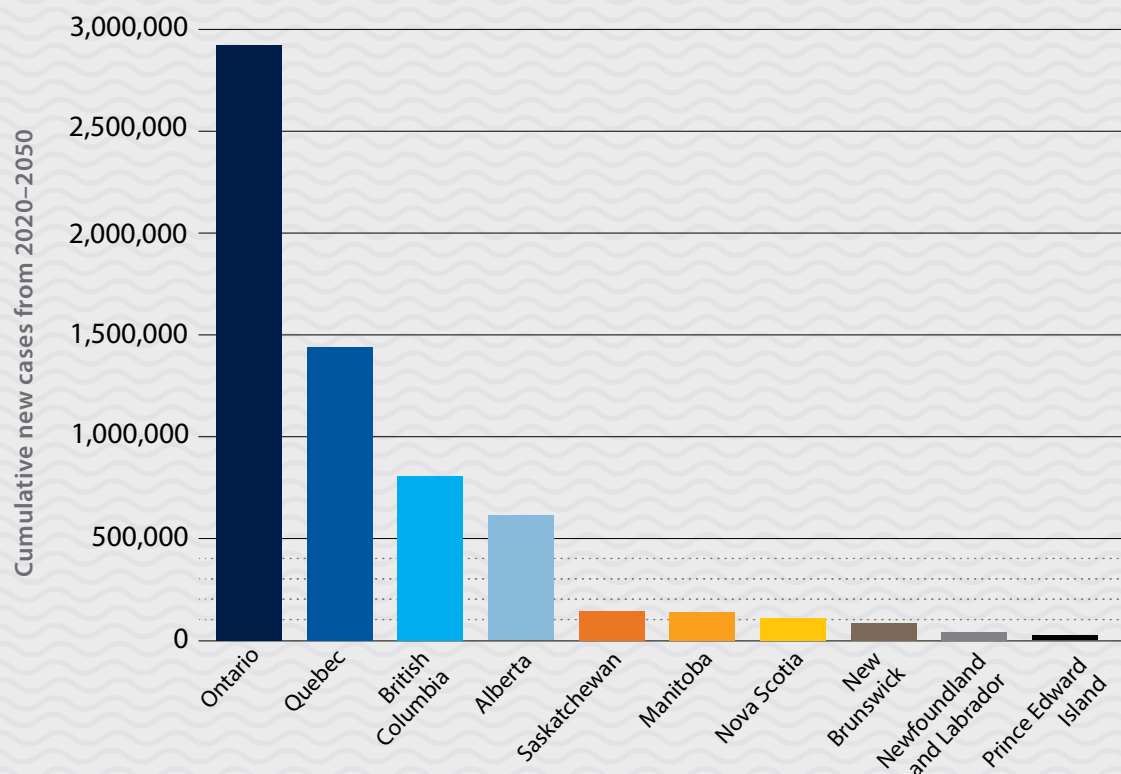


Figure 8. Percentage increase in people with dementia by region, 2020 to 2050

Figure 9. Total new cases of dementia by type and region, 2020 to 2050



Note: Data not yet available for projections in Yukon, Nunavut and the Northwest Territories.

Caregiving needs across the provinces

Alberta is expected to see the largest percentage increase in the number of care partners for people living with dementia (290% increase, **Table 11**) and the number of hours of unpaid caregiving (302% increase) compared to the rest of the country. On average, Canada will see a 188% increase in the total number of care partners and a 193% increase in the number of hours of unpaid caregiving.

Table 10. Estimates of the number of people living with dementia in 2020 and 2050, by province and sex at birth*

	YEAR 2020			YEAR 2050			% INCREASE
	FEMALE	MALE	TOTAL	FEMALE	MALE	TOTAL	TOTAL
BC	46,000	31,700	77,700	155,500	91,800	247,300	218%
AB	31,800	20,200	52,000	126,300	74,600	200,900	286%
SK	10,900	6,600	17,500	26,500	15,800	42,300	142%
MB	10,800	6,700	17,500	24,600	14,600	39,100	124%
ON	153,400	96,900	250,300	473,700	282,400	756,100	202%
QC	91,600	55,500	147,100	225,300	134,800	360,100	145%
NB	7,200	4,600	11,800	14,100	8,200	22,300	89%
PEI	1,500	900	2,400	3,600	2,100	5,700	138%
NS	9,700	5,600	15,300	19,000	9,700	28,700	87%
NL	3,600	2,000	5,600	6,600	3,100	9,700	73%

Table 11. Annual number and percentage increase of care partners in 2020 and 2050, by province and sex at birth*

	YEAR 2020			YEAR 2050			% INCREASE
	FEMALE	MALE	TOTAL	FEMALE	MALE	TOTAL	TOTAL
BC	23,600	22,000	45,600	74,900	70,000	144,900	218%
AB	16,000	14,300	30,300	62,300	55,800	118,200	290%
SK	5,200	5,000	10,200	12,600	12,200	24,800	143%
MB	5,900	4,300	10,200	13,300	9,700	23,000	125%
ON	78,200	68,300	146,500	233,800	210,600	444,400	203%
QC	49,600	36,500	86,100	121,300	90,300	211,600	146%
NB	3,500	3,400	6,900	6,600	6,500	13,100	90%
PEI	800	600	1,400	2,000	1,400	3,400	137%
NS	4,800	4,200	9,000	8,800	8,000	16,800	87%
NL	1,800	1,500	3,300	3,100	2,700	5,700	72%

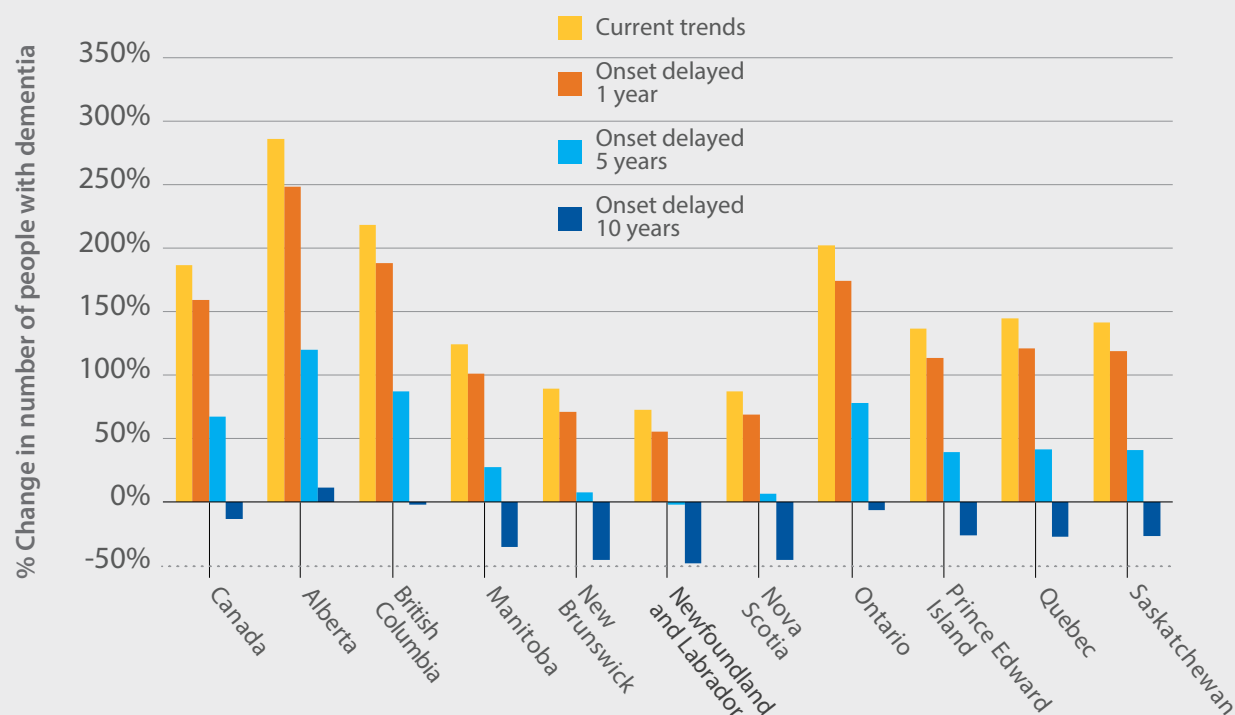
**Note: Numbers based on current trends.*

Delay in dementia onset across the provinces

Our study also examined the potential impact of delaying dementia onset at the provincial level. Delaying onset by 10 years would have different impacts on each province and territory. Projecting to 2050, the Atlantic provinces would experience the largest decreases in dementia. Ontario, British Columbia and Alberta would see their 2050 numbers remain similar to those in 2020, completely changing the trajectories projected without a delay (**Figure 10**).

Likewise, the impacts on care partners in different provinces and territories would vary. With a 10-year dementia delay, by 2050, Ontario would need 305,400 fewer care partners and 440 million fewer hours of unpaid caregiving (equivalent to 220,000 full-time jobs). In this scenario, even a small province like Prince Edward Island would need 2,300 fewer care partners in 2050 (**Table 12**).

Figure 10. Change in the number of people with dementia in 2050 relative to 2020



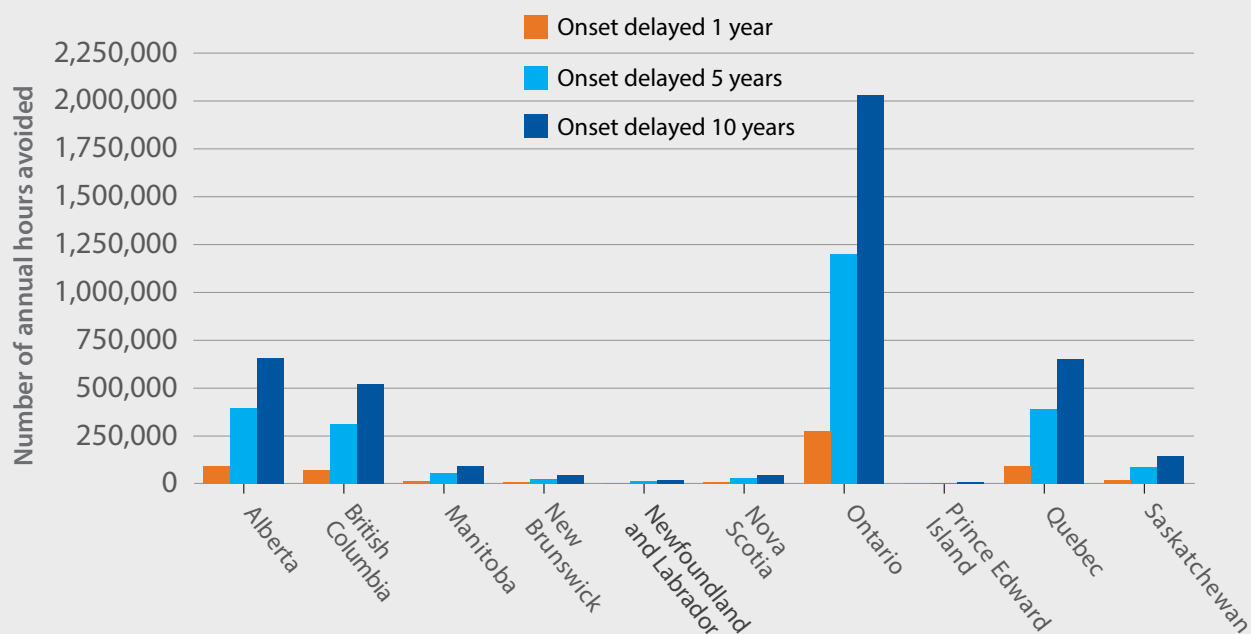
Notes: Numbers show current trends and projections across the three scenarios. Data not yet available for projections in Yukon, Nunavut and the Northwest Territories.

Table 12. Reduction in number of care partners in 2050

PROVINCE	DELAYED 1 YEAR	DELAYED 5 YEARS	DELAYED 10 YEARS
ALBERTA	11,500	50,400	83,700
BRITISH COLUMBIA	13,500	59,100	99,600
MANITOBA	2,300	9,800	16,300
NEW BRUNSWICK	1,300	5,600	9,300
NEWFOUNDLAND AND LABRADOR	600	2,400	4,000
NOVA SCOTIA	1,600	7,200	11,800
ONTARIO	41,100	181,000	305,400
PRINCE EDWARD ISLAND	300	1,400	2,300
QUEBEC	20,800	88,900	148,300
SASKATCHEWAN	2,300	10,200	17,200
CANADA-WIDE TOTAL	95,200	416,000	697,900

Note: Numbers show the three scenarios where dementia onset is delayed by 1, 5 or 10 years.

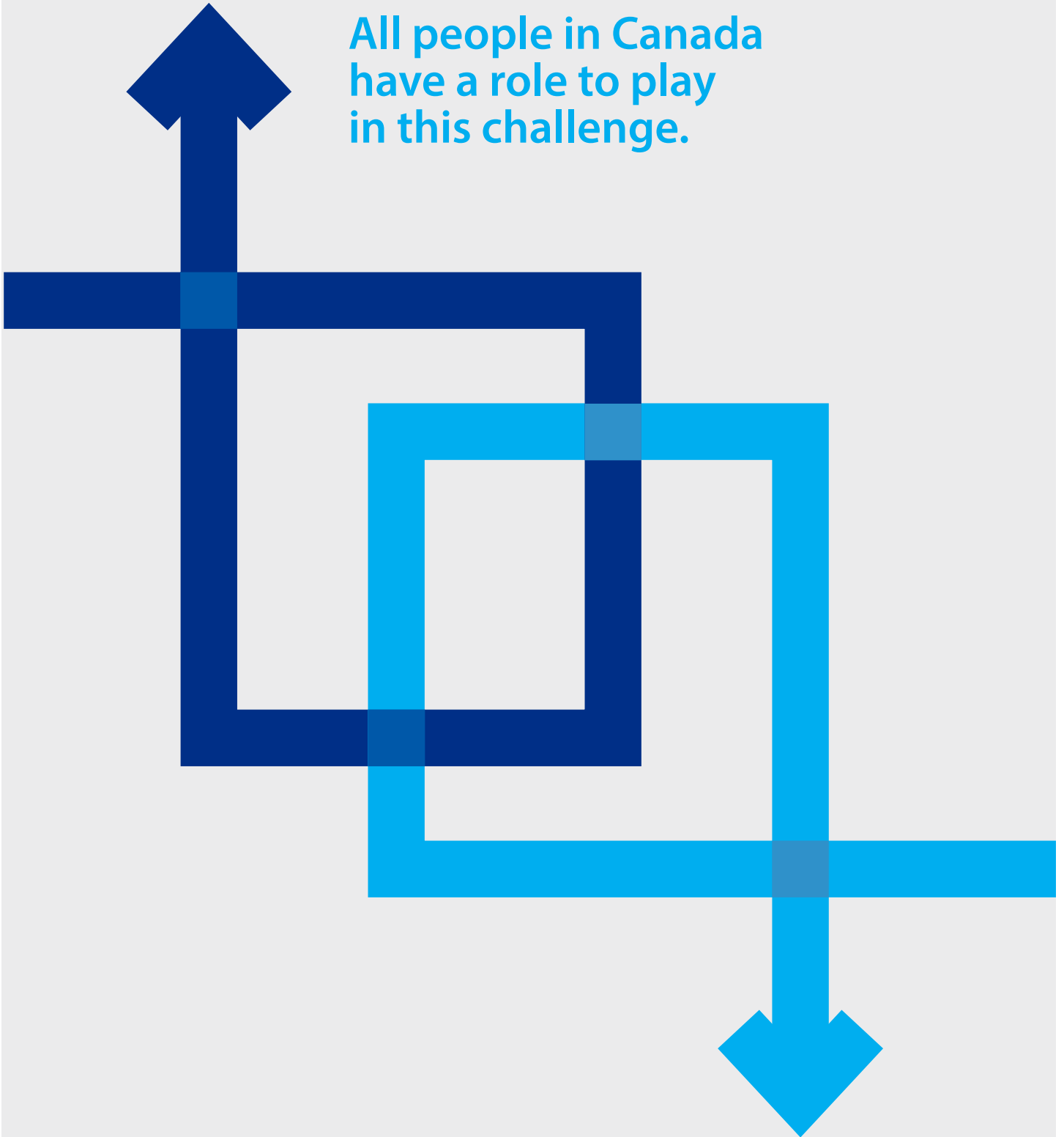
Figure 11. Reduction in unpaid caregiving needs in 2050



Note: Numbers show the three scenarios where dementia onset is delayed by 1, 5 or 10 years.

FINDING THE BEST PATH FORWARD

All people in Canada
have a role to play
in this challenge.



Summary

Dementia will continue to be a growing issue in Canada, with the number of people living with some form of dementia projected to triple over the next 30 years. If current trends continue, all regions of the country will see a dramatic increase in the number of people with dementia and the demands placed on care partners.

Based on current trends, 1.7 million people in Canada could be living with dementia by 2050, with over 6.3 million diagnoses of dementia occurring from 2020 to 2050.

By 2050, over 650,000 family and friend care partners will be needed to support people living with dementia. This amount of caregiving is expected to total almost 1.4 billion hours annually, equivalent to 690,000 full-time jobs.

These surging dementia caregiving needs will pose a big challenge to families, friends and other people who provide unpaid care for people living with dementia. The challenge is only partly due to the hours required. Caregiving demands occur for most people when they are 45 to 65, influencing workforce participation, personal finances, pension earnings and overall economic activity. When caregiving is performed by spouses or partners, they may have their own age-associated health challenges. For care partners who are 35 or younger, it can be challenging to launch a career, continue an educational path, or raise young children.

Measures which bring about even small delays in the onset of dementia could significantly reduce the demand for dementia care.

The Landmark Study model demonstrates that if the onset of dementia is delayed by 1 year, almost 500,000 cases of dementia in Canada could be avoided over the next 30 years. If the incidence of dementia could be delayed by 10 years, over 4 million diagnoses of dementia could be avoided, and most regions of the country would see fewer people living with dementia in 2050 than today.

While all regions of Canada are expected to see a substantial increase in the number of people living with dementia if current trends continue, some provinces will experience greater change. Provinces with higher growth rates and faster-aging populations (such as Alberta, Ontario and British Columbia) are expected to see the number of people with dementia increase much faster than the other parts of Canada.

Opportunities to improve the path

While a cure or an effective treatment for dementia has not yet been discovered, we can take a wide range of actions to create positive outcomes for people living with dementia and their care partners.

All people in Canada have a role to play in this challenge. As a result, these sections have been organized to address the following various perspectives: What can Alzheimer Societies do? What can health-care systems do? What can the federal, provincial/territorial and municipal levels of government do? What can researchers do? What can individual Canadians do? For all of these groups, it is important that this work is done collaboratively with people living with dementia and their care partners.

WHAT CAN ALZHEIMER SOCIETIES DO?

- ⦿ **Reduce stigma and raise public awareness** about dementia so that all Canadians know about dementia-friendly community programming and the IG Wealth Management Walk for Alzheimer's.
- ⦿ **Grow supports and services to fill the gaps in health care** through the First Link® system navigation program, National Dementia Infoline, provincial and regional dementia infolines, Minds in Motion and other invaluable local programs.
- ⦿ **Increase funding for out-of-the-box research** that explores radical new ways to advance our knowledge of dementia and enhances the quality of life of people living with dementia and their care partners.
- ⦿ **Continue building relationships and resources for diverse communities** across Canada.
- ⦿ **Engage people living with dementia and their care partners** in all aspects of advocacy and programming in keeping with "nothing for us, without us."
- ⦿ **Collaborate** with other organizations on issues related to dementia and dementia care.

WHAT CAN HEALTH-CARE SYSTEMS DO?

- + Provide **primary care clinicians** with:
 - **Better education** on timely detection of dementia symptoms, diagnosis, and particularly ongoing care.
 - **Better access to the right tools** to diagnose dementia and provide ongoing management.
 - Support **medication review** and deprescribing initiatives that are readily accessible.
- **Provide education on risk reduction approaches** to dementia.
- **Changes to fee structures** so that clinicians have the right time allocation and remuneration to provide proper support to people living with dementia and their care partners.

- + **Provide dementia education and training to a broader circle of allied health professionals** who can support management of dementia, including pharmacists, nurses, social workers and personal support workers.
- + **Increase the dementia workforce** and the resources available to all allied health professionals who care for people living with dementia, regardless of where they live in Canada.
- + **Grow capacity for dementia-specialized community clinics, community and home care systems, and long-term care.** Home and community care is the more affordable and requested option by people living with dementia.
- + **Recognize the specific needs and supports of care partners and people living with dementia** to improve care.
- + **Work to address barriers for access to care among underserved populations,** including rural communities, Indigenous Peoples, and other diverse communities.
- + **Require that health records indicate mild cognitive impairment and early, middle- or late-stage dementia.**
- + **Provide effective support for dementia care partners through primary care and health professionals.** This includes connecting care partners with local Alzheimer Societies and other local supports, asking about care partner stress, making sure that a primary care partner is identified, assessing care partners prior to hospital discharge, and considering care partner status when determining care transition plans.

WHAT CAN THE FEDERAL GOVERNMENT DO?

- 🏠 **Cost out and fully fund the National Dementia Strategy** to optimize the work done toward the three national objectives: (1) prevent dementia; (2) advance therapies and find a cure; (3) improve quality of life of people living with dementia and care partners. Furthermore, develop key performance indicators, benchmarks or metrics for the strategy so that the successes and failures can be evaluated.
- 🏠 **Increase investments in dementia research to reach the goal set in the National Dementia Strategy** of 1% of dementia care (approximately \$105 million annually), including work in health systems and health promotion.
- 🏠 **Actively work to reduce stigma against dementia through national awareness campaigns,** and promote measures toward creating dementia-friendly communities.
- 🏠 **Support the development of national dementia clinical guidelines,** and fund the development of clinical tools related to dementia care.
- 🏠 **Empower and fund the Public Health Agency of Canada** to do what is called "dementia surveillance"—that is, **making sure every case of dementia in Canada is counted and tracked.**
- 🏠 **Recognize modifiable risk factors** for dementia and integrate health promotion strategies across non-communicable diseases of aging, including neurological disorders, heart disease, cancer, and diabetes.
- 🏠 **Provide additional targeted funding for technological solutions** to the challenges that come with dementia, clinical dementia care, and caregiving.
- 🏠 **Enhance strategies to improve the mental health of older Canadians,** with the specific targeting of reducing depression in people over the age of 65.
- 🏠 **Support implementation of care partner leave more widely**—put it in Canadian law—including paid leave for long-term conditions.

WHAT CAN PROVINCIAL AND TERRITORIAL GOVERNMENTS DO?

- ⚙️ **Create new community care and long-term care spaces that are dementia friendly**, and encourage dementia-friendly community developments.
- ⚙️ **Plan for increases in spending for home care, social supports, and long-term care** to match the expected increases in the number of people living with dementia and their care partners.
- ⚙️ **Improve access to memory clinics**, with additional focus on underserved urban regions and rural areas.
- ⚙️ **Take a World Health Organization “Health in All Policies” approach** to public policy that systematically takes into account the health implications of decisions, seeks synergies, and avoids harmful health impacts of all new provincial policies.
- ⚙️ **Continue to improve efforts by public health agencies** in the following areas: prevention and treatment of vascular conditions; discouraging smoking and heavy alcohol use; and encouraging healthy lifestyles.
- ⚙️ **Develop policies that encourage social, cognitive and physical activity across the life course for all.** This process should include robust efforts to effectively address the social determinants of health.
- ⚙️ **Enhance strategies to improve the mental health of older adults**, with the specific targeting of reducing depression in people over the age of 65.
- ⚙️ **Improve education for all ages**—from primary school to adult education—to enhance the brain health of all Canadians.
- ⚙️ **Consider how annual brain health check-ups for people over 50 might work** within each province or territory. The science of brain health has evolved to a point where biomarkers and imaging technologies could be used in health system-level risk reduction activities.
- ⚙️ **Support federal efforts in dementia surveillance**—provinces must urgently start to enhance the tracking of diagnoses more accurately.
- ⚙️ **Create policies and processes that support culturally safe dementia care** and public health initiatives for people of all backgrounds, including Indigenous Peoples, Black Canadians, and other racialized and intersectionally oppressed groups.
- ⚙️ **Destigmatize and enhance supports for younger care partners.**
- ⚙️ **Respond to care partner challenges**, specifically in rural and remote settings where supports are often lacking.
- ⚙️ **Support workplaces** in providing flexible supports for employed care partners.
- ⚙️ **Build up a system of interventions** designed to assist care partners that may include:
 - Case management
 - Psychoeducational approaches
 - Counselling
 - Psychotherapeutic approaches
 - Respite
 - Support groups
 - Multicomponent approaches
 - Healthy living

WHAT CAN MUNICIPAL GOVERNMENTS DO?

- ➔ Work toward developing **age-friendly and dementia-friendly action plans**.
- ➔ Work closely with public health units to support their messaging and **programming around brain health**.
- ➔ **Support intergenerational social interaction and physical activity** for all ages through suitably funded and maintained parks and recreation programs, community centres, and public health programs.
- ➔ **Reduce air pollution** and encourage more green space.
- ➔ **Support existing community cultural organizations in delivering brain health programs** appropriate to their members and target audiences.
- ➔ **Support accessibility initiatives** in urban planning and design that include clear wayfinding signage and transit accessibility.
- ➔ **Consider health impacts in all policy making**, and support health promotion efforts by other levels of government.
- ➔ Encourage all city staff to take a dementia-friendly course via alzheimer.ca/DementiaFriendlyCanada.
- ➔ **Fund local support networks** for people living with dementia and their care partners.
- ➔ **Encourage more dementia-friendly spaces** and parks and recreation programming.

WHAT CAN RESEARCHERS DO?

- ⊞ **Include people living with dementia and their care partners in research projects**, as part of the research team and as study participants.
- ⊞ **Embrace a range of dementia research**, including fundamental bio-medical and clinical research, dementia in health systems and services, dementia in populations, the societal and cultural dimensions of dementia, and the environmental influences on dementia.
- ⊞ **Support an integrated approach** to dementia research that brings together researchers, health-care providers and policy-makers with industry and patient groups from across the country.
- ⊞ Continue to conduct studies to understand **protective effects, risk factors, and interventions for dementia over the life course**.
- ⊞ **Support brain health-oriented research**, such as further investigation into the factors that lead to resiliency and cognitive/brain reserves.
- ⊞ **Ensure that dementia research populations reflect the diversity in our Canadian population**. Increase recruitment of heterogeneous samples to improve our understanding of differences such as socio-economic status, race, ethnicity, language, disability, and gender.
- ⊞ Continue research on the **COVID-19 pandemic and its association with dementia outcomes**.
- ⊞ **Work to develop new insights on the care needs of people living with dementia**, the needs of care partners, and ways to improve the health and social systems that support them.
- ⊞ **Study how the social determinants of health** (i.e., social and environmental attributes beyond an individual's control) affect the risk of developing dementia and the well-being of people living with dementia and their care partners.

- ✚ **Foster interdisciplinary collaborations** to tackle the complex problems that exist in dementia research. For example, quantitative research projects may benefit by including data scientists with expertise in areas like machine learning, artificial intelligence, or other modern data science approaches.
- ✚ **Conduct research on technological and non-technological innovations aimed at improving dementia care** (e.g., assistive technologies, virtual reality applications, human-based interventions). Some of this work should include harnessing sensor technology and the Internet of Things for applications in dementia management and care (e.g., remote monitoring of appliances, tracking of biometrics, medication management).
- ✚ **Identify common causes** of hearing loss and head trauma (e.g., occupational exposures), and work to reduce exposure to these risk factors (which have been shown to elevate dementia risk as individuals age).
- ✚ **Conduct health system research** on implementing better coordination and integrated care that is patient-centred and dementia friendly.

AS AN INDIVIDUAL CANADIAN, WHAT CAN YOU DO?

- 🧠 **Support care partners** within your families and social networks.
- 🧠 **Grow your awareness about dementia** and how it impacts people, support dementia research and enhanced services for people with dementia, and be prepared to act as a care partner.
- 🧠 **Advocate for your community to become dementia friendly** and for more funding for the National Dementia Strategy or your provincial dementia strategy.
- 🧠 **Access programs available through your local Alzheimer Society** if you or anyone you know is concerned about or living with dementia.
- 🧠 **No matter what your age group**, from youth to older adults, actively improve your brain health and take dementia risk reduction measures:
 - Be physically active each day.
 - Protect your heart.
 - Stay socially active.
 - Manage your medical conditions.
 - Challenge your thinking.
 - Get a good night's sleep every night.
 - Have depression treated.
 - Avoid excessive alcohol intake.
 - Maintain your hearing.
 - Find meaning in life.
 - Avoid all types of head injury.
 - Adopt a healthy lifestyle by making healthy food choices, reducing avoidable stress, quitting or reducing smoking, and getting regular check-ups with your doctor.

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APPENDIX

SUMMARY OF MICROSIMULATION MODELLING METHODS

The Landmark Study uses the socio-economic statistical analysis platform from the Canadian Centre for Economic Analysis (CANCEA) to model and estimate the challenge of dementia in the Canadian population over the next 30 years. In the model, “agents” are used as statistical representations of persons. Each agent is associated with several demographic characteristics (including age, sex and ethnicity) which match those of the Canadian population, as informed by publicly available data from Statistics Canada. The initial state of the population is established with age- and sex-specific prevalence of long-term health conditions, such as heart disease, smoking, hearing loss, or low level of physical activity, and the comorbidities between them.

The model simulates the agents and their interactions over time as they age and pass through various states, such as dementia

diagnosis, hospitalization and death. While similar to other microsimulation models like the Population Health Model (POHEM) (Hennessy, et al., 2015), CANCEA's platform can run at the individual level, include interactions and connections between agents (such as family structure), and can include extensive economic accounts. This allows the single model to provide estimates and forecasts over time for measures of health (incidence, prevalence, mortality) and economics (direct and indirect health-care costs, government revenue lost, caregiver costs). This allows researchers to compare the impact of dementia across different segments of the population, namely by sex and ethnicity, and to identify populations particularly vulnerable to dementia in Canada.

The section below provides an overview of the approach used by CANCEA in the Alzheimer Society of Canada Dementia Model.

Model overview

The model is based on the simulation of a statistical representation of the Canadian population at the individual level. Each person (agent) in the model has extensive data associated with it including the following:

Demographics	Health State
<ul style="list-style-type: none">● Date of birth● Sex at birth● Location of residence (census subdivision level)● Ethnicity● Family members	<ul style="list-style-type: none">● Diabetes● Obesity● Stroke● Diet● Hypertension● Mood/anxiety disorders● Hearing loss● Level of physical activity● Alzheimer’s dementia*● Vascular dementia● Other forms of dementia

** A note on word choice: “Alzheimer’s disease” is an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge. “Alzheimer’s dementia” is the later stages of that same disease; during these stages, problems with thinking, memory, mood, behaviour and/or communication are evident.*

The model tracks the population through their lives and interactions, changing their state according to rates and risks reported in literature.

Updated relative risk values have been reported since the original Rising Tide report. The factors included in the analysis are presented in the

table below. Hearing loss has been recently recognized as a risk factor for dementia, with studies showing that even mild levels of hearing loss increase the long-term risk of cognitive decline (Livingston, et al., 2017; Thomson, et al., 2017).

Potentially modifiable dementia risk factors included in the analysis

RISK FACTOR	SOURCES FOR RISK	SOURCE FOR CANADIAN PREVALENCE
Diabetes	Gudala et al., 2013; Ott et al., 1999; Smolina et al., 2015; Haroon et al., 2015	Public Health Agency of Canada, 2021
Obesity	Tolppanen et al., 2014	Public Health Agency of Canada, 2021
Stroke	Kuzma et al., 2018; Nabalamba & Patten, 2010; Cerasuolo et al., 2017	Public Health Agency of Canada, 2021
Western Diet	Sofi et al., 2010; Lourida et al., 2013; Akbaraly et al., 2019	Statistics Canada, 2021
Hypertension	Ng et al., 2013; Tariq & Barber, 2018; Nabalamba & Patten, 2010	Public Health Agency of Canada, 2021
Mood/Anxiety Disorders	Nabalamba & Patten, 2010; Byers & Yaffe, 2011	Public Health Agency of Canada, 2021
Hearing Loss	Gurgel et al., 2014; Thomson et al., 2017; Lin et al., 2011; Livingston et al., 2017	Feder et al., 2015
Physical Inactivity	Scarmeas et al., 2009; Tariq & Barber, 2018	Statistics Canada, 2021

Additional factors such as education and genetics have been incorporated into the base incidence rate. By doing so, we assume that the educational profile and genetic risk profile of the population is not changing over the analysis period. Since people at risk of dementia by 2050 would already be born and have completed most of their education, the relevant genetic and educational profile of this population is not changing over time.

The ethnic groupings used in the analysis are taken from the designations used by Statistics Canada in the 2016 Population Census (Statistics Canada, 2017). When the census was completed, a long-form question asked participants to self-identify their ethnic origin and year of immigration. This information provides the basis for both the ethnic profile of the population and the primary sources of recent immigration.

While the primary countries of origin can change over time, for this analysis, it is assumed that the distribution of countries of origin and age will remain similar to that seen over the last decade. Note that while the relative rate of immigration of some ethnic groups (e.g., people of African origin) has increased compared to historical sources of immigration (e.g., Europe), the percentage of immigrants within the population evolves more slowly.

The relative risks of dementia associated with ethnicity, mapped to the Statistics Canada ethnic groupings relative to people of Asian origins, are taken from the 2016 paper by Mayada and colleagues. The risks are adjusted to account for other comorbid factors, and Mayada found no clear remaining factors to account for the differences between ethnic groups.

Historical data reconciliation

Most historical data is not available in a form that is directly usable by the agent-based model approach. For example, while the prevalence of individual conditions may be presented, the full set of comorbidities between all health states by age and sex is not available. Similarly, while the relative risk of the onset of dementia given one or two other characteristics might be found in the literature, the combined relative risk from multiple factors is often not published.

In order to combine all of the data sources into a consistent picture, a full representation of the population and all state transitions over the last 10 years is constructed such that it is aligned with all of the input data. This is not a trivial task, with billions of variables being adjusted to minimize the differences between the representation of the population and the dataset.

Once the unique profiles are consistent with the historical data, the conditional probabilities of changing from one health state to another (or for any other event such as death) can be calculated. As a validation process, the calculated transition probabilities are tested with historical data to ensure that history can be statistically reproduced. Once validated, these conditional probabilities provide the basis for the forward simulation stage.

Simulation stage

For each agent, the time of its next event is calculated using the time-dependent exponential conditional probability distributions calculated in the previous stage. Note that since the probability for most events changes with age, the probability calculation accounts for changing likelihoods over time. For the agent with the next event to occur, the state of the agent is changed (such as changing “vascular dementia” from “no” to “yes”). The time of the next event for this agent is then recalculated and the next agent is processed.

While the mechanics of the simulation stage are relatively straightforward, the underlying conditional probabilities that are used can result in complex dynamics arising within the model.

Output stage

At periodic intervals during the simulation (usually at the end of each year), the state of every agent in the system is recorded in the database, along with any changes in state that occurred since the previous output time.

Agents who have died or emigrated in the interval between outputs are no longer recorded in the output state, but their removal is recorded in the change of state. Similarly, new agents (through birth or immigration) are included in the new state output, as well as in the change of state records. This ensures that all output is internally consistent, with all agents accounted for.

Since each simulation generates stochastic output, after a set of simulations are run, statistics are calculated on the set of simulations for the variables of interest. For example, the average number of new cases of a disease for people in a given age range and geographic region can be calculated.

Dementia-specific extension

The Landmark Study model extends the basic agent to include a care partner trait, which is a link to another agent in the model. When a person has dementia, there is probability (based on age) that a person will require a care partner. Using the family structure of the person with dementia, and the distribution of people who provide unpaid caregiving (such as partners, children, or friends), another appropriate agent in the model is identified as a care partner.

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